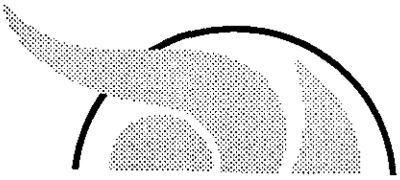
HEALTH PROMOTION
AND
CHRONIC ILLNESS

Discovering
a new quality
of health



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HEALTH PROMOTION AND CHRONIC ILLNESS

Discovering a new quality of health

A collection of papers and background documents
presented at the
International Symposium on Health Promotion and Chronic Illness
organized in Bad Honnef 21-25 June 1987
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INNOVATIVE APPROACHES IN HEALTH PROMOTION

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CONTENTS

PART I

Coping with Chronic Illness: Concepts and approaches

1. CONCEPTUAL FRAMEWORK

2. RECOVERY FROM HEART ATTACK: FOCUS ON SELF-RELIANCE, SELF-HELP AND SELF-DETERMINATION

3. CANCER: TOWARDS INNOVATIVE HEALTH PROMOTION APPROACHES

4. CHRONIC PAIN CONDITIONS: A NEW UNDERSTANDING

PART II

Innovative approaches in the implementation of health promotion concepts

5. BUILD HEALTHY PUBLIC POLICIES

6. CREATE SUPPORTIVE ENVIRONMENTS

7. STRENGTHEN COMMUNITY ACTION

8. DEVELOP PERSONAL SKILLS

9. REORIENT HEALTH SERVICES

9.1 *Training: needs are on two levels*

9.2 *Health care: a community base is emerging*

9.3 *Health research on chronic illness: the situation is unsatisfactory*

PART III
A call for action

FOREWORD

by Jo Erik Asvall

Chronic illness is a condition that is a much larger problem in Europe than is often realized. About one person in ten lives with a chronic illness or disability and with the rapidly growing number of the very old, this proportion is increasing. Chronic illness often inflicts much suffering on the individual and the family, and it represents a major challenge for the health care system and society in general.

People with chronic disease and disability face a triple problem. One is the loss of basic function, and the chronic suffering from pain and other symptoms that are the direct result of the illness or accident. Another problem is due to secondary consequences of the predicament as regards the ability of individuals to function as socially and economically productive members of society. This is directly linked to their objective disability and, indirectly, to the attitude of society. As a rule, there is a tendency to underrate the possibilities for a disabled or chronically ill person to contribute actively - albeit in a modified manner - to the economic and social productivity of society. The third problem - by no means the least difficult - is the negative impact of the situation with regard to the self-esteem, hope and drive of the chronically ill or disabled person himself or herself. All these factors contribute to the downward spiral of inactivity and apathy and to the feeling of helplessness and uselessness that often threatens the quality of life of the persons who are chronically ill and disabled.

In 1984 the 32 Member States of WHO's European Region adopted a new common health policy and set 38 targets to be reached by all the countries in the next 10-15 years. Adopting the slogan "Adding life to years", target two states: "By the year 2000, people should have the basic opportunity to develop and use their health potential to live socially and economically fulfilling lives", and target three stipulates: "By the year 2000, disabled persons should have the physical, social and economic opportunities that allow at least for a socially and economically fulfilling and mentally creative life." Putting such ideas into practice requires not only a different attitude towards the disabled on the part of society; it also demands that very practical measures be pursued with vigor at the national level and in every local community, by the health care sector and many other sectors, by public and private institutions and organizations, and by the chronically ill and disabled themselves.

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Encouraging developments have taken place in recent years in a number of countries where organizations of the chronically ill and disabled have refused to accept the old passive labels that society had given them. These organizations have forced through a series of innovative programs that have helped to bring a new understanding of how each individual's potential for a healthy life can be enhanced – also for those whose life situation has been afflicted by chronic disease and disability. One has come to realize that through appropriately selected sports, activities to strengthen social networks, special counseling, better planned housing, sensibly designed public transport and other aspects of the working and living environment, the quality of life can be substantially improved for the chronically ill and disabled.

However, such programs and such attitudes have not yet taken firm hold throughout Europe and there is a pressing need to spread knowledge and create motivation for changes in our part of the world. In order to clarify the complex needs of people with chronic illness and to outline practical possibilities for action from health and other institutions, the WHO Regional Office for Europe and its Collaborating Center, the Federal Center for Health Education in Cologne, Federal Republic of Germany, organized a major International Symposium on Health Promotion and Chronic Illness. I am confident that this publication – which is an outcome of the Symposium – will make a significant contribution towards strengthening the resolve of countries to take action that can improve the quality of life for the millions of people who, in Europe, not only struggle with the immediate effects of chronic disease and disability, but are still so often denied opportunities for exploiting fully their own potential for healthy living and a fulfilling life.

PREFACE

by Elisabeth Pott

The subject of health promotion and chronic illness appears first as contradictory, illogical, and even inconceivable. Does illness not exclude health? It is extremely difficult to achieve a consensus on the meaning of health between the various professional groups as well as between professionals and lay persons. But when it comes to health promotion, it is even more difficult to reach an understanding, especially with regard to its implementation within the health system.

The first International Conference on Health Promotion, organized by WHO in 1986 in Ottawa, was concerned with the need to establish definitions and outline strategies. Worldwide experiences in health promotion were evaluated, compressed into principles, and became the essence of the Ottawa Charter, which expresses the philosophy of health promotion and provides an orientation for action and evaluation standards. Two aspects of this Charter are of particular significance when dealing with chronic illness:

- first, the concepts of self-determination and participation, both at the level of the individual and of the community; these are expressed in three principles: advocate, enable and mediate;

- second, the ecological concept of health which calls for healthy public policies, supportive environments, strengthened community action, the development of personal skills and the reorientation of health services.

These various factors reciprocally influence each other and facilitate the achievement of health.

A "first" in health promotion

The Bad Honnef Symposium represents the first major international event in this new focus of health promotion on chronic illnesses. It brought together 84 participants from 12 European countries, Canada and the USA, representing a broad spectrum of disciplines: medical practice (including specialists in cardiology, rheumatology, oncology and chronic pain), epidemiology, psychology, physiology and physical medicine, as well as policy makers and administrators, researchers, medical journalists and

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representatives of governmental and non-governmental organizations and self-help groups.
The meeting was part of the continuing process of program development in health promotion in the WHO European Region, involving a long series of international seminars and workshops and research dealing with lifestyles, self-help and health promotion. Many of these activities have been organized in collaboration with the Federal Center for Health Education. This is linked to the fact that health promotion has been on the list of priority concerns in the Federal Republic of Germany for quite some time.
The workshop on "Healthy Cities", held in Dusseldorf two weeks prior to the conference on chronic illnesses is one outcome of this interest. It is related to a broad public health project initiated in 1982 with the purpose, in particular, to intensify health education/health promotion in public health services and give a new impetus to the use of positive models and innovative approaches. Its focus is on community and lay participation, on social and environmental factors, and on the implementation of new strategies at different action levels. These principles are in full harmony with those of health promotion as expressed in the Ottawa Charter.
The working world is another area where the Federal Republic of Germany has been keen to promote health promotion. The international conference organized jointly on this subject in 1985 by WHO and the Federal Center served to emphasize the considerable gaps which exist in this area with regard to the role of stress and the influence of psychosocial factors at the workplace. The conference also highlighted some very promising initiatives implementing a holistic approach to health.
Health promotion has therefore a long history, not only in the Federal Republic of Germany but in many other countries as well. The Ottawa Charter is the outcome of these trials and innovative approaches which show clearly that health promotion:

- is based on the concept of health as defined by WHO, i.e. physical, mental and social well-being;

- stems from a positive view of health which encompasses social, personal and biological factors;

- considers health as a resource for everyday life – not the objective of living; and last but not least,

- provides the broad strategies needed to achieve health for all by the year 2000.

These concepts take us beyond prevention, health protection and health education. Their central focus is on compounding individual approaches with structural measures, conventional health care with self-help and lay care, and psychosocial therapies with medical treatment. The active participation of the public, rather than its education, is seen as the key factor.

Enabling people to live a full life

Health education has considerably altered its style in recent years - from authoritarian to liberal, from deterring to positive. Yet, health itself is still often seen as an objective that can be best approached through fitness programs, ideal weight and dieting packages, and more recently through the aerobic movement. Starting from a broader context, health promotion aims to *enable* people to live a full life rather than to live for health. This implies feelings of self-worth and self-awareness, the capacity to be active and take decisions, the development of personal skills, the provision of support on a person-to-person basis or through a small network, and an environment conducive to health. In this perspective, health promotion becomes not only possible but *necessary* to cope with chronic illnesses.

The current concern with chronic illness is related to the steadily growing impact of this type of disease on the population. The greater the number of persons reaching the limits of life expectancy which is regarded as biologically possible, the greater the importance of "adding life to years", rather than "years to life" and of improving health and the quality of life. Policy and practice should no longer aim exclusively at protecting the healthy against illness in old age, but also promote an active and independent lifestyle for those already ill.

Health promotion of the chronically ill shows clearly the close link that exists between prevention, health education and health care, as well as the need to develop personal skills *and*, simultaneously, to create a supportive environment. In this perspective, a number of critical issues such as unequal health opportunities for different social groups, the influence of psychological and social factors on the occurrence and development of illness, and the impact that the workplace may have on health should no longer be ignored in favor of an individualistic health education approach.

To achieve these broad goals, we need to be concerned not only with the findings of medical research but also with those of epidemiology, of social epidemiology and of psychoneuroimmunology, which should be more actively applied in practical work. To be sure, knowledge derived from psychosomatic research is being more widely discussed today, both in public and medical circles, but this discussion has not been followed by action with regard to health promotion nor has it generated new approaches and therapies.

Four key issues

Which are the deficiencies in the provision of care that are felt most strongly by the chronically ill, and which are the factors with the most influence on the quality of life? These questions remain to be answered.

At present, the situation of the chronically ill is characterized above all by the fact that therapies applicable to acute illness are used for the treatment of chronic illness. This means, on the one hand, that the symptoms of the illness are treated instead of the person, and on the other, that the treatment aims only at curing instead of *focusing on how to help the patient* live with a long-lasting illness. Hopes are placed in the discovery of the miracle drug that will "one day" provide a cure. This attitude, rooted in the belief that research will ultimately solve the problem, is shared by many patients and doctors. But it overlooks the fact that the patient is much more likely to live with a chronic illness for the rest of his or her life. This has a number of *consequences*.

First, a chronically ill person – even more than a person suffering from an acute illness – needs *to know* how the illness will develop and what it will mean in his or her life. Psychological and psychosomatic knowledge provides a theoretical basis for intervention. However, as already mentioned, there is little practical application of this knowledge.

Secondly, the chronically ill person has to learn to accept the illness. This requires a considerable change with regard to the quasi-obligation, in our society, to be in "good health" – a concept which frequently narrows down to the ability to perform, to work, and to enjoy life. But health represents other values as well. This narrow concept, mainly concerned with productivity, does not do justice to the wish, deeply felt by chronically ill persons, to be treated *as subjects, as individuals, as suffering* human beings.

The chronically ill person has a need, and indeed a right, to receive the kind of support that will enhance these other values. This involves a change in our perception of illness, in our attitudes, and it requires the use of health promotion approaches.

Thirdly, the chronically ill person needs support *to cope* with the restrictions, the *isolation and the disruption of social contacts* resulting from a chronic illness; otherwise, further illnesses may develop. The provision of small networks, social support and self-help is a key requirement for the quality of life of the chronically ill, who depend in a particular manner on voluntary care and personal contact. These are important health promotion approaches.

Finally, we must overcome the lack of cooperation and coordination between the many different institutions working within the health and social security systems. At present, the support and care of the chronically ill is made considerably more difficult in many countries by this situation. The fact that protective care and institutionalized treatment represent still today the predominant health approach is a matter of serious concern. Reference needs to be made here to the concepts of the Ottawa Charter, particularly those concerned with *enabling* people to achieve their fullest health potential.

A clear objective

A number of factors which have a negative influence on the quality of life of the chronically ill require our full attention. They include:

- first and foremost, the social norms that exist regarding health and the resulting expectancy that everybody has to be in "good health", the word health being equated here with the capacity to perform, to work and to enjoy oneself;

- expectations from the medical profession linked to the progress of medicine, according to which chronic illnesses should no longer exist;

- the lack of support given to the chronically ill for coping with fears, social isolation, and helplessness; and

- the inability of the health system to react adequately to the situation.

Fundamentally, we should all take the view that even a chronically ill person has a considerable health potential and that this potential should be awakened, strengthened and promoted. A person suffering from an illness should not be reduced to the illness itself, but taken seriously as a human being in a state of illness. The Symposium has provided some sound suggestions on ways to achieve this objective.

INTRODUCTION

by Rosmarie Erben

Chronic illness represents a special challenge for the persons affected; for their families and social reference groups; and for the various environments and institutions concerned, namely the community, the workplace, and the medical and social services. The International Symposium on Health Promotion and Chronic Illness was called by the Federal Center for Health Education and the Regional Office for Europe of the World Health Organization to critically assess the experience and knowledge available to meet the rapidly growing needs of people suffering from chronic illness and suggest ways and means to strenghten their coping capacity and support those who care for them.

The types of practical help and measures that are necessary largely depend upon the nature and onset of the disease and its expected course. The disability that results, and the changes in physical integrity and bodily functions vary greatly. But more important yet, in developing adapted support measures, it must be recognized that persons suffering from a chronic illness are more than just "chronically ill people". Their daily life has a different starting point from which they not only perceive themselves and their environment but are in turn perceived by this environment.

Assessing the needs

What possibilities exist for self-help and mutual help? How can they be promoted and supported? What special requirements must be met in order to develop and promote the existing health potential of people suffering from chronic illness? How can their changing needs be met with regard to social relations, social recognition, nutrition, activity, affection and care? How is it possible, simultaneously, to respect and promote their personal development and independence as vital elements of their health?

Many of those affected by chronic disease have sought and developed quite individual ways of achieving a new and different quality of life. The rapid establishment of self-help groups in the medical field has been decisively influenced by people with chronic health problems.

Public institutions responsible for disease prevention and health care have hardly been able to keep pace with this development. Chronically ill people require more than straightforward welfare

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and institutional care. They need, in equal measure, information and practical guidance in self-help as well as support for their right to quality of life despite their "life-determining disease". Chronic illness only becomes a destructive stigma when society reduces such afflicted persons collectively to the status of "the chronically ill".
The aim of the Symposium was therefore:

- to clarify the complex needs of people with chronic illness, specifically those with chronic pain conditions (with emphasis on rheumatic diseases), cancer or recovering from a heart attack;

- to make a broad assessment of the personal and social implications of these diseases, as well as of the various options for health promotion;

- to identify corresponding needs for action from health and other institutions exercising social responsibility in the community.

The family and self-help groups, the workplace, the community, and the health care system were selected as areas from which a maximum of experiments could currently be drawn.

The process of the Symposium

With these objectives in mind, the Federal Center involved a large number of individuals, groups and organizations in the preparatory phase. This resulted in a most stimulating input from some 80 sources in Europe and North America, providing conceptual statements, overviews of current practice regarding the management of chronic pain, cancer and myocardial infarction, and specific examples of innovative projects illustrating health promotion in action.

The program of the Symposium provided experiences on four levels

First, the *plenary sessions* – Starting with statements on the program perspectives of WHO in the field of health promotion and reflections on health promotion and chronic illness, they went on to present recent findings and new concepts with regard to coping with the stresses of illness, chronic pain, complementary cancer therapies, institutional changes in relation to heart patients, the concept of the "healthy ill person", and the need for further education of physicians and medical personnel.
Second, a series of *working groups* enabled participants to exchange experiences in health promotion with regard to chronic pain, cancer and coronary heart disease, while a further session of working groups considered support activities in various settings: the

medical care system; families and self-help groups; the working world and the community.

The third aspect of the Symposium comprised *workshops* which provided for direct, personal experience in various complementary therapies, i.e. Feldenkrais exercises, visualization exercises for cancer patients, body perception in the treatment of myocardial infarction, and discussions on the underlying principles of alternative medicine.

The fourth dimension of the meeting – aimed at promoting interaction – was experienced in *the Bazaar*, an oriental market place where 24 innovative health promotion projects were presented by participants and invited groups on the second day of the Symposium. This particular feature of the meeting merits a special mention. Inviting participants to "stroll, chat and make contacts", it provided the kind of informal and relaxed atmosphere that is highly conducive to interaction. It started at 4 pm with a press conference and ended at 10.30 pm, officially... But at midnight, people were still discussing, arguing, explaining, experimenting with art therapy or with neuro-linguistic programing, obviously enjoying the experience and learning very much from each other. An open session entitled "Practice and idea exchange" also served as an "ice-breaker" at the beginning of the Symposium and enabled participants to meet informally and discuss their work and personal experiences.

A growing network

Participants in the Bad Honnef meeting unanimously adopted at the closing session a statement which outlines a strategy for action and pinpoints areas requiring urgent attention. They also voiced the feeling that the Symposium could well serve as a model for others concerned with similar problems at the national, regional or even local levels. It provided a good framework for stimulating the exchange of experiences and creating interlinkages between large numbers of professionals, groups and organizations in a position to influence the course of events.

With this book, this support-and-action network should greatly extend its scope and involve many more in the movement to improve the quality of life of persons suffering from chronic illness.

PART I

COPING WITH CHRONIC ILLNESS: CONCEPTS AND APPROACHES

1.

CONCEPTUAL FRAMEWORK

THE OTTAWA CHARTER FOR HEALTH PROMOTION

The first International Conference on Health Promotion, meeting in Ottawa this 21st day of November 1986, hereby presents this CHARTER for action to achieve Health for All by the year 2000 and beyond. This conference was primarily a response to growing expectations for a new public health movement around the world. Discussions focused on the needs in industrialized countries, but took into account similar concerns in all other regions. It built on the progress made through the Declaration on Primary Health Care at Alma Ata, the World Health Organization's document on Targets for Health for All, and the recent debate at the World Health Assembly on intersectoral action for health.

Health promotion

Health promotion is the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment. Health is, therefore, seen as a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy lifestyles to well-being.

Prerequisites for health

The fundamental conditions and resources for health are peace, shelter, education, food, income, a stable eco-system, sustainable resources, social justice and equity. Improvement in health requires a secure foundation in these basic prerequisites.

Advocate

Good health is a major resource for social, economic and personal development and an important dimension of quality of life. Political, economic, social, cultural, environmental, behavioral and biological factors can all favor health or be harmful to it. Health promotion action aims at making these conditions favorable through advocacy for health.

Enable

Health promotion focuses on achieving equity in health. Health promotion action aims at reducing differences in current health status and ensuring equal opportunities and resources to enable all people to achieve their fullest health potential. This includes a secure foundation in a supportive environment, access to information, life skills and opportunities for making healthy choices. People cannot achieve their fullest health potential unless they are able to take control of those things which determine their health. This must apply equally to women and men.

Mediate

The prerequisites and prospects for health cannot be ensured by the health sector alone. More importantly, health promotion demands coordinated action by all concerned: by governments, by health and other social and economic sectors, by non-governmental and voluntary organizations, by local authorities, by industry and by the media. People in all walks of life are involved as individuals, families and communities. Professional and social groups and health personnel have a major rsponsibility to mediate between differing interests in society for the pursuit of health.

Health promotion strategies and programs should be adapted to the local needs and possibilities of individual countries and regions to take into account differing social, cultural and economic systems.

HEALTH PROMOTION ACTION MEANS:

Build healthy public policy

Health promotion goes beyond health care. It puts health on the agenda of policy makers in all sectors and at all levels, directing them to be aware of the health consequences of their decisions and to accept their responsibilities for health.

Health promotion policy combines diverse but complementary approaches including legislation, fiscal measures, taxation and organizational change. It is coordinated action that leads to health, income and social policies that foster greater equity. Joint action contributes to ensuring safer and healthier goods and services, healthier public services, and cleaner, more enjoyable environments.

Health promotion policy requires the identification of obstacles to the adoption of healthy public policies in non-health sectors, and ways of removing them. The aim must be to make the healthier choice the easier choice for policy makers as well.

Create supportive environments

Our societies are complex and interrelated. Health cannot be separated from other goals. The inextricable links between people and their environment constitutes the basis for a socio-ecological approach to health. The overall guiding principle for the world, nations, regions and communities alike, is the need to encourage reciprocal maintenance – to take care of each other, our communities and our natural environment. The conservation of natural resources throughout the world should be emphasized as a global responsibility.

Changing patterns of life, work and leisure have a significant impact on health. Work and leisure should be a source of health for people. The way society organizes work should help create a healthy society. Health promotion generates living and working conditions that are safe, stimulating, satisfying and enjoyable.

Systematic assessment of the health impact of a rapidly changing environment – particularly in areas of technology, work, energy production and urbanization – is essential and must be followed by action to ensure positive benefit to the health of the public. The protection of the natural and built environments and the conservation of natural resources must be addressed in any health promotion strategy.

Strenghten community action

Health promotion works through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities, their ownership and control of their own endeavors and destinies.

Community development draws on existing human and material resources in the community to enhance self-help and social support, and to develop flexible systems of strengthening public participation and direction of health matters. This requires full and continuous access to information, learning opportunities for health, as well as funding support.

Develop personal skills

Health promotion supports personal and social development through providing information, education for health and enhancing life skills. By so doing, it increases the options available to people to exercise more control over their own health and over their environments, and to make choices conducive to health.
Enabling people to learn throughout life, to prepare themselves for all of its stages and to cope with chronic illness and injuries is essential. This has to be facilitated in school, home, work and community settings. Action is required through educational, professional, commercial and voluntary bodies, and within the institutions themselves.

Moving into the future

Health is created and lived by people within the settings of their everyday life; where they learn, work, play and love. Health is created by caring for oneself and others, by being able to take decisions and have control over one's life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all its members.
Caring, holism and ecology are essential issues in developing strategies for health promotion. Therefore, those involved should take as a guiding principle that, in each phase of planning, implementation and evaluation of health promotion activities, women and men should become equal partners.

Commitment to health promotion

The participants in this conference pledge:

- to move into the arena of healthy public policy, and to advocate a clear political commitment to health and equity in all sectors;

- to counteract the pressures towards harmful products, resource depletion, unhealthy living conditions and environments, and bad nutrition; and to focus attention on public health issues such as pollution, occupational hazards, housing and settlements;

- to respond to the health gap within and between societies, and to tackle the inequities in health produced by the rules and practices of these societies;

- to acknowledge people as the main health resource; to support and enable them to keep themselves, their families and friends healthy through financial and other means, and to accept the community as the essential voice in matters of its health, living conditions and well-being;

- to reorient health services and their resources towards the promotion of health; and to share power with other sectors, other disciplines and most importantly with people themselves;

- to recognize health and its maintenance as a major social investment and challenge; and to address the overall ecological issue of our ways of living.

The conference urges all concerned to join them in their commitment to a strong public health alliance.

Call for international action

The Conference calls on the World Health Organization and other international organizations to advocate the promotion of health in all appropriate forums and to support countries in setting up strategies and programs for health promotion.
The Conference is firmly convinced that if people in all walks of life, non-governmental and voluntary organizations, governments, the World Health Organization and all other bodies concerned join forces in introducing strategies for health promotion, in line with the moral and social values that form the basis of this CHARTER, Health For All by the year 2000 will become a reality.

A CONCEPTUAL FRAMEWORK: THE OTTAWA CHARTER

by Ilona Kickbusch

Health promotion is concerned with enabling people to maximize their health potential. *From whatever point one starts in life*, whether as a healthy baby or as somebody who has already gone through many life crises and has become chronically ill, *health and well-being can be enhanced and developed*. Such is the strong belief underlying the experiences and research reported in this book.

It stems from the *Charter on Health Promotion*, culminating point of the First International Conference on Health Promotion held in Ottawa, 17-21 November 1986. The Conference marked a new landmark in public health. It was jointly organized by the World Health Organization, Health and Welfare Canada and the Canadian Public Health Association, and brought together 212 participants from 18 countries – lay, health and other professional workers, representatives of governmental, voluntary and community organizations, politicians, administrators, academics, and practitioners.

In adopting the Charter, participants made very clear the need to mobilize all resources towards the goal of health for all and the fact that this goal cannot be achieved by the health sector alone. Health promotion demands coordinated action by governmental and voluntary organizations, by local authorities, industry, and the media. All sectors share responsibility in raising individual and collective levels of health.

This broad outlook is an outcome of the discussions on lifestyles which originated at WHO/EURO a few years ago and were followed by a series of stimulating discussions on self-help, the work environment, healthy cities and finally health promotion and chronic illness. This continuity in thinking, research and action is significant.

Towards a new public health movement

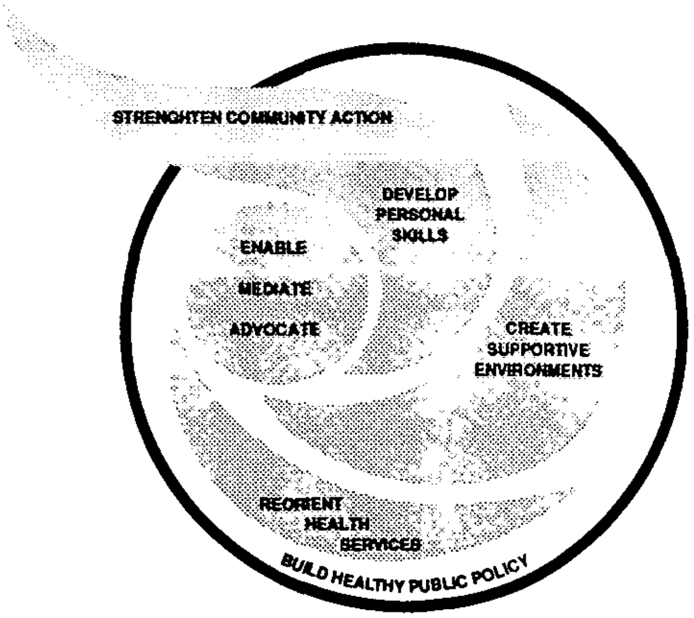
The health promotion concept, with its focus on personal participation, social and cultural factors and environmental conditions, represents a definite departure from the medical model. It puts health on the agenda of policy makers in all sectors and at all levels, it states that health aspects should always be taken into account in *shaping public policy* and reminds those who shape it that they are accountable for the health consequences of their decisions.

Health promotion calls for efforts to generate living and working conditions that are safe, stimulating, satisfying and enjoyable, i.e. *creating supportive environments*.

It urges a redelegation of responsibilities in health through the *strengthening of community action*. Developments in the community should also serve to define policy priorities: policy cannot be shaped in an ivory tower; it must emerge from a constant interaction with the community.

Health promotion stresses the importance of *developing personal skills* and enabling people to learn throughout life, to prepare themselves for all of its stages, and to cope with chronic illness and injuries.

Last but not least, it calls for a *reorientation of health services:* they need to become once again part of the community responsibility and to be sensitive to the total needs of the individual as a whole person.



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Three key strategies

Health promotion is "the process of enabling people to increase control over, and to improve, their health". It claims the importance for individuals and groups to be able "to identify and to realize aspirations, to satisfy needs and to change or cope with the environment" if a state of complete physical, mental and social well-being is to be achieved.
This concept highlights health as an essential element of the quality of life, both personal and social, which can be promoted at every stage of life. It also reflects the concern that health should not be misunderstood for health*ism* and the need to be very realistic and look at health in the context of people's everyday life. Health is seen as a positive concept emphasizing social and personal resources as well as physical capacities.
Three strategies are at the heart of health promotion:

- enabling action;
- mediating action; and
- advocating the interests and needs of people.

These three strategies are of particular importance in relation to chronic illness where the *enabling role* is needed to maximize the health potential of the persons affected; the *advocating role*, to promote the rights of those who do not have their full physical capacity; and the *mediating role*, to establish closer communication between the chronically ill and the part of society that defines itself as healthy.

Enhancing people's capacity to cope: the real challenge

The concept of health promotion for people with chronic illness is still in its infancy in medical practice. Public institutions responsible for disease prevention and health care have usually a very negative approach to chronic illness. Even at the level of health policies, many health promotion policies focus on prevention and promotion but do not extend to the broader dimension of *enhancing people's capacity to cope* with chronic conditions.
What is it that makes it possible for certain people to cope better than others? What are the supportive environments and the personal skills that enable some individuals and some families to deal with severe health problems more easily than others?
Enhancing this capacity to cope is the real challenge facing the chronically ill persons themselves, their families and their social network, as well as the caregivers – both professional and lay – and the various institutions concerned in the community, at the workplace, in the medical and social services. This includes *the non-governmental sector*: over the years – I should say, over the centuries – private organizations have been some of the first to take action in relation to disability, representing either the chronically ill themselves, or family members and relatives, or those who had to care for them.
There is an urgent need therefore to critically assess the experience and knowledge available. The Ottawa Charter urges the examination of current concepts and practices and the development and implementation of new approaches.
In the case of chronic illness it means exploring ways to deal with everyday stresses and anxieties in a way that does not always require medical intervention; it means taking seriously new ways of coping with pain, of using our limbs and senses; it means being concerned about the caregivers whose capacity to manage is no less important than the health of those for whom they care.
It also means moving away from these blocks and narrow sectors we have developed, that are called promotion or prevention here and rehabilitation there, and which perhaps mix in a more complex manner in relation to public health than we thought so far.

COPING WITH THE STRESSES OF ILLNESS

by Richard S. Lazarus

Abstract

How can we cope better, or help others to do so? The answer to this depends on knowing what an individual is coping with. This, in turn, depends on the appraisal, by the individual concerned, of the significance of what is happening for well-being – in effect, the source of harm, threat, challenge.
Cases of myocardial infarction, cancer and chronic pain have some harms, threats, and challenges in common but there are also unique factors in each illness. The patient with a chronic illness is continually appraising his or her symptoms, pains, disease progression with respect to their significance for well-being and survival, and coping accordingly.
The paper presents a microanalytic, contextual and process-centered approach to coping which is part of a broad system of thought, emphasizing cognitive appraisal and the person's ongoing relationships with the environment as factors of his or her emotional life.
Implications for prevention and treatment of illness in a perspective of health promotion are discussed as well as the need for research to predict long-term outcome from stress and coping.

Illness often imposes on us severe, acute, chronic, or recurrent conditions of psychological stress. At least three main types of stress-provoking chronic illnesses can be distinguished: *terminal* (with or without a sense of hope), *disabling*, and *life threatening*. Although it may share certain features with disabling illnesses, a fourth illness-related condition, *pain*, involves a unique blend of psychological and somatic causation and consequences, and has its own strategies of treatment.
Coping is the prime concern of this paper, especially theory and methodology in the study of the coping process. The central question in coping is a complex one, namely, *which forms* of coping, *in which persons*, and *under which conditions* result in positive and negative short- and long-term adaptational outcomes? A satisfactory empirical answer would also create a corollary question, namely, whether we can teach people to abandon dysfunctional forms of coping in favor of functional ones. I am not sure that anyone has yet provided, or can provide, a good answer to this question.
There are a number of issues about illness that require theoretical attention and their own research strategies. The major issues concern:

1) the possibilities and mechanisms of *psychosocial causation* and/or exacerbation of any given illness;

2) the difficult problem of demonstrating that *stress and coping have causative roles in illness;*

3) *the psychosocial overlaps and differences among the diverse types of illness,* for example, cancer and heart disease or subvarieties of cancer such as breast and lung cancer, or congestive heart disease and post-coronary conditions. A very important principle is that biomedical classifications may have little to do with psychological similarities and differences among illnesses that are based on whether there is a threat to life, disability, pain or interpersonal implications, and whether they have comparable requirements of daily management by the patient and caregiver. Therefore, while comparable in life threat, cancer and heart disease have markedly different psychological stress profiles; this applies to different types of cancer as well.

1. The traditional approach to coping

Ignoring the animal model of coping, which is limited mainly to avoidant and escape

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behavior under noxious conditions, the traditional clinical and research approach to coping has followed the *psychoanalytic ego-psychology* tradition. This has centered on broad, stable ways of thinking and dealing with one's personal agendas and the environment, and assumes hierarchies of ego-functioning ranging from the most healthy to the most pathological (Menninger, 1954; Vaillant, 1971, 1977; Haan, 1969, 1977). Haan, for example, uses the term *coping* for the most healthy or mature ego-processes, *defense* for neurotic ego processes, and *ego-failure* for fragmented or the most seriously disordered forms of adaptive activity; (healthy) coping is characterized by good reality-testing and flexibility, whereas (pathological) defenses are rigid and forced compulsively from within.
There are many problems with this traditional approach to coping. Some of the most important are the following:

1) the ego-psychology model, although it is a process theory of coping, has tended to generate *static, unidimensional typologies* for the measurement of coping, for example, repression-sensitization (or avoidance-approach), and the defense mechanism inventory (Gleser and Ihilevich, 1969), which assumes stable *styles of coping* compatible with concepts like Shapiro's (1965) neurotic styles;

2) unidimensional coping style concepts do not help us understand or predict what a person will think or do to cope in the specific stressful encounters of living. Clinically, we know that coping is complex and variable rather than simple and stable. For example, a person with cancer might deal with each of the many threats created by the illness quite differently; though not denied, the threat of death might be avoided in thought and action. However, when it comes to the threats involved in having to speak with friends or relatives about the illness, the coping process in that same person could be denial or distancing. And with pain or disfigurement, still another form of coping might be chosen. In short, many diverse coping thoughts and acts may occur in the illness context, each one dealing with different threat facets or at different moments or stages of the illness.

Broad styles of relating to the world do not usually help us to predict coping processes at a more microanalytic level. Yet, it is essential to know about coping at this level if we are to understand how the person is dealing at different times with the multiple harms and threats of a personal and social experience as complex as an illness like cancer. Thus, after mastectomy, a woman who can successfully avoid thinking about an uncertain prognosis when away from the hospital and working or taking care of the children will probably be unable to engage in avoidance the day before her appointment for a CAT scan. We must be able to describe what is going on as the coping process changes over time, as the illness improves or regresses, and as the patient deals with each type of threat.

2. The Lazarus-Folkman approach to coping

The above problems of the ego-psychology approach to coping, and the need for more detailed information, led in the late 1970s to a newer approach. For example, Folkman and I turned to a different approach for the conceptualization and measurement of coping (Folkman & Lazarus, 1980; 1984a; 1984b; 1985; 1986; in press; Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986; Folkman, Lazarus, Gruen & DeLongis, 1986; Folkman, Lazarus, Pimley & Novacek, 1987.
A similar approach was also being evolved at the same time by others such as Pearlin (Pearlin, Lieberman, Menaghan & Mullan, 1981; Pearlin & Schooler, 1978; Stone & Neale (1984); Moos & Billings, 1982).

The newer, more microanalytic, contextual and process-oriented approach has four key features:

1) there is an emphasis on the *description of thoughts and actions* that are taking place or have taken place in specific stressful encounters or at various stages of a stressful encounter;

2) the measurement is contextual, process-centered, and transactional. That is, we do not ask what the person might have done or thought, or usually does, but what actually happened in a *particular context*. In addition, the assumption is made and evaluated that what happens or happened *changes with time* (as a process) or with the *changing context*. Finally, what is done and thought is considered to be the result of the *active interplay* of person and environment (transaction) and depends on the changing psychological *relationship* between person and environment;

3) the design of the research observations

of coping requires that the same person (or persons) be assessed from moment to moment or from one context to another in order to evaluate stability and change in coping thoughts and acts;

4) one must be wary about evaluating whether any given coping process is inherently good or bad since this depends on the particular person, the personal agendas the person carries into situations, the type or stage of the stressful encounter, and the particular outcome of concern, i.e. subjective well-being, social functioning or somatic health. I shall have more to say later about whether some forms of coping are generally more favorable in outcome than others, as is usually assumed in the ego-psychology model (Vaillant, 1977).

Lazarus and Folkman (1984) define coping as constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. This definition is process-centered rather than trait-centered, implies a distinction between coping and automatized adaptive behavior by limiting the concept of coping to conditions of stress, uses the term "efforts" in order to avoid confounding the coping process with its success or failure in producing good or poor outcomes, and uses the term "manage" which can include minimizing, avoiding, tolerating, and accepting negative conditions of life, thus avoiding the equation coping = mastery.

2.1 The Ways of Coping checklist

The earliest version of our coping measurement procedure (Folkman & Lazarus, 1980) was based on a theoretical analysis of coping by Lazarus & Launier (1978), and several earlier treatments of the subject (Lazarus, 1966; Lazarus, Averill & Opton, 1974). In the checklist we asked subjects to identify a recently experienced stressful encounter and to indicate whether they had used each of 67 coping thoughts or acts in that encounter. Later we revised the checklist, which resulted in the present version of 66 items, and added a Likert scale addressing how much a coping thought or act had been used, which made it possible to perform a rigorous factor analysis that resulted in eight coping factor subscales (Folkman et al, 1986a). The psychometric properties of this revised Ways of Coping Scale have been reviewed by Tennen & Herzberger (1985). And the scale, or the basic approach, is widely employed to study coping with stress in general, and coping with the stresses of illness in particular. The eight scales of the Ways of Coping comprize variations of the two basic functions of coping we have long emphasized, namely, problem-focused and emotion-focused coping.
Problem-focused coping consists of efforts to change the actual circumstances of an adaptational encounter, e.g., by changing the environment or oneself. This includes:

- *confrontive coping* (e.g. stood my ground and fought for what I wanted;

- *self-control* (e.g. I tried to keep my feelings to myself);

- *seeking social support* (e.g. talked to someone who could do something concrete about the problem);

- *accepting responsibility* (e.g. criticized or lectured myself);

- *planful problem-solving* (e.g. I knew what had to be done, so I doubled my efforts to make things work).

Emotion-focussed coping involves purely cognitive activities that do not directly alter the actual relationship with the environment but do alter how this relationship is cognized. This includes:

- *distancing* (e.g. went on as if nothing had happened);

- *escape-avoidance* (e.g. wished the situation would go away or somehow be over with);

- *positive reappraisal* (e.g. found new faith).

Thus, one can try to control what is attended to, say by avoidance of certain facts or their implications, or one can attempt to reappraise these facts or their implications, for example, by denial or distancing. Emotion-focused or cognitive coping regulates emotional distress by affecting what is being attended to or by changing its meaning. When this process succeeds, there is little or no reason to experience emotional distress since the harmful or threatening relationship has been made subjectively benign. This approach to coping measurement has been discussed in considerable detail in our published research with the scale, in our monograph (Lazarus & Folkman, 1984), and in a recent analytic review of our metatheory, theory, and methodology (Lazarus & Folkman, 1987). In this paper, I will offer only some broad-brush generalizations from our research on coping over the past ten years.

2.2 Empirically based generalizations

Since a process formulation about coping requires both intraindividual and interindividual research designs and data analyses, we have regularly – usually simultaneously – employed both in our research. In intraindividual analysis, the coping of the persons or the samples in one encounter is compared with the coping in another encounter, which is a way to learn about the influence of the stressful context. In interindividual analysis, every person's coping is averaged or aggregated in some way across all stressful encounters, and then compared across persons or subgroups.

2.2.1 Inter-individual (normative) generalizations

a) Most people use nearly all eight forms of coping in every stressful encounter, although the emphasis on one or another form of coping changes with the *type of encounter,* the *way it is appraised,* and the *particular person.*

b) The pattern of coping changes from one stage of an encounter to another. We have found this to be the case, for example, with students coping with an examination (Folkman & Lazarus, 1985). In the anticipatory stage just before the exam, students tended to *seek information* from others and otherwise engage in *problem-focused* coping; however, after the exam but before grades were announced, the predominant form of coping shifted to *distancing,* which was sensible since there was nothing to do but wait. Other forms of emotion-focused coping were emphasized after the outcome of the exam had been announced. The changing mental state at different points in time has also been amply documented by disaster researchers who recognize warning, confrontation, and post-confrontation as stages. If a researcher tries to summarize what has happened over the three stages, as is usually done when an exam is treated as a single stressful event, there will be considerable distortion about the actual and changing psychological processes in each individual and for the total group.

c) Some forms of coping are more stable than others, that is, people who use them heavily in one stressful encounter tend to use them heavily also in other encounters; conversely, other forms of coping are heavily contextual, meaning that they show very little stability across stressful encounters over time. In our research (Folkman, Lazarus, Gruen & DeLongis, 1986), *problem-focused* coping strategies tended to be highly *variable* across stressful encounters; autocorrelations over five encounters averaged from .17 (seeking social support) to .23 (planful problem-solving). However, some *emotion-focused* coping strategies tended to be moderately *stable;* the average autocorrelation for positive reappraisal was .47 and for self-controlling coping .44. This suggests that most problem-focused forms of coping are very responsive to *contextual factors* whereas certain emotion-focused forms are influenced mainly by *person factors.* The stability and variability of coping over time and across diverse stressful encounters becomes a very important issue when we wish to use coping to explain and predict long-term mental and physical health outcomes.

2.2.2 Intra-individual (ipsative) generalizations

a) The strategy of coping employed by a person depends on the type of *stakes* that person has in the outcome of a stressful encounter. For example, when their self-esteem is at stake, people are wary of seeking social support from others compared with occasions in which other goals are at stake. Shame seems to make us want to hide from others, which is why people would rather be alone to face a bad situation involving shame rather than seek comfort from others; however, social support or comfort will be sought when there is anxiety – without shame – about one's own or another person's well-being. This is an example of the role of what we have been calling *primary appraisal* in the choice of coping strategy (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986).

b) The strategy of coping employed by people also depends on whether or not they think *something can be done to change* harmful or threatening conditions for the better. When little or nothing can be done, the emphasis is apt to be placed on emotion-focused coping processes such as avoidance or distancing. On the other hand, when the person judges that the situation is changeable or controllable, problem-focused strategies will predominate. This is an example of the role of what we have been calling *secondary appraisal* in the choice of coping strategy (Folkman et al, 1986a).

c) Coping is clearly a *mediator* of emotional reactions generated in a stressful encounter. I am using the term mediator to refer to a process – generated in the encounter that actively changes the mental state that would have occurred in its absence – rather than as a variable that is present at the outset. The latter type of variable is usually referred to as a *moderator*. The theoretical and methodological distinction between mediators and moderators has only recently been explained and emphasized (Baron & Kenny, 1986; Zedeck, 1971) and is now also being applied to stress and coping (Frese, 1986; Stone, 1985).

Our findings show clearly that coping affects emotions during stressful encounters. Drawing on data from two studies and using a series of hierarchical regression analyses, we found that some forms of coping increased positive emotions such as feeling confident and being happy, and decreased negative emotions such as being worried and angry, from the beginning of the encounter to the end. On the other hand, other forms of coping made things worse. Specifically, planful problem-solving appeared to have a salubrious effect on the emotional state, whereas confrontive coping and distancing appeared to make things worse in our subjects and under the particular stressful conditions they described.

2.3 Functional and dysfunctional coping

Are we in a position to claim that some forms of coping, say, wishful thinking (a part of the escape-avoidance factor), are dysfunctional, and that other forms of coping, say, planful problem-solving and positive reappraisal, are functional? It is probably a good guess that much of the time wishful thinking is counterproductive because (a) it expresses desires and expectations that are not in keeping with the realities of a stressful encounter, and (b) it is incompatible with realistic problem-focused actions. Rather than wishful thinking, which defeats planful and constructive action, it is probably useful to have positive thoughts about what might be done to actualize one's preferred goals. Our data show in fact that positive reappraisal is commonly associated with planful problem-solving, suggesting that the former is compatible with and perhaps facilitative of the latter; wishful thinking does not show this pattern.

Recent studies and thoughtful analyses (Scheier & Carver, 1987; Scheier, Weintraub & Carver, 1986) give testimony to the principle that the tendency to be optimistic in the face of negative events can be an asset with respect to long-term adaptational outcomes such as subjective well-being and somatic health. These authors suggest that optimists use different coping strategies than pessimists, including a greater emphasis on sustained problem-focused coping: they are likely to be realistic, and to use emotion-focused coping strategies such as acceptance/resignation only when the situation is appraised as uncontrollable. As Singer & Killigian (1987, p. 542) have put it, "At least in our society it seems likely that we sustain positive emotional states and a consequent tendency towards relatively effective day-to-day action through a pattern of illusory hopefulness." I would wish to add here that optimism or positive thinking and positive reappraisal alone, in the absence of planned and sustained effort to deal with real problems, can also be a dangerous outlook, since the real problems remain to haunt us later.

Despite the possibility that some forms of coping might be generally functional or dysfunctional, we have consistently argued that any given coping process may have favorable or unfavorable results depending on who uses it, when it is used, under which circumstances, and with respect to which adaptational outcome. We are wary of making strong generalizations about good and bad coping because of our premise that *the functional value of the coping process can seldom if ever be divorced from the context in which it occurs.* A sound conceptualization about this might be that what is good or bad about the coping process depends on its *fit* with the situational and intrapsychic requirements of an adaptational encounter. We believe that researchers need to examine the coping process and its outcomes under diverse stressful conditions before any generalizations are made about this.

Although observations are relatively scarce, others have obtained findings that support our contextual emphasis. For example, Collins, Baum & Singer (1983) found that the residents of Three Mile Island who persisted in problem-focused efforts after a nuclear accident showed more psychological symptoms than residents who used emotion-focused efforts. Given the circumstances, problem-focused strategies were unrealistic since there was little to be done to change the actual situation, and persisting in trying to do so was unproductive. On the other hand, engaging in emotion-focused or cognitive coping processes, such as distancing, denial, avoidance, or positive reappraisal, fit the requirements of the situation better. It is probably unnecessary to note that this principle has major ramifications for coping with illnesses that are refractory to change. It is also in keeping with the motto of Alcoholics Anonymous, which states: "God grant me the serenity to accept the things I cannot change, courage to change the things I can, and the wisdom to know the difference." Here we have a statement of the distinction between problem- and emotion-focused coping, of the principle of secondary appraisal, and of reality-testing, all integrated within a common bit of folk wisdom.

3. Dilemmas in predicting long-term adaptational outcomes from stress and coping

In moving away from the older tradition of broad, general styles of thinking about and relating to the world and engaging in a microanalytic, contextual and process formulation of coping as specific thoughts and acts employed to manage particular stresses of living, have we sacrificed the potential of the coping concept to help us understand and predict long-term adaptational outcomes? There is indeed some risk of this in our approach. Others as well as ourselves have had only modest success in establishing an empirical relationship between coping or appraisal and long-term outcomes. One reason for this may be the highly contextual and therefore variable nature of appraisal and coping processes. To explain and predict long-term outcomes requires that we measure mediating processes that are stable enough to yield a representative index of what a person does in confronting countless stressful encounters over a substantial period of life or in an ongoing long-term crisis such as major illness. Our autocorrelations of coping processes over five stressful encounters, occurring over five months, do not reveal much stability even for the more stable coping strategies: after all, a correlation of approximately .5 accounts for only about 25 percent of the variance. So it is possible that a microanalytic approach to coping will be inadequate when it comes to predicting long-term health outcomes.

When we came upon the scene, the macroanalytic ego-psychology strategy of seeking broad styles of coping was already failing, and had left us unable to describe what a person actually did to manage specific stresses such as those occurring in major illness. The microanalytic approach, however, has not been applied long enough, or with the appropriate longitudinal designs, to tell us how far it can take us in explaining and predicting long-term adaptational outcomes.

3.1 What is the influence on health status?

What are the major, unresolved *dilemmas* that thwart attempts to demonstrate what we all believe, namely, that stress and the ways it is coped with affect subjective well-being, social functioning, and health status? I want to discuss four of these dilemmas briefly, especially as they apply to health status, because I believe they are not widely or well understood.

1. Health status is affected by a very large number of factors, including genetic-constitutional ones over which we have little or no control, accidental factors, and a host of lifestyle factors. After the variance contributed to health status by these factors has been accounted for, the remainder on which to assess the influence of stress and coping – or try to influence it by intervention – is probably quite modest. This makes it difficult to demonstrate to everyone's satisfaction that stress and coping affect health, even if we employ the appropriate longitudinal and multivariate or systems research designs.

2. The conceptual and methodological guidelines for evaluating health are inadequate. This can be illustrated by the problem of how to weigh various physical conditions, diseases, and symptoms in creating a *measure of health status.* Should we, for example, center attention on *longevity* or on *functioning* as a criterion? Mucous colitis probably has little relationship with longevity, but it can have a major impact on daily functioning; a person who can barely leave the vicinity of a toilet is apt to be considerably

handicapped in social relations and work. On the other hand, hypertension is a major risk factor for heart attack and stroke, but if the person is unconcerned about it and if it is untreated, it will have little or no impact on social or work functioning. It makes a big difference in the assessment of a person's health whether we emphasize longevity or the quality of social functioning.
Another difficulty is that somatic health is confounded with factors that are largely psychological in nature, for example, energy level and the sense of physical well-being. Should these factors be separated, and if so, how?

3. Health status, as it is usually measured, is a very stable variable. In our research, its test-retest correlation over one year was .69 in one sample, and in another sample it was .59. To show effects on health requires change. Change is apt to be greatest in early life, in old age, during the course of major illness, and perhaps under prolonged stress.

4. Finally, as I noted earlier, to show the role of stress and coping in long-term health, say, over a period of one or more years, requires that we identify stable stress and coping processes during the time interval in question because it is not what happens in a single stressful encounter that affects long-term outcomes but what we do time and time again over a long period. There are two possible alternatives to the solution: first – though doing this successfully now seems improbable – researchers must identify a stable stress and coping pattern from one or a few observations during the first period, which can serve as a predictor; or second, researchers must be in a position to monitor stress and coping processes in any given person or group over the time interval in question.

If, as I have said, many coping strategies are unstable, or if as I think is true, no single stressful episode can stand for stress that is typical of the person without this being checked out by repeated measurement over time, then it becomes necessary to monitor what is happening in the person's life in the interim between the first and second periods to determine the stable stress and coping processes that might have an influence on long-term health.
In research to date, longitudinal designs in which what is going on in stress and coping in target persons or groups is monitored carefully over time have been extremely rare, and when they have been done the time periods involved have been very short (Caspi, Bolger & Eckenrode, 1987; DeLongis, Folkman & Lazarus, 1988; Eckenrode, 1984; Stone & Neale, 1984). There is an irony in the fact that although the study of stress, coping and long-term health outcomes requires careful monitoring of stress and coping processes and of these outcomes over time, the economics of research forces us to examine this important problem with less costly and inadequate cross-sectional research designs. I fear this is very shortsighted and, as we have seen above, constantly limits what we can say about whether and how stress and coping processes affect these health outcomes. One can only hope that newer biomedical concerns about how the immune process is affected by stress and coping will encourage a stronger commitment to the study of the covariation of these mediating processes over significant time periods, together with the neurological and biochemical features of the immune response and other physiological changes. To do this would be costly, but eminently worthwhile.

4. Practical and clinical implications of stress and coping theory

Although I have dealt above only with coping, the theory, metatheory, and methodology of my approach is part of a much broader system of thought that also emphasizes cognitive appraisal and the person's ongoing relationships with the environment as factors in his or her emotional life (Lazarus & Folkman, 1984). This system of thought has a number of implications for those concerned with intervening in the prevention and treatment of illness and in health promotion and I will now take up three issues of widespread interest which I believe have not received enough thoughtful attention: (1) socio-cultural prejudices about how a psychologically healthy person should think and feel; (2) the multiple meanings of social support; and (3) the importance of understanding what is going wrong in an individual or group in trouble and, conversely, what is going right.

4.1 Prejudices about mental health

For a long time, mental health professionals have assumed that certain types of coping processes, most notably *denial* are pathological or pathogenic. Our professional culture has said that a mentally sound person does not engage in denial, and should be encouraged to abandon it as a coping strategy that is not in the best interests of mental health.

One thing wrong with this view is that most, if not all people, including quite sound ones, use denial-like modes of coping from time to time (Lazarus, 1983). There are occasions, for example, when nothing can be done to alter a damaging situation and when denial-like modes of coping may not only be necessary but will also have positive consequences. The positive value of denial-like coping processes may be illustrated with a personal disaster such as spinal cord injury; immediately following the injury, the person usually does not yet have the psychological or physical resources to examine what has happened realistically and to mobilize systematic efforts to deal with it in a planful way. The continuance of this mode of coping beyond the initial stage of the crisis is apt to be counter-productive; the stricken person must ultimately come to terms with the handicap, at which time there is apt to be some depression and anger, and address it in a problem-focused way. Nevertheless, denial may be the most constructive mode of coping in the early stages. Moreover, a growing body of research, though showing somewhat conflicting results, has suggested that denial-like forms of coping may have value in post-coronary care and recovery (Hackett & Cassem, 1975; Hackett, Cassem & Wishnie, 1968; Levine, Warrenburg, Kerns et al, 1987; Shaw, Cohen, Fishman-Rosen, Murphy, Stertzer, Clark & Myler, 1986).

I have used the clumsy expression "denial-like" coping to point out that there are a number of seemingly related but different types of denial that may not all be equally valuable or dangerous. Thus, *denial of the fact* of handicap or illness, say a cancer with poor prognosis, is certain to require being abandoned in time as the symptoms worsen and the denial of the fact of illness becomes more difficult or even impossible to sustain. On the other hand, *denial of the most negative implications* of handicap or illness, such as the imminence of death or the end of worthwhile living, is less vulnerable to disconfirmation. The expression denial-like coping helps us understand that many processes of denial look alike but are quite different in content and consequences. For example, avoidance may mimic denial in that the person refuses to talk or think about negative aspects yet fully understands them; thus, a terminal cancer or AIDS patient may be unwilling to speak of the future with others, yet this is not denial because the bleak situation is not necessarily disavowed.

What is happening with respect to coping is often nature's way, so to speak, of helping the person through a crisis, and we need to be wary about making hasty and unwarranted judgments about the *functional or dysfunctional* character of the coping process. Rather, we should take into account the circumstances being faced, the timing or stage, the alternatives, and the person's agendas and resources, all of which are important considerations about the adequacy of coping and its consequences for well-being.

Related to the above is the paradox that although we tend to be prejudiced against denial, we also encourage it by *trivializing distress* in people who are facing illness crises (Lazarus, 1985; Wortman & Lehman, 1985). Health care professionals do this by downplaying the negative and accentuating the positive, which undermines the sense of the legitimacy of ill persons' distress. It is as if one were saying to the victims of tragedy that they have no right to feel bad about having lost what they regard as the most precious of life's possessions. Distress is treated as unworthy and even pathological, a failure of good coping. As a consequence many patients must inhibit expression of their real feelings or deny them, and all this leads them to doubt that they are either understood or accepted as they are (Coates & Wortman, 1980; Weakland, Fisch, Watzlawick & Bodin, 1974).

The motivations for trivializing distress are sometimes altruistic, as when we believe that positive thinking can overcome misfortune, and self-serving, as when we are threatened by the failure of justice and blame the victim (Lerner, 1980) or discomforted by the emotional demands ill persons make on us (Hackett & Weisman, 1964). The mechanization of medical treatment today also increasingly distances the patient from health care personnel.

4.2 The multiple meanings of social support

Specialists in health care need to be clear about these meanings because the distinctions among them are relevant to social support interventions, which are of great importance both in professional practice and for lay self-help groups. There are four main meanings of social support: support as (a) subjectively available; (b) profferred when needed; (c) received; and (d) sought or used in stressful encounters.

a) The most common approach to social support is as *subjectively available* in the social environment; the person believes he or she can count on others for information, tangible aid, and/or emotional support (Schaefer, Coyne & Lazarus, 1982). This approach says something about how the person perceives the social environment but not about how things actually are (Antonucci & Israel, 1986; Heller, Swindle & Dusenbury, 1986). Therefore, this social support variable may be predictive of the person's usual sense of well-being, but is not necessarily of relevance to interventions under conditions of stress.

b) Social support *as profferred in stressful encounters* refers to what significant figures or clinical workers actually offer the person. However, lack of skill and sensitivity to the person's psychological needs, on the one hand, and that person's willingness to accept or use the support, on the other hand, often makes what is profferred irrelevant (Lehman, Ellard & Wortman, 1986; Dunkel-Schetter, 1984). Mechanic's classic observations (1962) on the often faulty efforts by spouses to offer reassurance to their student marital partners who are facing a crucial examination points up how important it is to have the right kind of social support, and the need to train those who might help in how to provide it. For example, a spouse who tries to reassure the anxious student by saying that she is not at all concerned because she knows he (the student) will do fine, adds to the threat because the sense of threat is thereby challenged, adding to the existing pressure. On the other hand, the spouse who states that she understands and shares the apprehension – after all, the stakes are high – but who also adds that they will manage whatever the outcome, accepts the sense of threat – validating the student's judgment – and offers the reassurance that as a couple they will come through whatever happens, thereby lowers the threat and confirms the soundness of the relationship.

c) The above discussion points to a distinction between what is offered and what is *actually received* by the person in times of stress. These are not necessarily the same. If we measure what is offered we may not be taking into account what is received; what is received is a more proximal variable than what is offered by the environment. The person may not take what is offered as genuine, or may not be able to accept it because of a contrary value that to accept help is to prove oneself inadequate.

d) Social support as *sought and used* in stressful encounters comes closest to the concept of the coping process. A person may or may not use what is perceived to be available or may solicit it as a strategy of coping. The close connexion between social support and coping is beginning to be recognized (Thoits, 1984; Heller, Swindle & Dusenbury, 1986). It would make sense to think of *seeking social support* as a basic strategy of coping.

The latter three meanings of social support, as profferred by a caregiver, as received in times of stress, and as sought as a form of coping, are particularly relevant in clinical health care. Still another meaning of social support, the actual social network of the person and its characteristics, has not been included here because it seems to be of less significance for intervention than the others.

4.3 Understanding what has gone wrong or right with the person

The final implication of the approach to stress and coping I have presented, concerns what we need to know about the person in order for this approach to be of solid help, either in treatment, prevention, or health promotion. From the standpoint of stress and coping theory, one must have an assessment of a person's degree and type of stress. The theoretical and empirical basis of such an assessment would require an extended paper of its own.

I should mention, however, that there has been much controversy about the merits of *life events lists* as a basis of measuring degree and type of stress, in which I have played a role (Lazarus, 1984; Lazarus, DeLongis, Folkman & Gruen, 1985). My theoretical and empirical work on the measurement of stress reactions has centered on what my colleagues and I have called *daily hassles*. This type of measurement is not directed at environmental demands or stressors but at daily annoyances and crises as appraised by the person – which can be chronic or role-related and are measured subjectively – and is both a dependent and an independent variable in the overall emotion process and its consequences for adaptational outcomes. It is also important to have some indication of the content of stress in a person's life, that is, the areas of living or settings in which stress will occur, as well as the magnitude of stress. Such a pattern can tell us much about what is going on in the person's life, or in the lives of those in a particular social group (Lazarus, 1984).

Of even greater value in understanding what is going wrong or right in the person's life are the *emotions* experienced by that person in a given time period. Stress is primarily a unidimensional variable. The kind, duration, intensity and pattern of occurrence and recurrence of emotions, both positive and negative, provides much more insight into a person's deficits and strengths than simply the degree and content of stress. Recurrent *anger*, for example, tells us something different about the person's relationship with the environment and how it is appraised than, say, recurrent *anxiety*. From the recurrent anger we learn that the environment is frequently viewed as assaultive, whereas from the recurrent anxiety we learn that the environment frequently seems threatening. Similarly, a pattern of *shame* means that the person frequently believes he or she has failed to live up to an ego ideal; a pattern of *guilt*, on the other hand, reflects the frequent belief that the person has transgressed against internalized social standards of conduct.

Each emotion expresses its own special relationship with the world, and so when it occurs or recurs, it can be the diagnostic of a particular kind of troubled relationship with that world. The same applies to positive emotions such as happiness, pride, compassion, love, or eagerness. By evaluating the person's or the group's emotional life, we obtain the most useful information on which to predicate prevention, treatment, or health promotion.

Clinical intervention is best centered on an understanding of what is going wrong emotionally, due to the person's faulty appraisals of circumstances of life, and/or deficits in the coping process. Not only can distress and dysfunction arise from a poor fit between a person's appraisals and the realities on the person-environment relationship, but, as we indicated before, a person may cope inappropriately, for example: persisting in problem-focused coping when there is nothing to be done; choosing an inappropriate form of problem-focused coping; failing to regulate emotional distress by suitable forms of emotion-focused coping; or lacking in skill to properly employ an appropriate coping strategy. An understanding of what is going wrong in the appraisal and coping process puts therapists in a better position to address the problem with their interventions.

When there is continuing emotional distress and dysfunction we can be sure that there is what might be called disconnexion among the constructs of the mind, or between mind and environment, and mind and action (Lazarus, in press). Disconnexion refers to a condition in which the components of the mind are responsive to divergent influences and generate contradictory actions. What the person thinks is out of touch with the emotions experienced or the motives that shape action. For the opposite of disconnexion to occur, short-term goals must be in harmony with long-term goals and contribute to them as means to ends. Conflict among goals is disruptive of harmony and results in the components of the psychological structure being pulled apart rather than working together. Motivation must accord with understandings of what is possible, likely, reasonably safe, properly timed and properly sequenced. Emotions must be accurate reflections of the significance of encounters for well-being.

All conflict theories of psychopathology and mental health follow the basic reasoning that integration signifies mental health, and fragmentation or ego-failure signifies mental illness (Menninger, 1954). Disconnexion happens when a person makes efforts to cope with a troubled person-environment relationship by distorted appraisals and inappropriate coping processes that put the components of mind out of touch with each other, and out of touch with the environment and action. The ego-psychologists refer to this as self-deception or defense.

Development of the child normally brings with it increasing integration of the constructs of the mind. These constructs, namely, cognition, emotion, and motivation become welded into a system which, although under tension, must remain in touch with the environment and in control of actions in the interests of helping the person survive and flourish. The links between actions and the demands, constraints, and resources of the environment, as well as among the components of the mind, are forged and changed developmentally and dialectically by continuous adaptational transactions. The movement towards integration is not smooth (Block, 1982; Piaget, 1952; Fisher & Pipp, 1984), but occurrence of periodic crises forges reorganization when the established psychological structure is no longer viable. Diverse therapeutic approaches have been designed to attack disconnexion; they must address the five basic constructs of the psychological apparatus, namely: cognition, emotion, motivation, the conditions of the environment being faced, and actions in an environmental context. Preventive strategies too must help the person avoid disconnexion or fragmentation. When there already is a crisis, for example, major illness, we must think in terms of secondary prevention to help the person resist disconnexion in the face of the very substantial stresses posed by such illness.

4.4 Therapy and prevention: six important principles

I do not propose to discuss therapeutic and preventive strategies in any depth in this paper. However, a few principles consistent with what I have been saying about appraisal and coping, and about integration and disconnexion, might be of value. Though I have elaborated somewhat on them elsewhere (Lazarus, in press), I shall simply state them briefly here:

1) therapeutic or preventive strategies should match the client's problems of living, personal agendas, and styles;

2) this matching requires psychodiagnosis, not merely labeling but an understanding of what has or is going wrong with appraisal and coping;

3) therapy or preventive efforts must bring new understanding to clients if change is to occur or clients are to be strengthened against fragmentation; this statement is consistent with a formulation of emotion that is both cognitive and relational;

4) cognitive change is necessary but is not alone sufficient to produce therapeutic change or improved psychological resources; the new knowledge must be integrated with motivational and emotional patterns, and lead to changes in action towards the environment; this has sometimes been defined as emotional insight in contrast to intellectual insight;

5) those concerned with prevention and health promotion should be wary of the pathology mystique in which emotional distress and dysfunction are automatically relegated to the idea of sickness rather than being seen as active adaptational struggles of a person under stress, who is trying to cope as best as he or she can;

6) those concerned with prevention and health promotion should recognize that there are two avenues by which distress and dysfunction, or disconnexion, can be fought:

(a) by trying to change the *pathogenic environmental conditions* the person faces, i.e., the institutional setting and arrangements that defeat effective coping; an example of this reasoning may be found in the observations of Hay and Oken (1972) on institutional nursing arrangements needing change in an intensive care unit of a hospital because they were unnecessarily stressful;

(b) by trying to strengthen the person's coping skills; some cognitive behavior therapists even speak of psychotherapy as *coping skills training* (Goldfried, 1980; Rosenbaum, 1983; D'Zurilla & Nezu, 1982; Meichenbaum & Jaremko, 1983).

5. In summary

1) Each illness has its own unique source of psychological stress (harm, threat, challenge), and shares some too with other illnesses.

2) There are great differences between individuals in appraisals of the meaning of the illness: e.g. challenge, fate, punishment, self-blame, etc. These lead to different coping processes; individual differences may be as great or greater than across illnesses.

3) There are also great differences *within the same individual* over time, i.e. over the course of illness as it changes, or in different episodes or crises within the illness course.

Therefore:

1) The coping process we should encourage will depend on the person's appraisal of meaning, the coping style (Martelli et al, 1987), and the stage of the illness. Martelli found that the result was better when the coping intervention matched the patient's preferred coping style.

2) It follows from this that *general* strategies of stress management might succeed with some but fail with others. Sulz, Sanders & Labrecque (1986) found that urging people to relax can lead to increase rather than decrease in blood pressure if they do not also receive systematic instruction on how to relax or control blood pressure. In other studies, training in relaxation has made some subjects anxious.

3) The best intervention will involve careful assessments of the appraisal and coping variables for each patient, or subclass of patients, taking into account personal agendas, personal circumstances, illness and prognosis, life stage, etc.

4) Intervention should depend on listening to the patient carefully, discovering his/her sources of threat, harm and distress. This is something now almost absent in medical practice, namely, a great concern and awareness of the patients' emotional life.

This may seem impractical and costly. But general approaches that fail to take into account the specific characteristics of individual patients are likely to be superficial and of less value than is needed and possible. There are no shortcuts, other than professional self-deception. Unless appraisal and coping theory and research influence clinical practice, their practical value will not be fully realized. In turn, one of the richest and best sources of knowledge about stress and coping processes is the clinical setting, where perfectly normal people are facing illness crises. We should, therefore, aim at bringing together clinicians and researchers so that they can add to a growing data base by programmatic observations of persons struggling to manage the stresses of major illness, and find ways of bringing the insights of stress and coping theory and research into the strategies and tactics used by clinicians. Judging from the long-standing gap between research and practice, this is obviously easier to say than do.

Chronic illness: a constant process of appraisal

How sensitive are health care providers to the emotional needs of patients with a chronic illness? Do they provide them with clear and adequate information to minimize anxiety? Are they aware of the individual sources of threat and ambiguity which lead to constant appraisal? The following are some of the appraisal-related questions which are common in patients with a chronic illness and on which coping is apt to be based.

Heart disease

Am I likely to die suddenly, and without warning, from a further attack? How vulnerable am I? What clues can I use about my health status?
What happens to my life commitments if I die? To my family? How should I deal with my life commitments in view of the risks of dying? Should I give them up and search for new ones or simply go on as before?
Does anyone care about my fate? My spouse, children, friends, business associates? Of what help are the various health maintaining programs suggested to me for dealing with the threat of another attack and how much reliance should I place on them? Diet? Exercise? Bypass surgery? Costs and benefits? What are my chances for a disabling stroke?

Cancer

What is the status of the cancer? The answer, of course, depends on stage – e.g. biopsy, post-surgery. Has surgery eliminated the malignancy? How sure am I (or the oncologist) that I am free of it? How likely is it to return? What about those terrible stories I have heard – do they apply to me? What kind of death am I facing? How long? How much pain? How much incapacitation? What are the signs I must pay attention to?
How did I get this thing? What did I do that was wrong? Why am I a victim at this time of life?
What must I do to survive or to slow down the growth? How can I live with inevitable deterioration and use the time well? What do I need to do with the rest of my life?
How should I communicate with other people about my condition? My spouse? My children? My parents? My friends? Potential lovers? What should my attitude be? How frank? How much distress to display? Does anyone need to know? Will it help to tell someone? How are others (spouse, friends etc.) supporting me materially, emotionally, informationally? How much could they help?
How do the treatments affect my ongoing life and work? Costs and benefits? Are the sacrifices worthwhile? How much confidence can I have in what physicians do and tell me? Am I getting the truth? Do I want to know?

Chronic pain

What does the pain mean? Does it signify a permanent ailment, a threat to life, getting progressively worse (e.g. cancer, aging and decline)? Will it get better?
How can I live with the pain, and make it less psychologically debilitating? What should I do about medication? Pain management programs? How long will it last? Will it get worse? Can I get any pain-free time? How can I manage my obligations and commitments with this pain?

R.S.L.

"HEALTHY ILL PERSONS" – SOCIAL CYNICISM OR NEW PERSPECTIVES FOR LIVING WITH A CHRONIC DISEASE?

by Helmut Milz

"Second-hand knowledge may perhaps be valuable as a guideline but, all too easily, it can be taken as the way itself or even as the ultimate objective."
Alan Watts

Some while ago, I had a discussion with a medical colleague who devoted many years of her life to psychotherapeutic practice with the chronically ill. During the discussion, she pointed out that the concept of health, as it is generally accepted, has little relevance for her patients. For them, health is not a matter of returning to the situation prior to the illness. Instead, they focus on the possibility of coping with the illness, of personal development and of a different lifestyle. A reevaluation of personal knowledge and experience, confidence in the future and the conviction that life can be meaningful despite the illness, are now central factors in their recovery and in the healing process. These factors help them to find new hope and motivation, to make new plans, and finally, to seek new objectives, strategies and values. A different understanding of oneself and others and changes in personal attitudes and behavior provide the chronically ill person with various possibilities for becoming a "healthy ill person".

Along similar lines, but from a sociological perspective, Dimond (1983) remarked: "The ultimate measure of achievement of successful adaptation to a chronic illness is found in a way of life that sustains hope, diminishes fear and preserves a quality of living that takes account of, perhaps transcends but is not controlled by, the limitations of an illness."

One of my friends, the father of two grown-up children, has been considerably handicapped by a spastic paralysis since birth. For many years, he has been one of the most reputed and creative initiators of health promotion projects, in addition to being a high administrative official, not only in his own country but at the international level. For me, he is an example of what a "healthy ill person" can achieve, a person from whom I can learn a lot. Yet he does not always remain even-tempered nor does he accept his illness simply as fate. Often he despairs, suffers setbacks owing to frequent bouts of pain and resents the impossibility of doing things independently without having to call on the assistance of others. He has repeatedly searched for means of practical assistance through complementary therapies such as eutony, yoga, Feldenkrais, etc. which would open up new possibilities of action for him.

Sharing the experiences of this friend and also those of my father – who has been physically handicapped for many years due to an apoplectic insult – has provided me with important insights into other dimensions of the "healthy ill", namely the significance of movement and body awareness as experienced autonomy.

All chronic illnesses can give rise to considerable conflicts with respect to one's body image. While physiotherapy may be helpful, it is far from being sufficient. New ways of training, such as the improvement of sensory-motor body perception, seem to be vitally necessary for concrete health promotion with the chronically ill. In this respect, several examplary teaching models have been developed in recent years. I will cite the Feldenkrais method (Feldenkrais, 1988), the eutony method developed by Gerda Alexander (1976), and the work of Mathias Alexander, (Barlow, 1981). In comparison to medical, social and psychological measures, teaching possibilities of a body-related nature have been all too neglected in the past.

What is a "healthy ill person"?

Against what yardstick can such persons be measured? What standards are we prepared to accept? How are we to judge these per-

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sons and what entitles us to form such a judgment?

After having overcome a serious illness, Nietzsche wrote:

"One comes back out of such abysses, out of such severe sickness, and out of the sickness of strong suspicion – *new-born*, with the skin cast; more sensitive, more wicked, with a finer taste for joy, with a more delicate tongue for all good things, with a merrier disposition, with a second and more dangerous innocence in joy; more childish at the same time, and a hundred times more refined than ever before."

His book, *Die fröhliche Wissenschaft*, is an expression of his altered insight of the "truth": "Nothing but a revel after long privation and impotence: the frolicking of returning energy, of newly awakened belief in a tomorrow and after-tomorrow; of sudden sentience and prescience of a future, of near adventures, of seas open once more, and aims once more permitted and believed."

Persons who suffer from chronic illness often wonder to what extent they are the "perpetrators and victims" of their present situation. Ways to cope with an illness can be very different, as Richard Lazarus clearly demonstrates (see article p. 12). Which is the "right" or "correct" way to become a "healthy ill person"?

May I, at this point, cite two examples of colleagues and friends in my age group, suffering from different types of cancer. Both were aware of the medical implications of their prognosis, their "chance of survival". One of them lived more intensively than he had previously allowed himself to do, attempted to catch up as much as possible on neglected opportunities of the past, bought a second-hand sports car and continued to smoke. He suffered a great number of agonizing operations and medical treatments. In between he was able to work again, to travel, and he lived longer than his "prognosis" had forecast. At a later time in his life, he worked extensively with psychotherapy and experimented with anthroposophic healing processes. He died at home within the circle of his friends.

My second colleague became aware that she had cancer shortly after the birth of her first child. She underwent, in consequence, a considerably impairing operation. Today, psychotherapeutic treatment, essential alterations in her diet, a reduced workload and physical exercises as well as opportunities for new experiences, involvement in self-help groups and political initiatives against the dangers of atomic war, are all part of her daily routine. She separated from her partner and currently runs her own practice. Meanwhile she has remarried and given birth to two more healthy children.

I would not presume to make any judgment as to which of these two persons found the "best" way to new health. The period of survival alone is certainly no criterium.

Components of effective support

In working together with persons suffering from chronic illness, what measures should we envisage to open up new pathways to health? Social scientists and epidemiologists have investigated the various components of illness and healing processes at macro- and micro-social levels. The range of these enquiries is considerable; they attempt, for example, to determine the influence of: the type of illness, its severity and the time when it occurs; choice and effect of various therapeutic treatments; adequate and reliable indicators of health envisaged both as a static and a dynamic process; quality and frequency of social contacts, and their impact; subjective state of health; expectancies and values, both of those directly affected and of their social environment; reintegration into work; socio-cultural conditioning and behavior; religious influences; etc.

All these studies may very well provide us with important knowledge and help in decision-making. Could they not show us the "right" way of providing the kind of support needed to promote the health of sick people? In a critical summary of epidemiologic studies available Kasl (1983) reaches the conclusion that, up to the present, there have hardly been any systematic or comprehensive research attempts to investigate the influence of psychosocial factors on the progress of specific illnesses. With a few other studies available, the one presented by Badura and his colleagues on myocardial infarction has set the standards for the future (Badura, 1987; see also article, p. 54).

If we want to help support and widen health-promoting lifestyles as well as existing potentialities in a person, we must try to investigate the complex real-life situation of that person, including social and ecological interrelationships. Only then might it be possible to offer a useful mediation to help solve the frequent conflicts resulting from the divergent inner logic of organic, mental and social processes and show that "healthy ways of living" are mainly the result of personally coming to terms with the contradictions of daily life.

On this last point, Horn (1984) has remarked: "Where decisions about one's life are, by and large, geared to the relatively short-term safeguarding of one's existence, for reasons of lesser job security, for instance, or less years spent in education, it is not reasonable to expect that, in the health sphere, behavior oriented towards the future will be developed."

Setting all therapeutic aids aside, the extent to which a sick person is able to develop his or her health depends on socio-economic factors and the degree of social and political support that we, the "healthy" part of society, are prepared to provide. A multi-dimensional understanding of illness and healing processes is necessary. Recognition of this need will lead to increased efforts towards interdisciplinary cooperation and exchange. It becomes clear that functional and structural disturbances need to be evaluated differently, depending on the level being considered:

- the physical and physiochemical level (disease);

- the psychological, subjectively perceived level (illness);

- the psychosociocultural level (illness as a socially defined role, with legal and insurance dimensions).

Methodologies used for scientific data collection in the various research areas continue to be based on an expert-oriented system of classification, with rigid separations disconnecting results not only from other influences but also from the complexity of everyday relationships. This leads to the accumulation of a considerable quantity of unrelated facts in the various fields which only a few experts can understand. There is now a gradual development towards integrated forms of research with less rigid disciplinary boundaries. Here, the aim is not simply to acquire further knowledge but to develop a deeper understanding of life processes and their relationships and to make them understandable to the broader public. When the contrasting results of phenomenological observation and analytical evaluation are seen in relation to one another, their complementarity becomes evident (Nizetic et al 1986). In the context of a systemic and holistic approach, decision begins to waver regarding which factors are "primary" (physio-chemical-anatomical-histological causality factors) and which ones are "complementary" (psycho-socio-cultural factors).

This leads us to ask: In what ways can epidemiological and anthropological research contribute to finding new ways of promoting the health of the chronically ill?

Placebos and drugs: an equivalent effect in 50% of cases?

The effects of many "complementary" healing factors have been grouped, in the past, under the rather disparaging title of "placebo". Recent research has clearly shown that every form of interaction with sick people – regardless of whether it be on an institutionalized medico-therapeutic level or just person-to-person – can have a placebo/nocebo effect on the healing process.

The question is: How can we take account of these effects in the most positive way, so that they will be of benefit to the health and healing process, yet avoid making false speculations or introducing new side-effects? When there is a serious debate on "placebo effects" and whether such effects could be equivalent to about 50% of all pain-killing drugs of varying strengths, what entitles us to place virtually 100% of our medical and scientific effort in the "primary" effects of such medication?

If it is true that a deliberate application of the placebo effect – composed of new confidence, strong belief, changed expectancies, perception, knowledge and experience – can substantially further the effectiveness of biomedical intervention, then why are we not making this knowledge more widely known? Why are we not sharing it more actively with the medical profession, with those affected by illness and with the general public, so that all may use it to their advantage (White et al, 1985)?

The dissemination of such information – which is, as it were, a "translation" of expert knowledge into general everyday knowledge that can be put into practice – contains however a number of conflicts.

Starting from where the person stands

As Gibson points out (1982), an ecological observation of perception processes shows that perception always aims to comprehend action-related differences. Bateson (1980) similarly underlines the fact that infor-

mation arises from the perception of differences which receive their significance only in their respective and specific context. Information about differences alters the form and manner of our perception structure, leads to new forms of enquiry into one's own physical and psychological existence and consequently, to a modified pattern of selection and reception of new information (Neisser, 1979). Memory, experience, emotion and mood control perceptive processes within an ordered framework. Thereby, depending on the situation, they influence our understanding of action-related information. What can such findings, and other findings from perception research, teach us with regard to joint efforts to support the health of persons with a chronic illness?
McGuire (1983) has investigated possible key elements of self-healing processes and comes to the conclusion that the form of information we provide must be oriented towards the "language" of the persons concerned in order to help them develop their self-healing potential. If we include not only words but also the behavior and actions of a person under the term "language", then our efforts to support the chronically ill must begin in their respective environment and take into consideration the fact that:

a) the ability of "language" to promote an altered perception of the arrangement of an event depends on the degree of congruence between the "language" used in providing the information and the context of the "language" of the persons concerned;

b) the understanding of one's own potential of influence is decisive for improvement (from external dependence to inner participation and personal action).

Our supportive action must take place irrespective of our own preferences. This means that some conflicts can likewise arise within our own patterns of perception and action. One case in point is the system representing the action levels of health policies and institutional health measures in which we mainly use the following hierarchical approach:

- health promotion;
- health protection;
- early detection of poor health;
- early diagnosis of illness;
- prompt treatment;
- continued treatment;
- rehabilitation.

Should health promotion not come last as well?
How sensible is this system? Do we not see that research findings in the area of self-help point the way to efforts which extend beyond mere illness, as well as to the possibilities towards health promotion?

Towards new forms of self-realization

All the papers in this book illustrate common approaches in the search for a new quality of individual health, independent of the specific form of illness. Often, these approaches focus on the training of body awareness, relaxation and new possibilities for physical exercise. They also stress ways of developing inner awareness with the aid of various therapeutic techniques leading to a new appreciation of individual experience and of the socio-ecological environment. They indicate that parallel to a "willingness to accept" and an "ability to accept" a specific illness, the "willingness to change" and the "ability to change" in terms of the whole person stand in the forefront.
For the "healthy ill person", these approaches appear to me as striving towards new forms of self-realization via new self-awareness.
Can we now answer the question: What is a "healthy ill person"? Is it the person who follows all the well-intentioned advice to promote health which is given at all levels by the "experts"? Will he thereby be caused to suffer new stresses or harm on prescription? Or, is it someone who, as a result of illness, makes "health" his sole life objective? To what extent will he perhaps become incapable of consciously taking risks and dealing with risk situations?
Are "experts" able to show reliable ways to those affected on how to become a "healthy ill person"? To what extent are we, the "experts", programming and introducing new dependencies and how many spontaneous learning processes do we thereby prevent?
Or is, perhaps, a "healthy ill person" the one who accepts all medical and therapeutic treatments without questioning their merit and complies with them to the full? How many opportunities for personal initiatives are thereby lost and to what degree is the mobilization of the existing self-healing potential reduced?
This paper has to be understood in terms of stimulation for debate, as a contribution to a necessary discussion over pos-

sible ways towards joint support. The term a "healthy ill person" may even awaken in the minds of some people an association with a hypochondriac (is illness only a matter of the "mind", of the psyche and of individual attitudes?).

Health promotion: an integrated concept leading towards new health

Health promotion, within the terms of the WHO Ottawa Charter, sees its central tasks in enabling, mediating and advocating the health of the individual and his social community. Furthermore, health should neither be standardized nor prescribed.
The term "healthy ill person" can stand for a new life perspective for those affected, but it can also be misused in a chauvinistic and paternalistic manner. Some may decide they do not want to be healthy again – for reasons related to their individual life situation or due to perceived environmental threats which may be either personal or collective in origin. Such a decision can represent a legitimate, personally satisfying response and therefore a "healthy" approach to one's illness.
Health promotion, if it is to become a humane strategy beyond any social cynicism, must recognize and respect such decisions and accept that "the shadow" may be "the embodiment of the unlived and a full part of life" (Dürkheim, 1974).
For his part, the individual stands solitary, face to face with the task of finding a lifestyle compatible with his illness, in his particular world. For him, there is no general guideline and the process he will follow can never be identically repeated (Jaspers, 1956).
"Healthy ill persons" are those seeking a new way of living. Health promotion, as it is conceived in the Ottawa Charter, represents a social, ecological and holistic concept. "Taking care" of each other is an essential constituent of this concept.
Health promotion is no new form of medical treatment. It is rather an outline for a combined approach to health that aims *to enable* all persons, whether ill or not, to have greater control over their health and its enhancement.

The extent to which a person, despite or because of his chronic illness, can experience a full life and find new health is also determined by all five of the following action levels of health promotion:

- healthy public policy;
- supportive environments;
- stregthened community action;
- development of personal skills; and
- reorientatiion of health services.

The healing process is the development of new relationships at a variety of levels. It presupposes the recognition of the sickness and/or the illness by those who suffer. Health promotion is to be understood as a process contributing, at all social levels, to the opening-up of new health opportunities and supporting people in their efforts.
"Healthy ill persons" ... Is it a utopia? Or is it, in view of the millions who suffer from a chronic illness, an imperative, humanitarian necessity to which we must contribute with all available means at our disposal?
Finally, do we not find in the term "healthy ill person" yet another indication that we are not ready to leave the arbitrary and dualistic view of health versus illness? Yet, the way is shown both by healers of many traditions and cultures, in accordance with their empirical experience, and by modern researchers such as Menninger, Mitscherlich, Dubos, Antonowsky and others as a consequence of their scientific work.
Perhaps then, the healthy-healthy, the ill-healthy, the healthy-ill and the ill-ill can come to a new alliance for a personal, social and ecological health expressing a continuous process of learning and gradual change, as well as of development and growth.

2.

RECOVERY FROM HEART ATTACK: FOCUS ON SELF-RELIANCE, SELF-HELP AND SELF-DETERMINATION

INTRODUCTORY NOTES

We are witnessing a gradual broadening of the concept of rehabilitation of cardiac patients. The reduction of risk factors, of morbidity and mortality and the reintegration in the working world are no longer considered as sufficient. Today, the all-important factor in rehabilitation programs is the quality of life of the affected person. Hence the focus on two factors influencing this aspect, namely: lifestyles, which have proven to contribute as much to the progress of coronary heart disease as, for example, bypass surgery; and social support, which enables people to regain "a sense of coherence", to overcome negative emotions and promote positive feelings, and to achieve a self-concept that is realistic, stable and positive.

Even though a heart attack is a somatic event, changes in the life of heart patients are only partly determined, if at all, by their physical state. Therefore, an essential role is played in the process of recovery by self-reliance, self-help and self-determination. As well, the work status of the patient, with its social and psychological consequences, has tremendous importance. There is also ample proof that the active participation of people in social life is just as important as physical and psychological well-being.

These observations are valid for all types of chronic illnesses.

AN OVERVIEW OF THE REHABILITATION PROCESS: ISSUES AND INNOVATIVE APPROACHES

by Hanneli Döhner and Stephan Görres

1. Introduction

The objective of this background paper is to provide model innovative approaches to coping with the situation following a myocardial infarction which correspond or come close to health promotion as defined by the Ottawa Charter.
The starting point for this paper was the latest research in the field, in particular the findings of the Oldenburg Longitudinal Study (Badura et al, 1987) which are directly relevant to our subject (see article p. 54). The data for our paper were obtained by letter, telephone and personal interviews followed by visits to selected persons, projects and health care institutions. With the three phases of rehabilitation defined by the World Health Organization – acute phase, convalescence phase and late rehabilitation phase – as its framework, the paper provides an overview of:

- current concepts and trends with respect to epidemiology and causation theories, research on coping with chronic illness and health promotion;

- health care structures in the Federal Republic of Germany for patients with myocardial infarction;

- innovative approaches to health promotion both in the Federal Republic of Germany and in other countries.

In addition, the paper focuses particularly on the following aspects: inpatient and outpatient care; the medical and non-medical areas (doctors and other professional groups); the professional and self-help lay areas; patients and their social environment; patients' main problems and various correlations with life events.
In the context of health promotion, the aim of "comprehensive rehabilitation" of cardiac patients should not only be to reduce risk factors, morbidity and mortality and facilitate reintegration into the working world, but also to enhance the patient's quality of life. This must become the most important objective of rehabilitation. The practical application of health promotion for the chronically ill is still in its infancy and not yet fully integrated into medical practice. Two questions arise with regard to the situation following myocardial infarction: first, in which areas of the existing structures are qualitative changes possible, and second, should new approaches replace or complement traditional ones? This paper takes the standpoint that "the concept of health promotion must still be evaluated and improved, in the same measure as proposals must be formulated for its practical application" (WHO 1987, p.3).

2. Myocardial infarction: current concepts and trends

2.1. Epidemiology, causation theories and development

Every year, in the Federal Republic of Germany, there are approximately 600,000 to 800,000 new cases of cardiovascular disease, of which 200,000 to 250,000 are myocardial infarctions (Mathes, 1986, p. 35). By comparison with figures from other industrialized countries such as France and the USA the number of deaths following a myocardial infarction is still not on the decline.
According to information from the Office of Federal Statistics, around 80,000 people die annually as a result of an infarction. As a percentage of total mortality in the Federal Republic of Germany, death from this cause increased from 4.7% to 15.3% between 1952 and 1971 (Schaefer & Blohmke, 1978, p. 184). Bauer & Lehmann (1981, p. 185) conclude that death from an

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acute myocardial infarction has increased, for men in particular. It must also be assumed that increasing numbers of younger people are being affected and that the incidence of infarction in women is also noticeably rising (Mathes, 1986, p. 36).
The treatment of the myocardial infarction is essentially oriented to the concept of risk factors in accordance with the main common medical risks of hyperlipidemia, hypertension and smoking (Schaefer & Blohmke, 1978, p. 195). Oral contraceptives, overweight and lack of exercise are considered relatively low risk factors, which it is possible to influence.
The further development of the concept of risk factors has led, on the one hand, to a multitude of relevant results from stress coping research and social epidemiology (secondary risk factors), and on the other, to establishing a list of risk factors in order of importance. As the somatic risk factors could explain only a small proportion of coronary heart diseases, the concept has been extended primarily to encompass psychological and social variables (Schaefer & Blohmke, 1978, p. 187). These are social mobility, social incongruence, occupational stress, psychological stress and anxiety, depression, sleep difficulties and Type A behavior.
There seems to be a correlation – albeit less strong and consistent – between the risk of developing an illness and work overload, chronic conflict situations and socio-structural variables such as social mobility, migration, level of education and number of life events (Bauer & Lehmann, 1981, p. 197).
Prevention strategies also focus particularly on the above risk factors and have developed from unifactoral, multifactoral and community-oriented intervention studies to the German Cardiovascular System Preventive Study (Laaser, 1986, p. 212).
Bauer & Lehmann (1981, p. 199) state that the literature on the subject of causation and development of coronary diseases contains ideas that differ considerably from one another and are to some extent controversial, and that both problem areas require further clarification.

2.2 Coping with the illness

According to Badura et al (1985, p. 5), there are three reasons why we should concentrate not only on the primary causation and development of a myocardial infarction but also, to an increasing extent, on the coping process:

- firstly, the number of persons who survive a myocardial infarction has increased sharply in this century;

- secondly, the psychosocial consequences of the illness cause problems which are of an equal and sometimes even greater magnitude than the infarction itself;

- and finally, there is widespread uncertainty about how to handle these problems on the part of patients, their families, the medical care institutions, the relevant social insurance institutions and health policy makers.

In fact, a multitude of stressors confront the patient and influence the process of coping with the illness:

- fears, depression, threats and impairments;

- ignorance, uncertainty, behavioral uncertainty;

- problems of adjusting to change, in particular those relating to resumption of work, but also those relating to the patient's whole lifestyle;

- illness-related stresses and disturbances in the family and work context; and

- problems relating to institutionalized care (Badura, 1981, p. 171).

A positive assessment of the recovery process is particularly important for coping with the illness, according to Lazarus (1966) and his colleagues, and depends initially on the institutional support given to the affected person, i.e. on the quality and duration of medical treatment. However, the effectiveness of medical measures does not merely depend on the treatment but also on (1) the extent of emotional support given to the patient, (2) the quality of the information and advice provided, and (3) how successfully the patient's emotional strength and social support potential can be promoted. While institutional care can be of considerable help to the patient in coping with the everyday problems of a serious chronic illness, it cannot remove them. The individual is dependent on the health promoting influence of social relationships and interpersonal processes in the context of his social environment in the form of mutual help, help from others and self-help endeavors (Badura et al, 1985, p. 15). It is for this reason that sensitivity towards problems and needs of the individual patients and the involvement of the most important people in their lives are of fundamental importance in helping patients to cope with a chronic illness (Badura, 1981, p. 8).

2.3 Health promotion and the rehabilitation process

A holistic approach to sickness and health, in line with the WHO concept of health promotion (1986), is gaining acceptance in the rehabilitation of myocardial infarction patients. This approach takes into account the psychological and social dimension of the illness, and in particular the self-help aspect. It centers on the individual and his possibilities and capacities and emphasizes social reintegration as an essential rehabilitation objective (WHO, 1969, p. 2). The quality of life of the affected person becomes the guiding principle of rehabilitation measures and physical, mental and social well-being becomes the criterium of success. Based on the analysis of illness-specific problems and stresses associated with a myocardial infarction, Badura (1981, p. 176) has developed a concept of "social support" which calls for :

- psychosocial support, i.e. encouragement, advice, care, moral support and appreciation on the part of the family, friends, relatives and neighbors as well as discussion and clarification of future possibilities and restrictions;

- information about the cause, course and treatment of the illness, and about medical support and social support that can be provided by the patient's spouse, colleagues, adults, children and friends;

- practical help easing the individual's burden and showing him consideration (when only limited changes of lifestyle are necessary);

- support with the learning and practising of coping strategies (when more extensive adaptations of lifestyle are necessary).

Restoration of the physical functional ability as the basis for successful rehabilitation is however not in dispute. Mental and social stability in particular can be built up again on this basis and health (in the widest sense) can be promoted.
Two key questions must be asked at this point in relation to current rehabilitation processes: to what extent is the patient included in the process as a responsible partner? Does this process enable the patient to become independent or does it lead towards a life-long subordination to medical check-ups and hence dependence?
We need to examine existing institutions and models to determine, first, to what extent they emphasize the patients' own responsibility, strengthen their self-respect, and make them partners in the process of rehabilitation. And second, to determine the extent to which these institutions are able to see patients not just as cases with somatic symptoms. Are they willing to motivate them, to activate their immediate environment such as their partner, family, friends, colleagues and self-help groups, and to integrate lay resources into the rehabilitation?
If one accepts the concept of a dual care system consisting of medical activities on the one hand and informal endeavors to provide support on the other, then health promotion must be directed to both areas (Badura, 1981, p. 8). We have therefore attempted in this paper to identify innovative elements in health promotion, both in the institutional area where the medical aspect dominates and in the non-institutional area, occasionally described as the "lay system". This has been done with the three phases of rehabilitation identified by the World Health Organization as the framework.

3. The phases of rehabilitation

3.1 The WHO concept

As already mentioned, the development of a concept of health promotion for the chronically ill is still in its infancy and has certainly not reached the stage of practical application. The rehabilitation of myocardial infarction patients is still dominated by concepts and provisions which are primarily oriented to medical paradigms. Psychosocial aspects are usually mere additions to the overall scheme.
The rehabilitation of myocardial infarction patients is normally divided into three phases along the lines of the WHO concept (Wenger & Hellerstein, 1978; WHO, 1968; 1969):
a) *Hospital phase*. During the first week(s) of hospital and involving low level physical activity and education;

b) *Convalescent phase*. Between initial mobilization and optimal recovery and involving progressive physical activity, continued education and psychosocial and vocational counseling as needed;

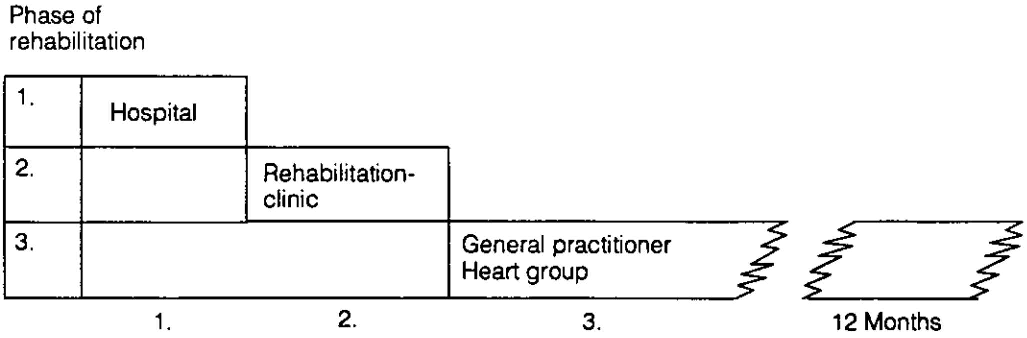
c) *Maintenance phase*. Continued efforts at secondary prevention including optimal physical activity. Return to work, retraining as needed. Psychosocial support as needed (König et al, 1983, p. 106).

In the following section the so-called "therapy chain" will be introduced as a typical example of the phase model in the Federal Republic of Germany. All the other innovative approaches are also based on the WHO phase model. In our paper we have dealt with the individual phases separately for the sake of clarity.

3.2 Situation in the Federal Republic of Germany: the therapy chain

The concept of post-infarction care which is recommended in the Federal Republic of Germany is the "therapy chain". The rehabilitation of patients is divided into three phases (Donat et al, 1986, p. 42; Krasemann, 1983, p. 221): (1) the patient is treated in hospital; (2) he is then transferred to a rehabilitation clinic; (3) upon return home, he receives further treatment by his general practitioner and should join an outpatient heart group in his community. This approach is also recommended by the Federal Working Group for Cardiac Prevention and Rehabilitation. According to Dransfeld (1985, p. 21) "the acute phase of illness in hospital is of necessity determined by the need for medical intervention and early physiotherapeutic mobilization" while "the transition to independence must be introduced" in the rehabilitation clinic and continued in the outpatient heart group so that the patient "can finally deal with his illness independently and with confidence".

THE "THERAPY CHAIN"



Source: Krasemann & Donat, 1982.

Such a smooth process of rehabilitation - with all patients growing continuously in independence - is far from reality, as will be seen later. However, even if the same rehabilitation measures were offered to everyone, it is doubtful whether such a structured procedure could take adequate account of the individual needs and interests of each patient. This very strict approach contradicts the essential principles of health promotion, in particular the principle of self-determination.

4. WHO Phase I of myocardial infarction rehabilitation: acute phase

4.1 WHO concept and current progress of international discussion

Phase I of cardiological rehabilitation begins with the onset of the acute infarction and ends when the patient can stand, walk about and climb stairs again. In this acute phase treatment normally takes place in hospital. *A cardiological rehabilitation team consisting of different professional groups* should be on hand, with the cardiologist acting as coordinator of the various measures (Acker et al, 1982, p. 218).

The principles and practice of *early physical mobilization* were drawn up by a WHO working group (WHO/EURO 1968), and its advantages are now accepted by most countries. It is assumed that it has a positive effect on the patient's psychological state and can help to reduce the length of time spent in hospital. It is also thought to reduce mortality and facilitate reintegration into working life at a later date, since overlong stays in hospital can be counterproductive.

Approaches to *psychological rehabilitation* vary; there too, a set of proposals has been drawn up by a WHO working group (WHO/EURO 1970). The greatest stress is created in the first few days through the fear of death, the pain and the monitoring equipment surrounding the patient (Degré-Cousty & Grévisse, 1982, p. 223). Emotional support together with intelligible and encouraging information and advice should be provided for patients who are suffering from anxiety and depression and also for their relatives (Kallio, 1973, p. 61; Bauer & Lehmann, 1981, p. 203).

4.2 Situation in the Federal Republic of Germany

Most myocardial infarction patients are brought into a general hospital as emergency cases, where they spend the first week in the intensive care unit under monitored surveillance. The mobilization phase begins in the second or third week and between the third and fifth week. According to results obtained by the Hamburg Infarction Aftercare Study, around 80% of the patients are transferred to the rehabilitation clinic (Weiss et al, 1981, p. 43).

The Oldenburg Longitudinal Study (cf. the paper by Badura, p.54) showed that the acute phase following the myocardial infarction lasted an average of 32 days for the patients studied, of which around 4-5 days were spent in the intensive care unit. Only just over 4% of the 980 patients were in hospital for less than two weeks, but a good 10% on the other hand were in for even more than six weeks. By comparison with other countries, this is a very long stay; it seems due to the fact that there is a longer wait before early mobilization is started. Since fear of another infarction, of death and of the return of the pain and general anxiety about the future are dependent on the length of the stay in hospital, but independent of the severity of the infarct and the age of the patient, this suggests possible iatrogenic influence (Badura & Lehmann, 1987, p. 328).

In addition it is precisely those patients to whom the legally established aims of rehabilitation – maintenance, improvement and recovery of fitness for work – are particularly applicable who seldom come for rehabilitation, as hospital doctors usually do not expect them to work again (Lehmann, 1987, p. 74). Patients with severe clinical symptoms (angina pectoris, shortness of breath) are also rarely referred to rehabilitation clinics, even though they in particular should receive such treatment at an early stage.

In general the patients themselves have hardly any influence on the selection of the institutions, with the exception of the self-employed. Thus the patients know relatively little about the selection process as a whole. The scope for catering to their wishes, according to Lehmann (1987, p. 77), is in any case very limited. This is attributed to organizational and economic conditions, in particular the necessity of using bed capacity to the full. Badura and his colleagues describe the over 36,000 courses of rehabilitation undergone annually (by men) as "mass processing with its own organizational legitimacy and only limited individual treatment" (Lehmann, 1987, p. 87).

In the Federal Republic of Germany the provision of *psychological and social* support and appropriate information and advice for both the patients and their families during the intensive care phase is inadequate. The ideas produced by a project carried out in Berlin on Patient-oriented intensive care will certainly be useful in this area (Grote, 1983).

4.3 Innovative approaches in other countries

4.3.1 The Assaf Harofeh approach

In this state hospital rehabilitation begins in the *intensive care unit*, as soon as the patient is stabilized. The aim of the cardiological rehabilitation team is the implementation of a *holistic, family-oriented and interdisciplinary program* involving not only the cardiologist but also the psychologist, the nursing staff, social workers, psychotherapists and dieticians.

The nursing staff – and if necessary also a social worker or a psychologist – talk to the patient within the first few days and give him an information sheet and a brochure with the aim of encouraging him to think optimistically about the future. The main idea behind this is that the patient should receive emotional support right from the beginning, especially if he is anxious and depressed, as is frequently the case in the early phase. In Assaf Harofeh the relatives or friends are involved at an early stage, when the patient is still in intensive care. Appropriate attitudes on the part of the rehabilitation team allow the technology that is also present here to retreat into the background so that it is not so threatening for the patients and their visitors. Patients are then *transferred as quickly as possible to a medical ward,* where they spend on average 8-10 days, provided there are no particular complications. At this stage they are encouraged to take part after their discharge, i.e. in rehabilitation phase II, in a short- or long-term outpatient rehabilitation program (cf. subsection 5.3.2 of this paper).

4.3.2 Other approaches

In general, discussion in other countries is centering on whether all or the majority of myocardial infarction patients need treatment in an intensive care unit or general hospital at all. In studies conducted in Scotland the usefulness of the intensive care unit in reducing mortality after a myocardial infarction is questioned (Hill et al, 1977; Hunt et al, 1977).

It seems that many patients – particularly when they have had an uncomplicated myocardial infarction – can also be treated on a medical ward or even by their family doctor at home. This view is supported by the fact that the patient is in a better position to receive emotional support and adequate information and advice which is also extended to relatives or friends outside the ward.

4.4 Summary comments on approaches used during the acute phase

For these reasons a plea should be made for keeping the stay in the intensive care unit – where this remains necessary – as short as possible and for examining the conditions which enable *early mobilization and rehabilitation to be brought forward within the whole process.* In the Federal Republic of Germany lengths of stay in hospital are very long by comparison with other countries, even though for most patients – again by contrast with many other countries - this is followed by a further period as an inpatient in a rehabilitation clinic (cf. section 5.3 of this paper).

It has not been proved that extending the acute phase aids the process of recovery and reduces mortality or the risk of recurrent infarction. The Oldenburg Longitudinal Study makes it clear that this may on the contrary lead to iatrogenic damage. A comparison of the approaches being implemented in different countries during the acute phase raises the following questions:

1) Is a stay in a general hospital, in particular in the intensive care unit, necessary and appropriate for all myocardial infarction patients?

2) For whom and under what circumstances can and should the hospital stay be reduced?

3) How can emotional support and adequate information and advice be provided in general hospitals?

4) How can the convalescence phase or rehabilitation, adapted to individual needs and requirements, be planned and prepared during the acute phase?

5. WHO Phase II of myocardial infarction rehabilitation: convalescence phase

5.1 WHO concept and current progress of international discussion

Phase II of cardiological rehabilitation begins when the patient can pursue the normal activities of daily life without problem. This phase is concluded when the patient has recovered to the extent that he can return either to his former job or other former activities. Estimates of the necessary duration of this phase vary. Kallio (1973, p. 62) works on the assumption of 8-10 weeks.

There is considerable disagreement about the best organizational form for this rehabilitation phase, with the result that in Phase II the differences within and between the various countries are particularly pronounced. There are as yet no studies showing the advantages and disadvantages of various organizational forms. Thus in some countries such as Israel, Great Britain and the USA there are few formal programs. Here, following the stay in the general hospital the patients either spend a short time in a rehabilitation unit (approximately one week) or go home immediately where they are invited to group sessions for several weeks in the familiar environment of the general hospital (cf. section 5.3 of our paper).

The advantages of this system are on the one hand that it is less cost intensive and on the other that patients are enabled to confront everyday life at a relatively early stage and are not allowed to develop a sense of remoteness due to lengthy stays in institutions. Furthermore, patients are not away from work for very long, which makes reintegration into working life easier (Badura et al, 1985).

The disadvantages may be seen in relation to certain "problem groups", for example women for whom there is a danger of their not being able or allowed to free themselves from their usually very strenuous housewife role in their home environment; and also patients who have had complicated myocardial infarctions or have even undergone heart operations and need a longer convalescence phase.

In general the idea is gaining ground that outpatient rehabilitation is only recommendable as a substitute for inpatient rehabilitation for certain patients selected with their individual circumstances in mind.

5.2 Situation in the Federal Republic of Germany: inpatient rehabilitation in special institutions

After a myocardial infarction or heart surgery patients are generally transferred from the general hospital to a cardiological rehabilitation clinic, for a period of 4-6 weeks. According to Donat et al (1986, p. 43) there are currently 75 such clinics in the Federal Republic of Germany (Bundesversicherungsanstalt, 1985).

The advantage of inpatient rehabilitation is that, away from his family and possible problems connected with it, the patient has the peace of mind to deal with his illness or the discipline to complete a certain training program under regular supervision (Halhuber, 1986).

From the results of the Oldenburg Longitudinal Study we know that there are in practice many ways in which the system falls short of the long-range objectives of a comprehensive, rapid and smooth rehabilitation process (Lehmann et al, 1985, p. 93). Both the range and the content of these provisions have resulted in a certain amount of confusion, in spite of the clearly defined structures such as that of the "therapy chain" with which they started out (Krasemann & Traenckner, 1986, p. 312).

In addition to its orientation towards those who will be able to work again (to the disadvantage of older people and women), rehabilitation in the Federal Republic of Germany characteristically focuses on the promotion and development of inpatient rehabilitation facilities, with a corresponding neglect of locally based outpatient rehabilitation. Phase II largely takes place in inpatient institutions, so that rehabilitation can almost be equated with a stay in hospital. One of the reasons for this is the traditional cure and sanatorium system, but the self-interest of the institutions and prevailing teaching opinions also play a part in creating this situation.

Even though the patients participating in rehabilitation measures who were studied by Badura et al (1987) were altogether positive about their stay, in particular about the company of fellow-patients and the psychological and social support they received from them, inpatient rehabilitation is nevertheless considered to be a source of stress.

Half of the participants assessed the separation from their family as a high or very high degree of stress. The absence of their normal contact with friends, neighbors and work colleagues (27%) and the physical distance from home (31%) were seen by many patients as stresses of a similar nature (Lehmann, 1987, p. 80).

In addition, 39% of the participants found the patients' constant discussion of their infarctions stressful, and for 21% the atmosphere of the rehabilitation clinic represented a high or very high degree of stress (Lehmann, 1987, p. 80). A further criticism was levelled at the equipment and diagnosis procedures of the rehabilitation clinics, which are making them more and more like the general hospitals.

Finally, the comparison of patients who had undergone inpatient rehabilitation with a control group showed that the rehabilitation patients had higher age-specific energy-capacity (measured in terms of watts) and in general complained less of chest pain and shortness of breath. There was however no significant difference with respect to the psychological data and the subjective assessment of recovery. In the long run therefore, inpatient rehabilitation only seems to have a positive effect on the physical aspects of the illness. The psychological and social situation, on the other hand, is not substantially influenced (Lehmann, 1987, p. 81).

5.3 Innovative approaches in other countries

The following innovative approaches will be discussed:

- family-oriented group therapy for patients and their relatives in the general hospital (example: Israel);

- outpatient rehabilitation with group therapy organized by a cardiologist operating from a practice in the community (example: West Berlin);

- forms of cooperation between the doctor and rehabilitation counselor or social worker (example: practice in a rural district near Ulm);

- outpatient rehabilitation within the framework of community medical and social services already in existence (example: Finland).

Since comparisons with other countries show that the convalescence phase does not have to take place in a clinic, alternatives to inpatient rehabilitation should be sought. The view is being expressed, in particular in England and America, that outpatient rehabilitation within the framework of the primary medical care system is preferable to a strongly formalized rehabilitation process in special institutions (Bauer & Lehmann, 1981, p. 226).

5.3.1 Inpatient rehabilitation focusing on the family (Israel)

In Israel the patient can normally either be transferred from the general hospital to the care of the general practitioner or can avail himself of the outpatient rehabilitation facilities offered by a general hospital.
For the small percentage of patients who still need monitoring (around 10%) there are special rehabilitation units to which they can be admitted such as that set up in Kfar Maccabiah Village near Tel Aviv. The object of this rehabilitation unit is to ensure convalescence after early discharge from the general hospital through provision of a secondarily prophylactic education program, with particular emphasis on the inclusion of the family.
This program lasts a week in all and the patients concerned are admitted directly from the surrounding hospitals, around 8-10 days after an uncomplicated myocardial infarction. The education of the patients in the rehabilitation unit falls primarily into three categories:

1) individual instruction from a member of the nursing staff with respect to tablets, pulse, blood pressure, etc.;

2) interviews with a social worker to discuss an early return to work and personal and family-related psychosocial problems; and

3) group meetings of patients and families with a cardiologist, who explains the normal physiology of the heart and the problems following a myocardial infarction, with particular emphasis on the avoidance of risk factors, but also on the leading of a normal occupational, family, sex and social life.
A further member of the rehabilitation team is the dietician, who introduces the patient to a proper diet designed to reduce weight, the serum lipids and high blood pressure and to control *diabetis mellitus*. The general hospital which originally admitted the patient subsequently carries out periodic checks with respect to the risk factors (J. J. Kellermann & Z. Schlesinger, personal communication).

Advantages and disadvantages

The particular advantages of this form of inpatient rehabilitation are the focus on "comprehensive rehabilitation" by involving an interdisciplinary team and the family; and also the reduction in the amount of equipment, the brief duration of the program in cases where patients can return to work and finally the lower costs. The criterium for admittance is the continuing need for monitoring after the acute phase, which in the case of pathological findings (e.g. extrasystoles) would otherwise frequently lead to the patient being transferred back to the general hospital.

5.3.2 Outpatient rehabilitation groups at a general hospital (Israel)

In the Assaf Harofeh Medical Center (Tel Aviv) both a short-term and a long-term rehabilitation program are offered in the form of outpatient rehabilitation groups. The *short-term rehabilitation* program consists of group meetings which take place over a period of six weeks. The patients are strongly encouraged to participate while they are still in the general hospital (cf. subsection 4.3.1 of this paper). It is also to be assumed that the patients know that rehabilitation at the hospital increases their compliance. The groups meet once a week, and the patients' partners are also invited, of whom about 50% attend. The participants have a meeting with the doctor, two meetings with a psychologist, a meeting with a dietician and two meetings with a graduate nurse, with whom finally social aspects are also discussed.

As an alternative to this, *long-term rehabilitation* is available, which follows the same principle as the short-term rehabilitation, but extends over a whole year and contains a much higher proportion of physical fitness exercises, whereas the short-term program has more relaxation exercises. Long-term rehabilitation is especially designed for those patients who have no problem of coping from a medical standpoint, but who do have problems of coping with the illness. 10-20% of all the myocardial infarction patients at this hospital take part in the long-term program.

Advantages and disadvantages

The principle of both rehabilitation programs — a similar form of which is to be found not only in Israel but also in Scotland, Ireland and the USA (Wenger & Hellerstein, 1978) - is that after early mobilization in hospital the patients participate for several weeks or months on an outpatient basis in a holistic and — especially in Israel — family-oriented program, which in addition to fitness training and medical checks also involves the provision of information, psychodynamic group discussions involving patients and their relatives and counseling with respect to psychosocial problems. There is also instruction on how to avoid risk factors and practice a healthier way of life (Drary, 1987).

This kind of short- or long-term outpatient rehabilitation has several advantages, the main one being that a majority of the patients return to work after 4-5 weeks, in particular those with a relatively uncomplicated myocardial infarction who do not need a comprehensive program. Patients can thus return punctually and on a gradual basis to their previous work situation and/or begin at a very early stage with an alternative employment program, which is important for their self-esteem. The general practitioner is also involved at this stage, so that on the one hand he takes over responsibility for the patient once again, and on the other hand, participates in the rehabilitation as the patient can provide him with important information.

Many patients do not participate in the long-term rehabilitation program for the full year, reaching the point where they no longer need this group. On the other hand, others take part for a much longer time, since the group has taken on the nature of a club for them.

The main disadvantage of the long-term program is the selection of the outpatients, which does not depend solely on the medical and psychosocial indications but also on external factors affecting participation such as social reasons (finances), transport problems (no car) or a lack of motivation (J.J. Kellermann & Z. Schlesinger, personal communication; Schlesinger, 1983, p. 336; Kellermann, 1982, p. 134; Schlesinger & Segev, 1982, p. 226).

5.3.3 Outpatient rehabilitation provided by a team of cardiologists (West Berlin)

In West Berlin there are now two joint cardiological practices which run outpatient rehabilitation programs. The one we visited consists of three specialists and specially trained staff (physiotherapists, physical training teachers, intensive care nurses and doctor's receptionists) (Schönstedt, 1986, p. 32).

After initial financing difficulties, there is now a slow but steady increase of rehabilitation patients as a result of close contact with general practitioners and hospitals. Most of the patients, as with inpatient rehabilitation, have had a myocardial infarction or recurrent infarction. In addition there are however also patients who have had a bypass operation, patients with therapy-resistant angina pectoris, or who have undergone resection of an aneurysm of the heart wall and patients with acquired or congenital cardiac abnormalities that have been operated on. The patients, usually divided into groups of up to six persons, come to the practice every day - with the exception of weekends - over a period of six weeks. The main part of the treatment consists of exercise therapy which is gradually increased and continuously monitored by video; it is individually adapted to each patient and includes an in-built control to check that the prescribed frequency of training is suited to the patient's ability. The phases include loosening up, stretching and breathing exercises, running and ergometer training, physiotherapy exercises, games of a non-competitive nature and balneotherapy. In addition, group and one-to-one discussions about the origins, nature and treatment of heart disease, backed up by audiovisual media, play a particularly important part. There are also discussions about risk factors and advice about diet. The patients' partners are invited to the meeting, so that joint psychosocial problems can be discussed. A further function of outpatient rehabilitation is also considered to be the continuation of the diagnostic process, whereby the staff work together with the relevant specialist departments of hospitals.

Advantages and disadvantages

One of the advantages of outpatient rehabilitation is the absence of a waiting period between the general hospital and outpatient rehabilitation. The transition to Phase III is also easier, as is shown by the fact that around 40-50% of patients subsequently take part in outpatient heart groups, compared with 30% in Hamburg (cf. section 6.2 of this paper). An additional positive factor is that the heart groups are attached to the local specialists' practice.

Finally it can be seen that the monitoring or emergency care of the patients can just as easily take place at home or from the local specialist's practice as in a rehabilitation ward. The costs of outpatient cardiac rehabilitation therapy are also lower.

One problem of outpatient rehabilitation is that many patients may view the daily visits to the practice merely as appointments and hence not as a self-contained rehabilitation program.

5.3.4 Rehabilitation counseling at a doctor's practice (Federal Republic of Germany)

In a further model of outpatient rehabilitation within the framework of primary medical care, specially trained health counselors or social workers work together with the doctor. In this way not only the purely medical side of rehabilitation and secondary prevention but also the psychosocial area can be included in the WHO Phase II (reintegration phase) or in Phase III for the rest of the patient's life, especially since it can be assumed that it is precisely the local doctor who has contact with his patients for the longest period of time.

In a rural district near Ulm in the Federal Republic of Germany an example of this model is represented by a practice in which, in addition to the cardiologist as the specialist, there is also a rehabilitation counselor or social worker. This practice is visited both by patients who have been in a rehabilitation clinic and others who have not. The main function of the rehabilitation counseling is to provide the patient with information about reintegration into the work process and apply for the financing of certain therapeutic measures. The rehabilitation counselor therefore proceeds independently with this, and the doctor is not present at the interviews. Following this discussion, counselor and patient analyze together the place of work in order, if necessary, to explore the possibilities of a transfer, taking the social context into consideration.

At the same time the doctor also runs the local coronary group, although the declared aim is eventually to make the coronary groups independent of medical leadership. In this the group differs from other coronary groups, where the aim is usually to continue exercise therapy under medical supervision for the rest of the patient's life (Halhuber, 1980).

Advantages and disadvantages

Overall this model of a rehabilitation counselor or social worker working in the practice of the local specialist is worth noting. It seems practicable also from the financial point of view if, for example, in a municipal area a social worker is financed by several doctors or joint practices. Psychosocial problems could, however, also be dealt with by rehabilitation counselors and social workers provided by the social services of the health insurance agencies. This is done for example by "health centers" belonging to the health insurance agencies.

5.3.5 Community-centered rehabilitation (Finland)

Community-based rehabilitation operates on the principle of using health services available in the community. This form of rehabilitation was practised as part of the North Karelia Project in Finland, where the incidence of ischemic heart disease is particularly high.

The rehabilitation program itself was part of official health policy and was financed by the National Board of Health, the County Health Administration and local health centers. The program ran from 1972 to 1977. A coordination center at the University of Kuopio developed a number of practical guidelines for its organization, and local heart associations also participated in the organization or financial support of the program.

The program consisted of systematic long-

term control by an "Outpatient Infarct Clinic" at the central clinic and of decentralized local rehabilitation groups, consisting of community health services already in existence which received guidance in rehabilitation and community work from the central hospital. The main components of the program were physical exercise, instruction in how to avoid risk factors, education about heart disease and occupational and psychosocial counseling. Explanatory literature and audiovisual aids were used to support the instruction. The wives of the patients were included in the program. It should also be noted that there was no selection of patients and the program was generally kept very simple (cf. the selection process in the coronary groups of the Federal Republic of Germany in section 6.2 of this paper).
While up to then rehabilitation programs had frequently been based primarily on medical fitness programs, the North Karelia Project – as a community study aimed at reducing the incidence of cardiovascular disease and resulting mortality – was based on the epidemiological risk factor concept and along the lines of comparable studies in the USA (König et al, 1983; Kallio & Cay, 1985; Schlesinger et al, 1986). In addition to the avoidance of the well-known risk factors (high blood pressure, serum lipids and smoking) change of lifestyle and the reduction of the participants' stress and anxiety were prominent elements of the program. It was hence designed to change individual behavior, with sole reference to the risk factors. Psychosocial explanatory models had little influence on the objectives and measures of the North Karelia Project.
The results with respect to mortality, the frequency of recurrent infarctions and the patients' return to work were compared with another population group in East Finland who only received treatment from the general practitioner on his own initiative. The North Karelia program proved overall to be more comprehensive and holistic than that of the comparable program, although the two regions did not differ in the incidence of first infarctions. In North Karelia the number of those who became ill again fell by 25%, which was mainly attributed to the rehabilitation program. In spite of administrative problems experienced by the community health services, the organizers generally considered their efforts to have been successful (König et al, 1985, p. 107; Kallio, 1982, p. 120 f.).
In 1984 a reform of the social and health services changed the rehabilitation system in Finland: it became the responsibility of the national health service, together with the hospitals and the community health centers. All patients who need rehabilitation after the acute phase may under certain conditions receive care free of charge, either in the community or in specific cases also in institutions.

Advantages and disadvantages

Although the North Karelia Project was a more holistic approach, on closer examination it can be seen to be dominated by the risk factor model with its medical orientation and objective of changing personal lifestyle. Essential factors involved in the illness are thereby omitted, in particular those which have received attention in newer theoretical approaches such as life-event research, the stress coping model or the social-epidemiological approach, which center on the psychosocial aspects of coping with illness (Badura, 1981).

5.4 Summary comments on approaches to rehabilitation in the convalescent phase

Against the background of the deficiencies of current rehabilitation institutions in WHO Phase II described at the beginning of this section, we have introduced various institutions and models which we believe represent approaches which go beyond what is generally available in the Federal Republic of Germany.
Using Israel as our example we first reported on rehabilitation approaches with an organized structure. This mixed system of treatment for patients who have had a myocardial infarction broadly offers two possibilities:

- admitting patients after discharge from hospital to an inpatient rehabilitation unit where they undergo a week-long training program;

- supporting patients who were discharged back home from the general hospital as outpatients in group sessions for periods of six weeks to a year.

In addition to the less extensive equipment, the low costs by comparison with long inpatient stays, and the practice of "comprehensive rehabilitation" through interdisciplinary treatment and family orientation, an advantage of this system is the promotion of an early return to

work. This system also provides an alternative to inpatient-oriented rehabilitation (which predominates in the Federal Republic of Germany), i.e. to confront the patient at an early stage with everyday life while at the same time offering medical help.
It has been shown in West Berlin that in view of the short supply of inpatient rehabilitation institutions or beds, outpatient rehabilitation is a perfectly conceivable complementary or alternative system. Patients are evidently much more highly motivated to take part subsequently in outpatient coronary groups than they are after a longer inpatient stay; and transition to the third phase of rehabilitation is hence made easier.
The example of cooperation between the doctor and rehabilitation counselor or social worker team in the practice near Ulm in the Federal Republic of Germany raises the question of what conditions must be fulfilled so that the local doctor is also in a position to provide rehabilitation as an alternative to the inpatient institutions.
Finally, using an example from Finland, we showed the extent to which, particularly in rural areas, decentralized rehabilitation groups integrated into the community health services can also be effective, particularly where secondary prevention is concerned. The development of means of support thus involves both the patients themselves and their family and the community as a whole.
An advantage of outpatient care is that no additional stress is produced by a separation from familiar surroundings. The patients are – wherever possible – confronted with their everyday problems, so that they can recognize and cope with the requirements of the social environment as soon as possible. Inpatient rehabilitation by contrast frequently entails a break with everyday life, so that on their return home the first thing the patients must do is learn how to cope with everyday life all over again. On the other hand certain "problem groups" (overtaxed housewives, patients with complicated infarctions or operations, etc.) can benefit more from inpatient rehabilitation (cf. section 5.1 of this paper). But even in this cases, if there are good diagnostic procedures in the general hospitals and early mobilization is practised, the interim stage of the rehabilitation clinic will not always be absolutely necessary.
Outpatient rehabilitation poses the basic question as to whether inpatient rehabilitation cannot be done away with altogether. The following points have been raised as the focus for further discussion:

1) When is inpatient rehabilitation indicated, and when can it be replaced by which forms of outpatient care? What would then be the role of the local doctor?

2) To what extent and in what form should the psychological or psychosocial aspects of coping with the illness be included alongside the somatic aspects of treatment?

3) How can the patient himself and his social environment (family, friends, etc.) participate to a greater extent in the decision-making during the rehabilitation process?

6. WHO Phase III of myocardial rehabilitation: late rehabilitation phase

6.1 WHO concept and current progress of international discussion

Rehabilitation Phase III begins with reintegration into the family and possibly also into working life, and continues for the rest of the person's life, provided there is no recurrent infarction. Its objective is to maintain the level of health recovered in the previous phases.
Opinions differ as to whether this period should be described as a rehabilitation phase or whether it would not be more appropriate to consider the rehabilitation – which automatically takes the illness as its reference point – as ended and to focus more strongly on health. This view is also reflected in the way rehabilitation provisions differ within and between the various countries. Since this phase takes place in the community, there is general consensus that it is the province of the local medical practice or family doctor. Support is even frequently expressed for the coordination of the whole rehabilitation process to be the responsibility of the general practitioner who would then, however, delegate various functions to other colleagues (Kallio, 1973, p. 63; Bauer & Lehmann, 1981, p. 205). Here, in addition to the doctor, the outpatient heart groups and self-help groups are felt to play a particularly important role.
Heart groups differ on the one hand as far as their connexion to particular institutions is concerned, and on the other with respect to the work of the group itself.

They differ from the self-help groups not only in orientation but also in that they are always run by professionals and are under medical supervision.

6.2 Situation in the Federal Republic of Germany

WHO Phase III in the Federal Republic of Germany is dominated by the outpatient heart group system. Supplementary to this are the "Doctor-Patient Seminars" that are primarily organized by the German Heart Foundation and frequently involve rehabilitation clinics or health insurance agencies, with financial support from the pharmaceutical industry: in 1987 there were 22 such seminars. According to Wendt (1986, p. 353) patient seminars are "a suitable forum for providing the public and patients with comprehensible information about the preventive and curative aims of medicine and improving both the doctor-patient relationship and compliance on a permanent basis". He goes on to suggest holding more frequent, smaller seminars for schools, senior citizens' groups and company personnel.
Contrasting with these professionally initiated and organized services there are a small number of self-help projects which are all interested in good cooperation with the doctors.

6.2.1 Gradual reintegration into working life

From a medical standpoint gradual reintegration into working life can obviously be very beneficial for myocardial infarction patients of employable age. For a long time this was obstructed by the fact that health insurance laws only provided for either full ability to work or inability to work, and no categories in-between.
The Techniker-Krankenkasse (Health Insurance Agency for Technical Personnel) was the first to make it possible for work to be resumed on a gradual basis, by introducing recovery benefit (Krasemann, 1976, p. 112) which was initially only offered to myocardial infarction patients, but later also extended to other categories of chronic illness. Under insurance law this was a therapeutic measure which the doctor recommended, but which the employer could not be obliged to implement. "It is interesting that for people in top positions a gradual reintroduction to work with reduced working hours and also full pay is not uncommon. No-one, however, had the idea of offering this possibility to the underprivileged citizen and for many patients there was simply a gap in the legal provisions" (Krasemann, 1976, p. 113).
The realization that gradual reintegration benefits everyone involved, also from an economic standpoint, was certainly the main motivating force that led all health insurance agencies to make provision for it – even if to varying degrees. We do not know the extent to which the firms support employees for whom this therapeutic measure is recommended.

6.2.2 The outpatient heart groups

When patients are discharged home from the rehabilitation clinic, they are transferred to the care of the general practitioner. The Federal Association for Heart Disease Prevention and Rehabilitation is of the opinion that patients should be informed while still in the rehabilitation clinic of the opportunities provided for continuing the rehabilitation measures already begun, in particular the exercise therapy, in outpatient heart groups – which constitute the third element of the "therapy chain".
The Federal Association, which has a strong influence on treatment concepts for heart patients, defines outpatient heart groups as follows:
An outpatient heart group is a group of patients with coronary heart disease or other heart diseases for whom exercise therapy is appropriate, which meets regularly on medical recommendation and under medical supervision, under the leadership of an appropriately trained instructor in order to compensate for the consequences of the heart disease and achieve tertiary prevention by means of exercise therapy, relaxation exercises and group discussions. Exercise therapy here means measured physical activity prescribed by the doctor which is adapted to the patient's capabilities and medically supervised (Bundesarbeitsgemeinschaft, 1985).
A distinction is made between training groups and exercise groups according to how much the patients can cope with. There are also mixed groups where no such distinction is made between degrees of resilience but where the groups are put together as a consequence of, for example, lack of space or personnel.
Participation in the various groups is prescribed by the patient's doctor. While at the beginning there were only purely "myocardial infarction exercise groups", which were later renamed "outpatient coro-

nary groups", today the term used is "heart groups". The reason for this is the very broad spectrum of patients for whom such exercise is indicated.
According to the Association's register, there was a total of 1,158 groups in the Federal Republic of Germany in 1985. Most of the groups (81%) are attached to sports associations (Krasemann, 1986, p. 21). The advantages of the sports associations, according to Krasemann, are as follows:

1) the necessary facilities for exercise therapy are available (halls, grounds, sports teachers, etc.);

2) medical institutions only offer exercise therapy;

3) other forms of therapeutic assistance can be incorporated (e.g. dietary counseling);

4) heart groups can be set up where doctors are available who are interested in such provisions (Krasemann, 1986, p. 21).

The group meetings take place once a week and last 60-90 minutes. The work in the heart groups initially focused very strongly on physical activity – based on the experiences of Gottheiner in Israel with the first groups of this kind. In the course of time the focus shifted considerably. Today the idea is frequently to provide therapy to help patients cope with life, although exercise therapy remains an important element.
Contrary to the idea behind the "therapy chain", of which activities in the outpatient heart groups are an integral part, the Hamburg Infarction Follow-up Study showed that only 27% of patients from rehabilitation clinics take advantage of the group provisions (Weiss, 1986, p. 282). The reasons for this are, on the one hand, the differing financing systems of the health insurance agencies, the way in which the general hospitals and rehabilitation clinics motivate patients to participate in the groups, fears of competition on the part of the general practitioners, and, according to medical opinion, so-called Type A behavior. On the other hand, achievement-oriented admission criteria have led to selection in favor of younger men from particular social classes with a high level of physical ability (Weiss, 1986, p. 282). The low participation of women is ascribed to the burden of housework and a more negative attitude towards sport. The groups were used least of all by the working class of both sexes. In the above study 70% of the participants were self-employed, salaried employees or civil servants.
Despite the advantages mentioned above, the attachment to sports associations has the draw-back that it is felt by many people to reinforce what is often an already exaggerated degree of achievement orientation. This orientation seems to be more pronounced in the training group than in the exercise group. This came out very clearly in a discussion with participants of a group in Hamburg, who said that they wanted to retain the status of an exercise group, also on a long-term basis. They too considered that the danger of the training groups was the overemphasis on the sporty and competitive element. In exercise groups, the tendency is more towards group walks, discussions or games, but with information about the illness and ways of coping also playing an important part. This information does not absolutely have to be provided by "professionals", since, in the opinion of the Hamburg group, the information they give is often too complicated and not very useful for everyday life. The group feels instead that their discussions are perfectly adequate as a source of psychological support and a means of sharing information. It was also interesting that the participants described the fears of the doctors that the patients would become too independent as a result of the information that they received from the group and would thus achieve greater equality with the doctor. The work of this group also clearly had affinities with the ideas behind self-help groups.
A report on another group in Hamburg was in complete contrast to this. Gröschler (1986) established that "neither informative lectures, nor group discussions, nor the encouragement of brief exchanges, even between only two individuals" took place. These two examples show how widely outpatient heart groups can differ.
It has frequently been noted how exercise – the main element in most outpatient heart groups – is a very good method for reducing depression and improving the patients' general mood (Hackett & Cassem, 1982, p. 216). There are however no known epidemiological studies which show that training helps to prevent coronary heart disease or aids recovery, nor has it been possible to prove that physical achievement is of prognostic value (Froelicher, 1982, p. 180). In the Oldenburg Longitudinal Study it was however established that by comparison with men who were not members of groups, the "psychological condi-

tion" of group participants was "in general somewhat more positive" (Lehmann, 1987, p. 83), independent of age and initial condition.
In the absence of comparative studies, a general assessment of the groups is not possible. We cannot therefore judge the extent to which participants in these groups succeed in progressively detaching themselves from their sick-role and from the medical system.

6.3 Innovative approaches in other countries

In this section the following innovative approaches will be introduced:

- company heart groups for currently employed and retired personnel (example: Texaco);

- self-help guidance for myocardial infarction patients from former patients and professionals (example: "reintegration through duos" in the Netherlands);

- self-help groups (examples: three different initiatives from Hamburg and "Take Heart" in England).

6.3.1 Company heart groups: the Texaco project (Federal Republic of Germany)

The fact that only a small proportion of myocardial infarction patients participates in heart groups led a company doctor in Hamburg to try and increase motivation by means of facilities within the company. This idea was implemented in 1980 at the headquarters of the German branch of Texaco (see article by Engelhardt, p. 174).
In addition to providing gradual reintegration, the company set up a heart group, which according to our information is unprecedented in the Federal Republic of Germany. This is freely available, not only for currently employed but also for retired personnel who have had a myocardial infarction (rehabilitative measure) or who are considered as being particularly at risk (preventive measure).
The company heart group model is largely unknown, since material about this example has only recently been published. More thought should be given to ways and means of promoting this idea. The unions should in any case concentrate on exploring ways of implementing health promoting measures in firms.

6.3.2 Reintegration through "duos" (Netherlands)

With regard to the participation of patients in decisions made during the rehabilitation process, Badura complains that the present approach tends to make the patients more passive and to individualize their problems; this reinforces certain tendencies which are counterproductive in view of the changed panorama of the illness (Badura, 1981, p. 9).
The "duos" example from the Netherlands can be seen as one way of combatting this problem. In 1976, as part of a larger research project at the Medical Faculty of the State University of Limburg, a model was developed with the aim to promote ways of helping the chronically ill and handicapped based on social medicine and self-help. The contribution by Bremer-Schulte (p. 273) describes experiences in which professionals and laymen (former patients) combine to help patients assume responsibility for their health.
The model shows that group aftercare is an appropriate response to an essential need of the myocardial infarction patients. The duos work is more of a supplement to rehabilitation work than a substitute for it. The model is based largely on Badura's view (1981, p. 91) that we need to see the consumers of medical services and their informal support systems as "co-diagnosticians" and "co-therapists", i.e. as active participants in the maintenance of health and the process of coping with illness and hence also as "co-producers" of medical services. Only then will we be able to do justice to the real importance of consumers in health matters.

6.3.3 Self-help groups as an addition to the rehabilitation system

There is a limit, both from a qualitative and quantitative point of view, to the support the professional system and the families can give to the myocardial infarction patient. This raises the question as to whether – particularly in view of changed family structures – there could not be very specific advantages to self-help groups run by doctors. In the view of various experts, self-help groups for myocardial infarction patients in the Federal Republic of Germany quantitatively play hardly any part at all. We were unable to obtain any details about the numbers of such groups, and thus limited our research to the Hamburg area. The register of "Self-help groups in the health service, Hamburg district" (as of August 1986) lists three different groups (Hamburg Health Authority, 1986).

a) Hamburg sports association

The group describes itself as a "discussion group for confidential exchanges and mutual help with problems arising from the illness". It developed in connexion with an outpatient coronary group and was intended to provide counseling as well as the opportunities to discuss problems and learn from others. In the coronary group problems such as threatened separation as a result of the illness, weight, the quantity or misuse of medication and sexual questions were not dealt with. This was mainly due to a lack of intimacy because of the size of the group ("gymnasium effect").
An inquiry at the contact address given showed that the group is currently in a state of transition. From the original ten people only four remain. The participants feel the crisis was caused by too much being expected of the group, but an attempt is nevertheless going to be made to start it again.

b) Self-help group "Hamburg Infarction Aftercare"

The group was created to fill the gap between the outpatient coronary groups and those groups that focus too strongly on the social aspect ("coffee mornings"). This group is designed for myocardial infarction and bypass patients, whose main problems are with family relationships, in particular where there is uncertainty about the sexual side. Discussions are held to try and reduce the anxiety which, for example, is constantly being revealed by the question: "What can I still do? What mustn't I do any more or not do yet?" The work of the group consists of telephone counseling, the provision of written material and the exchange of personal experiences. Due to problems in financing this work the group has now had itself registered as a charitable organization, through which it hopes to obtain financial support.

c) North German Cardiac Association

In the Hamburg Health Authority's register of self-help initiatives the aims of this particular self-help organization are formulated as follows: "Improved psychological counseling and care of heart patients in cardiological and heart surgery centers as well as in outpatient aftercare. Provision of care and assistance in the psychological, medical and social areas before and after the heart operation, or heart transplantation, for infarction patients and patients with pacemakers".
The group's wide-ranging provisions include a discussion group dealing with psychological problems led by a trained psychologist, a hobby, games and handicrafts group, a hiking group, a keep-fit group, dietary counseling, a parents' group for children with heart problems and a monthly meeting of the association with experts.
This association considers its work to be necessary because of the qualitative and quantitative deficiencies in the relevant area of medical care (Nass, 1983, p. 143). The association developed out of a small discussion group consisting of patients who had had heart surgery; they felt alone with the consequences of their illness, and therefore met occasionally to talk about their problems. As the group grew, they increasingly turned their attention outside with the aim of bringing about improvements in patient care, until finally in 1981 an association was founded. The growing number of members (today there are around 260) has led to the development of different kinds of meeting. Members attend those groups which correspond most closely to their needs, according to their personal situation and interest. The activities in the individual groups differ in emphasis: exchange of experience backed up by discussion, information and advice, practical support, contact and socializing or activities with more of an outward orientation.
The Hamburg self-help organization has however had to modify its aims with respect to one of its original priorities: supporting patients, especially from a psychological point of view, by visiting them in hospital both before and after the heart operation. While in 1983 the idea was still to extend visiting, today it is only being carried out in individual cases. One reason for this is that the former patients shy away from the stress of being confronted afresh with the hospital situation. In addition the visiting service is not always welcomed: in the university hospital, for example, according to one of the members, it was banned altogether in one of the wards.
From the observations she made as a result

of participating in this self-help group, Nass feels that it has important positive effects on its members (Nass, 1983, p. 190-192):

- "membership of the group increases the subjective independence of those involved" (p. 190);

-"the group focuses on the psychosocial dimension of chronic illness, which is neglected by the professional helpers" (p. 191);

- "the group considers the family of the ill person to be fellow sufferers" (p. 191);

- "membership of the group helps to normalize the life situation of the chronically ill" (p. 192).

If self-help groups can make a contribution of this nature, this should also convince the professionals that these initiatives are worthy of support. Recommendation of group membership by the patient's doctor has an important influence on actual participation on account of the accepted dependency on the medical care system.

d) "Take Heart" groups in England

The "Take Heart" groups are self-help groups for heart patients and their partners. They were initiated in 1983 by former patients, social workers, nurses and counselors (see article by Morland, p. 196). The groups now work independently of the "professionals" and also organize their own financial support. Their activities lie primarily in the psychosocial area, although they also consider exercise to be important. Medical advice is absolutely taboo, and patients are referred to their general practitioners.
With the growing numbers of members the group is also increasingly looking outside itself, i.e. it is making a greater attempt to have its interests represented in social and health policy. Its declared aim is to have a sufficiently large number of groups, distributed over the whole country, to be able to provide every heart patient with the opportunity of such support.

6.4 Health promotion model: The Munich Health Park

The health park is particularly important in connexion with health promotion for the chronically ill, since the principle of this model is the integration of healthy and ill people in the area of prevention and rehabilitation. In addition to its many other activities there are also group provisions specifically for heart patients (see article by Schmid-Neuhaus, p. 192). While most outpatient coronary groups in the Federal Republic — as mentioned previously — are attached to sports associations, what is different about the following example is the integration of the outpatient heart groups into the overall concept of the "health park".There are three main areas of action:

1. Health education and the prevention of illness;

2. measure to supplement and extend medical therapy;

3. Aftercare, rehabilitation and secondary prevention in connexion with medical treatment and cures.

"Health promotion in the Health Park thus ranges from preventive work (open program for no precisely defined target group) to work designed to accompany treatment, or curative work (for specific target groups e.g. certain risk groups: infarction patients, outpatient coronary groups, psychovegetative disorders)" (Eberle, 1985, p. 3).
It should be emphasized that the medical director of the Health Park is particularly interested in the rehabilitation of patients with cardiovascular diseases on an outpatient basis.
The outpatient coronary groups are easy to integrate into the concept of the Health Park, which includes the aim to "supplement and extend medical aftercare measures with secondary prevention and the continuation and consolidation of convalescent measures (which have up to now been expensive and often unsuccessful)" (Schmid-Neuhaus, 1986, p. 2).
The work of the Health Park as a whole is characterized by the emphasis of those in charge on the high quality of the staff as a major factor contributing to its success, by the good interdisciplinary cooperation, the great importance attached to the participants' individual ability and the variety of counseling available.
The medical director feels that there is a

tendency towards expansion in the area of measures accompanying treatment and rehabilitative measures. In order to maintain the concept of the Health Park, however, it is considered important not to let this area become too large. It should not exceed a third of the provisions both for reasons of content and out of economic considerations.

The example of the Health Park would seem to be an approach that indicates a means of improving the quality of life also for the chronically ill. Approaches tailored to particular illnesses are only followed to the extent that this is necessary and are integrated in good time into an overall concept of health promotion.

6.5 Summary comments on approaches used in the maintenance phase

In the Federal Republic of Germany, Phase III in accordance with the concept of the "therapy chain" for myocardial infarction patients provides for the general practitioner to take over the patients' care and for participation in outpatient heart groups. There are now around 1,200 groups all over Germany, of which most are so-called training groups; exercise groups are much less common. The main criticism of the outpatient heart groups is their pronounced achievement orientation and neglect of the important area of psychosocial problems.

An interesting alternative to the usual link between heart groups and sports associations is the model of the company heart group – which represents an attempt to motivate former heart patients, also after they have gone back to work, to become involved in secondary prevention. The experience of integrating heart groups into the work routine has been very highly rated by all participants and should be copied by other firms.

Two developments have arisen from the training and exercise groups: supplementary discussion groups have been formed within the outpatient heart groups which help to balance the one-sided focus on exercise, and self-help groups have been created as a new way of coping with illness. Three examples from Hamburg show that these groups help the patients become more independent and reintegrate themselves into everyday life.

We have assigned the self-help groups to Phase III, since most of their activity does not start until this point. It should nevertheless be strongly emphasized that support by fellow-sufferers in Phase I can be of great assistance in reducing the stress experienced by patients in the acute phase. This is illustrated by the example of the "Take Heart" groups from England, where hospital visits are a central element of the work. We have the impression that in some countries the self-help groups are already more widely accepted by the patients, their relatives and the health professionals than in the Federal Republic of Germany.

Another interesting method of promoting personal responsibility and orienting the individual away from the patient role is the "duos" model in the Netherlands, which combines professional and lay skills (involving former patients) in order to help patients return to their former way of life. The success of the model is explained by the active participation of the patient in the physical and psychosocial recovery process and the support he receives within the group.

One model that does not focus on particular illnesses but on health promotion in all areas and at all stages of life (including the post myocardial infarction stage), is particularly worthy of attention. This is the Health Park in Munich. Its basic principle is the integration of healthy people and patients in activities which keep them healthy or promote rehabilitation.

The many different provisions of the Health Park make it easy for patients who have had a myocardial infarction to take part in a whole range of activities, from forms of self-expression and physical exercise to creative and artistic occupations. The group activities that have been developed for heart patients include physical exercises, relaxation exercises and group discussions. Members of their family can take part in other Health Park programs at the same time.

This approach enables chronically ill people to develop their health potential on a number of fronts. Programs geared to specific illnesses are only pursued where necessary and those involved are integrated in a relatively short time into the general health promotion programs.

The following questions should be discussed with respect to Phase III of the rehabilitation of myocardial infarction patients:

1. To what extent does the former heart patient need the medical system and when is it more appropriate to support forms of health promotion that are independent of it?

2. Which provisions best help the individual to gradually relinquish the role of patient?

3. Is it appropriate and possible to change the outpatient heart groups so that there is more emphasis on the psychosocial aspects? How could this be done?

4. Should heart groups be integrated into the daily work routine?

5. Why are self-help groups for people who have had myocardial infarctions more successful in the USA and Great Britain than in the Federal Republic of Germany?

6. Should there be more promotion of self-help initiatives, and if so, how and by whom?

7. When are approaches geared to specific illnesses more appropriate?

7. Concluding remarks

The institutions, models, groups and initiatives that we have selected and described are examples of different ways of providing for myocardial infarction patients in accordance with WHO Phases I to III. As regards the Federal Republic of Germany, they indicate possible ways of introducing greater flexibility into the relatively rigid existing system. One of the important things to emerge from our research was the realization that it is not a case of replacing the old system with a new one, but of making the structures more interchangeable and introducing greater variety and flexibility into the available forms of support in order to meet the different individual and situational needs.
If such changes are to be brought about, a principal requirement and aim is effective participation at all levels. In addition, there must be a greater focus on the important long-term role of the family and other primary groups in the coping process. Finally the development and support of health-promoting ways of life should be intensified and the patients' knowledge and motivation and ability to maintain or recover their health should be increased (Project group "National Health Strategy 2000", 1984, p. 14).
The following key points emerge from this overview (Lehmann, 1987, p. 85 f.):

- the economic imperatives of hospitals and social insurance agencies, resulting in a certain autonomy of the care system and iatrogenic effects;

- narrow biomedical views of treatment;

- the clinical basis of rehabilitation, which prevents the systematic inclusion of the patients' psychological and social situation, with the result that the only long-term effects of rehabilitation are somatic, and relate to successful recovery;

- a biased selection of patients to the disadvantage of certain social demographic groups (women, old people, the unemployed);

- insufficient consideration of the patients' needs and social problems in counseling and treatment, with far less emphasis being attached to this aspect than to the medical aspects of treatment;

- the inadequate participation of the family;

- the general exclusion of the work environment from the rehabilitation measures; and

- the absence of opportunities for outpatient rehabilitation in which the patient can participate from home, as a result of which his orientation to his familiar environment is delayed and a temporal and spatial distance from everyday life is created.

What is therefore necessary overall is the gradual release of the individuals involved from their dependency on the medical system and their role in it as patients. It is also however necessary to change from looking back and focusing on the illness to looking ahead and focusing on health promotion, i.e. the optimal development of health and hence a better quality of life. Göpel summarizes this very well:
"Health is hence a utopia, a longing for the zest of life. It involves collective experience and individual endeavors. The prerequisite for health is an active balancing of internal and external drives and inhibitions. It is dynamic. The requirements and conditions for health change according to everyday life, the social environment and environmental conditions. It cannot be achieved by means of ritualized commands by apostles of health, but is much more likely to be brought about by the conscious development of certain hab-

its. It cannot be achieved by refining and extending the medical repair services but by consciously developing the environment. Nor by increasing the amount of control and supervision by others, but by developing self-confidence and collective experience. It is the mobilization of the 'nevertheless' in spite of the certainty that human life is finite, not in the form of bargaining with death in intensive care units or other authoritarian situations but in the form of a collective discovery of zest for life, as the result of a successful challenge, the product of successful resistance. Health is a sensitive, creative, enthusiastic and fortifying way of coping with contradictions" (Project Group "National Health Strategy 2000", 1984, p. 20).

EFFECTING INSTITUTIONAL CHANGE IN HEALTH PROMOTION OF HEART PATIENTS

by Bernhard Badura

Abstract

The paper deals with the need for institutional change and behavior change in the medical care and social security system of the Federal Republic of Germany. The data reported are from the Oldenburg Longitudinal Study (OLS), in which 1000 males suffering from a first myocardial infarction have been surveyed with mailed questionnaires five times in five years. In this study special emphasis has been given to the influence of social support from the spouse, the medical care system, and workmates on the coping process. Special emphasis has been given as well to institutional factors and organizational problems in the rehabilitation system of general practitioners, rehabilitation clinics and the social security system.
The paper concludes that there is a clear need for comprehensive services and other measures that promote self-reliance and self-help activities among patients and their relatives.
In the literature on heart disease, "health promotion" is mostly defined as behavioral change on the part of the individual - i.e. patients or members of what is conventionally called a "higher risk group". In this paper, however, I shall concentrate on another aspect which is no less important: the need for institutional change and behavioral change in the medical care and social security systems. This change, I argue, is needed in order to promote the health of patients who survived a first myocardial infarction.

A model of psychosocial adaptation

For nearly a decade I have been involved in the Oldenburg Longitudinal Study. In this study we apply a social epidemiological approach in order to learn something about how people adapt themselves to a serious chronic disease. Almost 1000 males suffering from a first myocardial infarction have been surveyed with mailed questionnaires five times in five years, i.e. shortly before leaving the emergency hospital, then six months, one year, 3 1/2 years and five years after the myocardial infarction. The study started in 1981 and we have finished the data collection in 1986. A representative sample of 213 hospitals in the Federal Republic was used. Questionnaires have been sent to the hospital physician, the patient, the patient's spouse and to his general practitioner. The data we have available now includes biomedical data, data about medical treatment, the social security system, personality variables, the family situation and the work situation.
Fig. 1 provides an overview of the main elements and hypotheses of our model of psychosocial adaptation and contains the most important variables and assumptions of the OLS. Social support, either from the informal network or from experts, can help to reduce or avoid potential or real stressors experienced by the patient or make these more bearable (arrows 1 and 2). The burdens caused by serious illness can have a negative effect on the social network of an ill person and on the efficiency of this network, for instance if existing partner problems are intensified by the illness (arrow 3). In most cases, a life-threatening chronic illness is initially experienced - independent from the social support received - as a very heavy burden, giving rise to anxiety and uncertainty and affecting self-confidence and self-esteem (arrow 4).
We presume that health-related physiological responses, transmitted through the central nervous system, and/or health-related behavior - for example, smoking and eating habits (arrows 5, 6, 7) - depend on the person, on the different ways of cognitive and emotional coping with the illness and its consequences, and on the extent and quality of social support.
Patient behavior, for example, resulting

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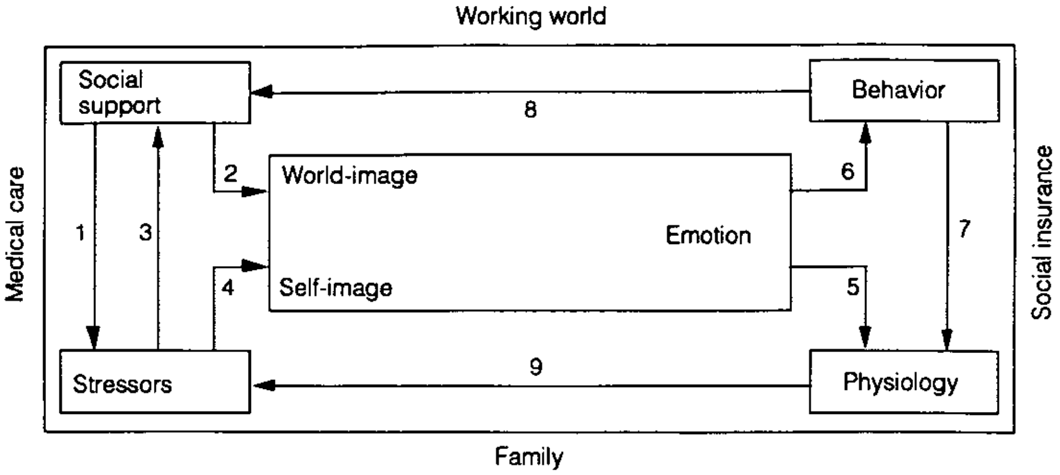
FIG. 1. A SOCIO-ECOLOGICAL MODEL OF COPING WITH ILLNESS



from a chronic depressive reaction to the illness, can have very negative effects on the partnership and the extended social environment (arrow 8) leading to progressive social isolation of the patient; alternatively, the partner or other members of the social network may feel unable to cope with the patient's behavior or his psychological condition. A decline in the state of health can finally intensify still further the existing anxieties and uncertainties and thereby increase the burden caused by the illness (arrow 9).

The family, the medical care and social insurance systems as well as the working world are the most important elements of social ecology for chronically ill people. The coping process, with its cognitive, emotional and behavioral aspects, and social support are at the core of this model.

Coping is defined by Lazarus (see page 12) as the way people deal with stress, that is with situations or events that they perceive as threat or loss. The concept of coping relates the social processes to the psychological processes and, in turn, the psychological processes to physiology and behavior.

Social support: meaning and functions

Social support is assumed to either reduce the level of stress or to enable people to better cope with the stress. Social support is a very ordinary phenomenon but one of importance to everybody's psychological well-being, not only to people confronted with a critical situation or a serious life event.

Religion might be a source of social support – if one has real faith - as it provides a "sense of coherence" or belief system that helps to perceive the world as understandable and predictable.

Social networks and interpersonal processes might be a source of social support because they provide us with significant others and opportunities for self-evaluation, with practical help and emotional gratifications, with stable reference points and a feeling of belonging.

Socially defined and culturally accepted roles might also be a source of social support because they structure our daily activities and interactions, provide us with social contacts and with opportunities to strengthen our sense of self-worth.

The data presented in this paper is focused on medical and social support and on the influence of the loss of work role on recovery from a first myocardial infarction.

Psychological well-being involves continual reciprocal interaction between social, environmental, cognitive, emotional and behavioral influences. Conceptual differences between sociologists (e.g. symbolic interactionists) and psychologists (e.g. cognitive phenomenologists) with respect to well-being are, in our view, a matter of emphasis, not of substance. Psychologists consider that cognitions and emotions are primarily an individual phenomenon. Sociologists, however, are more inclined to stress the *social* nature of cognitions and emotions and regard social support as an umbrella concept encompassing elements of the social environment, interpersonal processes, and/or the perception of these processes. In this perspective, the main functions of social support are the following:

1) to prevent cognitive disintegration or enable people to regain a "sense of coherence" (Antonovsky, 1979);

2) to help overcome negative emotions and promote positive ones;

3) to keep or to regain a self-concept that is realistic, stable and positive.

By our own behavior we all play a role in creating and promoting (and sometimes even destroying) our social networks in daily interactions. However, at the same time we all depend on these networks to cope with the difficulties of everyday life.

The provision of social support in the medical care and social security systems

In the following, the idea of health promotion will be used as a guideline in order to learn something about how, in the Federal Republic of Germany, the medical care and social security systems enable or restrict the recovery process from a heart attack.

As mentioned previously (see article by Kickbusch, p. 10), the Ottawa Charter defines "health promotion" as "the process of enabling people to increase control over, and to improve, their health". Self-reliance, self-help and self-determination are central to both the idea of health promotion and to the WHO definition of "rehabilitation". Rehabilitation is defined as "the sum of activities required to ensure patients the best possible physical, mental and social conditions so that they may, by their own efforts, resume as normal a place as possible in the life of the community" (WHO, 1969). The first question I shall try to answer is: to what degree does the health care system enable or restrict the self-reliance of heart patients?

Self-reliance

Among experts today there is unanimity about the health promoting function of the *early mobilization* of patients who survived a heart attack. The "Gotenburg Model" recommends to walk around the room the 7th or 8th day after the heart attack (Reindell & Roskamm, 1977). *Table 1* reports on the results of the OLS regarding early mobilization in the Federal Republic of Germany.

From the perspective of the Gotenburg Model, only 25% of the heart patients receive early mobilization in the Federal Republic of Germany. To our surprise, it was not only the physical state of the patients that influenced the time of early mobilization in our sample, but the type of hospital as well. The smaller the hospital, the less often patients were mobilized early. Nearly 20% of the patients reported that they remained in bed for more than 20 days.

TABLE 1. TIME OF EARLY MOBILIZATION

N = 998	
Until the 8th day	25.1%
Until the 12th day	21.7%
Until the 16th day	25.4%
Until the 20th day	11.0%
After more than 20 days	16.8%

On the average, members of our sample spent *32 days in the community hospital*. This is about twice as much as in countries like the United Kingdom or the United States. In the United Kingdom, as early as 1973 patients with acute myocardial infarction spent only 15 days in the hospital (UK Department of Health and Social Security, 1977). In the United States, patients with a "mild" infarction are kept in the hospital only 7-14 days (N.K. Wenger, unpublished manuscript, 1982). In the Federal Republic of Germany, however, about half the patients with "mild" infarctions are hospitalized for more than four weeks, even though most of these patients are referred afterwards to special rehabilitation clinics where they spend another 4-6 weeks. Again, the type of hospital has a significant influence on the length of the hospitalization: the smaller the hospital, the longer the patients are kept. The physical state of the patients has practically no influence on this pattern.

Table 2 reports the results from a multivariate analysis of the variable "days spent in the hospital". Contrary to our expectations, variance is not increased significantly by factors like "age" or "severity of the illness" but by factors like "time of early mobilization". The smaller the hospital, the more conservative its treatment procedures seem to be, and the longer patients are kept. It appears that patients with "mild" infarctions are used to "fill beds" and thus help to justify the oversupply of hospital services. This situation is not only counterproductive from the financial point of view, but as well from the point of view of the patient's well-being. Our data

TABLE 2. STEPWISE REGRESSION ON TIME SPENT IN THE HOSPITAL FOR ACUTE CARE

Variables	R2	Increment of variance	F-Value
Severity of illness (objective data)	0.08	0.08	7.4
Severity of illness (clinical assessment)	0.10	0.02	4.3
Type of hospital	0.12	0.02	8.6
Age of the patient	0.12	0.00	0.0
Length of intensive care	0.19	0.07	46.8
Time of early mobilization	0.35	0.16	185.9

TABLE 3. NEEDS FOR INFORMATION EXPRESSED BY HEART PATIENTS VERSUS THE INFORMATION ACTUALLY RECEIVED FROM THE PHYSICIAN (ACUTE CARE HOSPITAL)

Subjects	Patient needs N = 998	Needs met by physician
Illness and drugs	97%	92%
Weight control and diet	85%	70%
Smoking and alcohol	76%	87%
Sexual behavior	74%	19%
Physical health	95%	80%
Psychological problems with family and work	88%	59%
Return to work	92%	63%
Retirement (early)	68%	23%
Supervised heart groups	70%	25%

show that the longer the patients stay in hospital, the more they become afraid of a reinfarction, of their general future, and of death.

When it comes to the *counseling behavior of the physician*, even more obvious discrepancies exist between the patient's needs, on the one hand, and the activities of the health service, on the other.

From the point of view of health promotion, this situation is especially dissatisfying. Comprehensive counseling and the provision of consistent advice, easily understandable, seem to be among the most powerful means of improving the health of chronically ill persons.

Table 3 gives an overview of some of the main issues regarding patient needs for information and the information actually provided. Physicians concentrate very much on issues like "smoking", "medication" and so on but when it comes to psychological or social problems, they are much less able, or inclined to meet the information needs of their patients.

Now, if we add to this piece of evidence another one, namely the fact that about one quarter of our sample reported increased feelings of uncertainty caused by the inconsistency of the information, then the urgent necessity of behavioral change on the part of physicians becomes even more obvious.

Heart patients, like most of the chronically ill persons, need accurate information about their physical condition. They need sympathetic care. They need advice about the practical problems they are facing due to their illness and opportunities for discussing openly their feelings. They need help about how to seek, or to avoid early retirement, etc.

Self-help

The *social context* of the patient plays an important role in health promotion, disease prevention, and in the process of recovery from serious illness. We were interested, therefore, in gathering data on the following issues: what do physicians do about the social network of their patients? To what extent do they comply with the patient's wish to include important members of his/her social network in the therapeutic process?

The spouse plays an important role in the social network of married people, either as a source of social support or as a source of more or less serious stress. To include wives or husbands is important at least for two reasons: first, to help spouses cope with their own negative emotions and uncertainties; and second, to enable them to adequately support patients

TABLE 4. PHYSICIAN COMPLIANCE WITH THE WISH OF THE PATIENT TO INCLUDE SIGNIFICANT OTHERS IN THE THERAPEUTIC PROCESS

Significant others	Patients who express that wish		Compliance of physicians	
Spouse	420	(76%)	230	(55%)
Grown-up children	120	(32%)	16	(13%)
Employer/Superior	104	(26%)	11	(11%)
Company physician	137	(36%)	24	(18%)

TABLE 5. DIFFERENCES IN OUTCOME VARIABLES BETWEEN PATIENTS PARTICIPATING OR NON-PARTICIPATING IN PHYSICIAN-SUPERVISED GROUP ACTIVITIES

	Median of participating patients	Median of non-participating patients	T-test significance
Cognitive appraisal of illness	47.2	50.8	0.002
Coping with illness symptoms	51.8	49.4	0.008
Subjective assessment of health state	53.0	49.9	0.001
Depression	46.9	50.5	0.001
Anxiety	47.4	51.0	0.004
Positive effect	53.1	49.6	0.004
Self-worth	52.4	49.5	0.012

Median = 50 N = 608

and reduce interpersonal problems within the marriage.

Table 4 clearly suggests that the majority of heart patients want their spouse to be included. In addition to the spouse there are other significant persons whom patients would like to have included and informed.

Again, we have to recognize that patient needs go far beyond what is actually offered. In "networking", as well as in counseling, the compliance of the medical personnel is very low.

Physical exercise and informal gatherings in *physician-supervised heart groups* is getting somewhat popular among cardiologists, general practitioners and (former) cardiac patients in the Federal Republic of Germany. But although physicians get paid for initiating or running these groups, only 10% of the patients in our sample were actually informed about the existence of heart groups. Yet, such groups have been established in eleven regions and total 995.

Table 5 suggests that patients who join these groups do profit from it. Participants feel less threatened by the illness, report that they cope with it more effectively and are better off psychologically than non-participants. These positive effects are not influenced by age or the psychological state of the patients before they joined the group.

Self-determination

After having spent on the average more than four weeks in the hospital, 86% of our sample were referred to special rehabilitation clinics, where they spent another 4-6 weeks. One consequence of this heavy emphasis on the clinical setting is that heart patients are kept away from their home and their normal life for around 10 weeks or more. The vast majority of patients have no chance to influence either the length, the location, or the date of this second phase of hospitalization. This prolonged separation from family and home is experienced as a source of stress by more than 50% of the patients concerned.

The system of social security and welfare institutions in the Federal Republic of Germany is the result of an incremental growth of more than a hundred years. Even today, there is no central planning and no coherent health policy. No such thing as central decision-making even exists in the complex system of health and welfare institutions where almost one third of the Federal GNP is spent.

Cardiac rehabilitation falls under the jurisdiction of six different institutions of which the most important are the pension funds. These institutions often fight each other on matters of power and money. To settle these fights, patients are exposed to bureaucratic controls. For example, in order to clarify which institution has to cover the loss of income, the patient has to go to a special medical service of the institution concerned and submit to different diagnostic procedures. This special service decides as well whether the patient goes back to work or has to face early retirement.

This all takes place in addition to what is done by the hospital and the general practitioner. More than half of our sample had to accept these purely bureaucratic controls and one third had to return twice or even three times. Our data suggest that these controls are a source of psychological distress. They increase anxiety, depression and other psychological problems of patients. Perhaps, it is not the sole fact of being exposed to these controls that creates distress but the whole situation of increased threat and uncertainty related to the process.

What has been said so far confirms one of our main hypothesis: *even though the heart attack is a somatic event, changes in the life of heart patients are only partly determined by their physical state if at all.* The findings of our study with regard to work status serve to further emphasize forcefully this view.

The importance of the work status for heart patients

The future work status of a patient has a tremendous effect on his or her life. The last part of this paper will be devoted (a) to the determinants of work status of former heart patients and (b) to the social and psychological consequences of work status.

Determinants of work status

After one year only 45% of the blue-collar ex-patients in our sample were back at work. *Table 6* suggests that social class is one of the best predictors of return to work, which is probably the most important social aspect of recovery from heart attack.

Table 7 gives a summary of our inquiry concerning potential causal factors. While the physical condition of the members of our sample appears to exert no influence on employment status, this is not the case for age, social class and (as already mentioned) psychological well-being which are important potential predictors.

TABLE 6. WORK STATUS IN RELATION TO SOCIAL CLASS ONE YEAR AFTER MI (T3)

	Percentage back to work	Percentage not back to work
Blue-collar	45	55
White-collar	68	32
Civil servants	63	37
Self-employed	73	27
	57	43

N = 608 Missing values = 22

TABLE 7. DIFFERENCES BETWEEN THOSE BACK AT WORK AND EACH OF THE OTHER CATEGORIES

The results are based on T-tests or χ^2-tests of each category against the category "back at work". The number of + reflects the predictive value of each variable.

Potential predictors	Early retired	Retired "temporarily"	On sick leave
Medical data	0	+[b]	0
Socio-demographic factors:			
- age	+++	---	++
- socioeconomic status	+++	++	+++
Psychosocial variables:			
- subjective health	+	+	+
- psychological well-being	+	+	++
- type A behavior	0	---	0
- work satisfaction	0	---	0
- expectations of physician with respect to future work status	+++	+++	++
- expectations of patients with respect to future work status	+++	+++	+++

Social and psychological consequences of work status

Tables 8, 9 and 10 provide evidence of the central importance of the work status for recovery. Ex-patients who are back at work one year after their infarction are much better off psychologically and financially than those who are still on sick-leave or who had to accept early retirement.

TABLE 8. SOCIAL AND PSYCHOLOGICAL PROBLEMS OF THE EARLY RETIRED

Compared to those back at work the early retired are faced with/suffer from

- a significant lower income
- a more reduced family life
- more perceived family-stress
- reduced sexual activities
- reduced activities outside the family
- more feelings of boredom, meaninglessness and loss of orientation
- more anxiety and depression

TABLE 9. DEPRESSION IN RELATION TO WORK STATUS

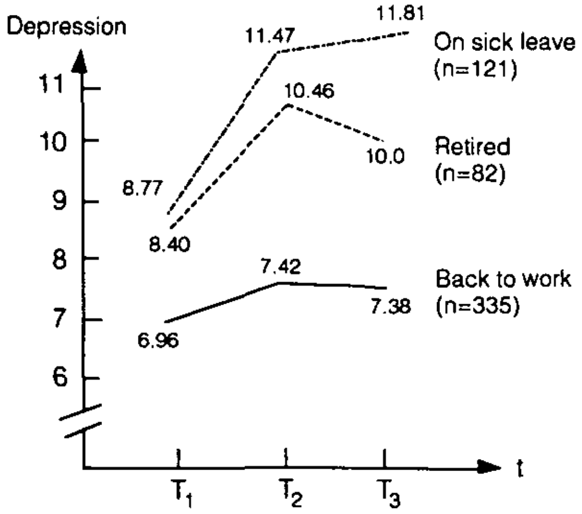
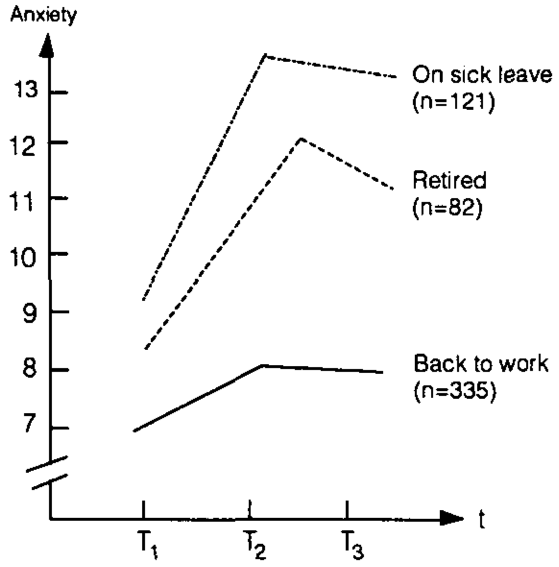


TABLE 10. ANXIETY IN RELATION TO WORK STATUS



These tables indicate that ex-patients whose future work status is still unclear after one year suffer most from the stress of illness and face the risk of getting chronically depressed.

Only 25% of the early retired ex-patients in our sample welcomed their new status spontaneously.

The other 75% were forced, more or less, to abandon their jobs.

These facts should worry us for two reasons: first, whether or not somebody seeks early retirement after a heart attack should be his or her own decision: such an important matter should not be decided in a dictatorial manner; second, the social and psychological costs of early retirement appear to be quite high and should, therefore be avoided, if possible.

CONCLUDING REMARKS: FOUR REQUIREMENTS MUST BE MET

We do need behavior change to promote the health of heart patients: behavior change on the part of the hospitals, of doctors and of the bureaucracies involved - not only on the part of the patients themselves. The requirements are:

Comprehensive rehabilitation services: In all developed countries the medical care systems tend to over-emphasize somatic problems during the acute phase of chronic illness, and they tend to neglect the psychosocial and practical problems of their patients as well as problems of long-term adaptation. The main thesis of this chapter is that the social context in the hospital, at home and at work is of central importance to recovery. Patients do require adequate medical treatment. But they need more than that in order to cooperate effectively during acute treatment and afterwards, and to cope with their social, practical and psychological problems. They need adequate information which is both consistent and clear; they need emotional support and practical help; and they need opportunities to openly discuss their feelings and uncertainties. Doctors need to know more about how to follow a comprehensive and socio-ecological perspective in treating heart patients, cancer patients and other chronic conditions.

Beyond that there might be a need for more social workers within the medical care system, who are specially trained and experienced in dealing with the psychosocial and practical problems of the chronically ill in active cooperation with the rest of the rehabilitation team.

Supporting the supporters: Social support has two faces. It is a potential source of health (for those receiving it). And it is a potential source of stress (for those who have to offer it). There is a clear need to support the supporters, especially the supporters of the terminally ill, in order to avoid the "burn out" syndrome. Doctors, nurses and lay caregivers, who are providing emotional and social support on an everyday basis, often work under severe stress. Caring for cancer patients seems to be especially stressful. Main supporters of the chronically ill should get more support themselves to be able to provide adequate care to someone else. Therefore support programs for the supporters should be developed and applied.

Towards a policy of active reintegration: Data from the Oldenburg Longitudinal Study and from other studies demonstrate the health promoting potential of the work role in industrial societies. These data suggest that former heart patients are facing serious problems because of the present situation on the labor market. A high level of unemployment and widespread public prejudices with respect to chronic illnesses like heart disease and cancer might in the future even increase the tendency to keep ex-patients out of the labor market and to discriminate against them at the workplace.

Networking: Health promotion emphasizes the importance of social integration and mutual understanding in coping with the stress of life and illness. Including the family and significant others in the treatment procedures, promoting patient groups in the hospital and self-help groups in the community are all important steps in health promotion for the chronically ill.
Both the prevention of social isolation and of distorted communication between the chronically ill and the rest of the community are perhaps going to be *two of the most urgent health policies in the years to come.*

B.B.

3.

CANCER: TOWARDS INNOVATIVE HEALTH PROMOTION APPROACHES

INTRODUCTORY NOTES

Cancer is a complex subject. The term refers to a group of some 100 somatic disorders, similar in the fears and stigmatization they evoke but differing with regard to possible etiological factors, treatment modalities, and clinical course.

Speculative writings and recent empirical findings suggest that psychosocial interventions which are geared to enhancing the quality of life may at the same time be supportive of medical modes of treatment and directly influence the mobilization of the organism's anti-tumor resources.

There are also clinical studies that strongly suggest, although they do not prove, that many different systems of profound stress reduction, imagery, hypnosis, psychotherapy and other psychological techniques may modulate tumor growth in humans in clinical practice.

Altering pathological styles of coping with stress is another area of concern for health promotion. This applies to the Type-C behavior pattern – repression of negative cognitions and effect, lack of emotional outlet, disturbed interpersonal relations, and feelings of low personal worth and self-efficacy – which has been shown to predict differences in survival in studies of patients with malignant melanoma and mammacarcinoma.

Although we know too little about the causes of cancer or about the influence of behavioral factors in the clinical course of the different malignant tumors, many oncological centers and lay groups of former patients are developing innovative programs for coming to terms with the manifold problems triggered off by a diagnosis of cancer and its medical treatment.

Psychosocial intervention projects are being tried out at numerous cancer centers, aimed both at the general needs of patients and at specific problems such as psychosexual functioning or social reintegration on the job.

Simultaneously, in many parts of the world, what can be described as a social movement among "exceptional cancer patients" has been growing larger with every passing year. These patients engage actively in the fight for recovery and a better quality of life through the use of studied complementary cancer therapies. There is little scientific evidence on which to evaluate these therapies; however, there *is* evidence that some patients do well while using complementary cancer therapies, and a significant convergence exists between conventional and complementary therapists on several important themes, including nutritional, psychological, and immuno-modulating approaches to supporting the general health of the cancer patient.

HEALTH PROMOTION AND CANCER CARE

by Millard Waltz

1. Introduction

Health promotion and cancer care is an extremely difficult topic. This is due, first of all, to the complexity of the subject and secondly, to the current state of the art regarding effective programs of medical and psychosocial intervention. In addition, health promotion should be viewed as involving not only the cancer patient but also his immediate social network and the medical system. Professionals frequently experience the so-called "burned-out" syndrome and, therefore, are also in need of supportive interventions. This is the essence of discussions which have taken place over the last few years in national, European, and international forums, bringing together individuals concerned with the promotion of physical, social, and psychological well-being among cancer patients. These forums have particularly focused on two aspects of health promotion: one is related to the general theme of *"quality of life"*, and the other to possibilities of *influencing the clinical course of the disease* by holistic approaches (Aaronson & Beckmann, 1987; Cunningham, 1984).
In attempting to identify the needs for health promotion in the field of cancer care and describe some innovative approaches to meet these needs, this paper will:

- define the goals and some basic concepts of health promotion;

- outline a categorization of patient and non-patient target groups;

- discuss current interventions which appear promising and may serve as models for health promotion in the future in relation: (a) to cancer patients at the four main stages of the illness; and (b) to professional and lay caregivers;

- pinpoint areas in which the needs are great but where current deficits or serious obstacles predominate.

2. The state of the art

The term *cancer* refers to over one hundred different disease entities differing in regard to etiology, treatment modalities, and clinical course. From a biomedical perspective, some cancers currently have a good prospect of being cured, whereas for others only palliative therapies are available. Thus, these malignant disorders may have very different impacts on the lives and well-being of different patient groups. Yet, all have in common the fears and stigmatization implied by the word *cancer*.
The psychosocial morbidity triggered off by a diagnosis of cancer depends to a certain degree on characteristics of the physical morbidity and its medical treatment. As an example, breast, gynecological, and testicular cancers all have in common a severe threat to body image and sexual identity but may differ considerably in respect to other social and psychological after-effects and to long-term survival. This is particularly true of cancers which are *age-related;* some cancers are most prevalent in childhood and early youth, at the beginning of adulthood or during middle-age, while others develop mainly during the latter decades of the life-cycle. The problems and the cancer-related psychosocial morbidity of these age groups may be very different, and health promotion intervention strategies should take this age component into consideration.
Since the turn of the century, biomedical cancer research has made astonishing progress in developing more effective modes of treatment and cures for a number of cancers. At present, large amounts of human and financial resources are being invested to continue this kind of biomedical research, but since the 1970s there have been no major breakthroughs in treatment for some highly lethal tumors and mortality rates have not been decreased. It would seem, therefore, that we may have already reached the point of decreasing returns on the cancer investment curve

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from this traditional approach (Schneidermann & Tapp, 1985; Engel, 1977).
New concepts appear necessary to acquire the kind of knowledge which is a precondition for developing effective cancer strategies for prevention and cure. Biopsychosocial or holistic approaches are still highly controversial, but a considerable knowledge base has been evolving, as indicated by several recent reviews of the current state or the art (Balitsky & Shmalko, 1987; Day, 1986; Solomon, 1985; Levy, 1985, 1982; Greer, 1985; Lloyd, 1984; Blalock, 1984; Temoshok et al, 1983; Holland & Rowland, 1981). Most important, factors amenable to behavioral intervention in the area of primary prevention also appear salient in cancer care and survival. Adverse life events and chronic stressors may be precursors of some cancers when they lead to a sense of hopelessness, and they also may be predictors of increased risk of metastasizing. If this proposition is true, it would have implications for interventions both for pre- and post-illness (Schmale & Iker, 1966; Goodwin et al, 1986).
As a broad generalization, both the literature on cancer etiology (Cox & McKay, 1982) and on adaptation/survival (Levy, 1985) focus on an overlapping group of psychosocial causal influences. The same is true of the emerging field of neuro-immuno-modulation (Kiecolt-Glaser et al, 1984-7). Influences of the social environment and predisposing factors, which are viewed as linked to major psychological and biological processes, include:

- lack of emotional competence (Jensen, 1984; Cox & MacKay, 1982);

- a stressful and non-supportive social environment during the lifespan (Jenkins, 1983; Joseph & Syme, 1982);

- a biography of particular adverse life events and poor mental health related to divorce, family disruption, unemployment, etc. (Moser et al, 1984; Fox & Goldblatt, 1982; Shekelle et al, 1980).

Effective intervention strategies before and after cancer in these areas could alter pre-illness immuno-competence (Kiecolt-Glaser et al, 1987) and cancer-risk differentials (Moser et al, 1984), as well as favor post-illness psychological adaptation and lower the risk of metastasizing.
Extensive research efforts within a biopsychosocial framework are necessary for providing the scientific foundations of common intervention programs in cancer prevention and cure (Schneidermann & Tapp, 1985; Temoshok et al, 1983; Engel, 1977).
The technical progress in the fields of brain research, endocrinology, immunology, and tumor biology over the past two decades make it now possible to explore the possible causal influence of these psychosocial factors in the initiation, development, and clinical course of tumors in both animals and humans (Rogers et al, 1979; Sklar & Anisman, 1979; Ader & Cohen, 1987-8).
Stress research has provided important new insights in the area of cardiovascular disorders related to prevention and survival, e.g. work on the psychological and physiological effects of stress and the Type-A behavioral pattern within behavioral medicine (Schneidermann & Tapp, 1985).
In due course, stress research may similarly provide findings that will enable policy makers to develop adequate strategies for the prevention and cure of some or all malignant disorders.
It is currently speculated that not stress *per se* but pathological patterns of coping with stress used by cancer-prone individuals may be of etiologic significance, either because of their immuno-suppressive impact or because they are in some other manner disease enhancing (Solomon, 1985; Dilman & Ostroumova, 1984). These insights, which have been subsumed under the notion of a cancer-prone or Type-C behavioral pattern (discussed on p. 70), are guiding therapeutic interventions in many cancer centers and seem to influence survival (Watson, 1988; Baltrusch & Waltz, 1987; Greer & Watson, 1985; Pettingale, 1985; Temoshok & Fox,, 1984; Renneker, 1981; Rogentine et al, 1979). A certain convergence of research findings in behavioral medicine and the development of therapeutic interventions in psychosocial oncology at the clinical level can be noted.

3. Health promotion and cancer care: major goals and basic concepts

Health promotion has currently two major goals in European psychosocial oncology. The first is concerned with enhancing psychological and social well-being or what might be termed the *quality of life* in a very broad sense (Aaronson & Beckmann, 1987). The second is directed towards the *physical well-being* and *survival* of individuals who have been treated for cancer. More precisely, it is concerned with the achievement of as long an illness-free period of life as possible and with the *mobilization of the antitumor resistance resources* of the organism in order to promote physical health. This metaphor refers to the possibility of modulating the efferent and afferent information system connecting the brain and the cell (Lloyd, 1984; Blalock, 1984; Borysenko, 1982). The term is used by Balitsky and his associates at the Cancer Research Center in Kiev and is based on their own insights into the problem of surgical stress, psycho-emotional stress, adverse biological processes and metastasis (Balitsky, 1983, 1986, 1987).

From both a biomedical and psychosocial perspective, cancers are a highly complex phenomenon. For this reason, the knowledge base from which we can develop effective intervention strategies is still quite tenuous. We know too little about the causes of cancer or about the influence of behavioral factors in the clinical course of the many different malignant disorders. Nonetheless, many oncological centers and lay groups of former patients in the various European countries are developing innovative programs for coming to terms with the manifold problems triggered off by a diagnosis of cancer and its medical treatment as well as for promoting survival by holistic approaches.

The following are some definitions of concepts which refer either to the aims of health promotion or to means for achieving these aims. They encompass terms which have been developed in the behavioral literature on coping, or on adaptation to chronic illnesss (de Haes, 1988; Badura, 1987, 1981; Cohen & Syme, 1985; Moos, 1984; Lazarus, 1984, 1974; Molleman & Pruyn, 1981; Cohen & Lazarus, 1979; Weisman & Worden, 1977).

Quality of life (QOL), happiness, and subjective well-being are synonimous terms which refer to a salient goal of health promotion programs among the *chronically ill* (de Haes & Knippenberg, 1985). QOL is a very malleable term but may be defined as a sense of satisfaction, of being in harmony with oneself and with one's social and psychological world (cf. the article by Beckmann on p. 95). Great progress has been made in operationalizing the concept and in developing psychometrically adequate measures of QOL, both for general populations and for the chronically ill. It is essential to determine whether or not a scale used to measure the level of depression in cancer patients is actually quantifying psychological status correctly and whether it enables the monitoring of changes in status over time, such as when the patient overcomes depression.

The Working Group of QOL of the European Organization for Research on the Treatment of Cancer (EORTC) is currently attempting to develop measures for quantifying differences in subjective well-being after cancer (Aaronson et al, 1988).

Among the chronically ill, QOL is associated with:

- objective/subjective health status;

- the effectiveness of coping with the situation after onset of illness;

- the level of happiness and life satisfaction prior to illness. (Waltz et al, 1988; Levy, 1985; Mendelsohn, 1979; Cohen & Lazarus, 1979).

Coping influences QOL via the emotional management of the *stress of illness*, as well as via self-image management. (A definition of coping is given on page 69). The reduction in negative feeling states (e.g. anxiety) due to effective coping behavior means *ceteris paribus* an enhancement of subjective well-being.

The same is true of coping with the sequelae of cancer as a threat to the pre-illness self-concept of the cancer patient. Self-image management is increasingly being discussed in regards to all chronically ill persons and to the situation of cancer patients in particular (Ray & Baum, 1985; Moos, 1984; Schain, 1980; Cohen & Lazarus, 1979). It may be defined as the maintenance of a positive attitude to one's body, an intact sexual identity, self-esteem, and a sense of personal agency or self-efficacy. These positive attitudes or assessments of the self are a major source of QOL (Waltz, 1987). At the same time they are probably health-promoting via neuro-endocrine pathways (e.g. neuropeptides or corticosteroids), as suggested by the research of Bandura and associates on pain control (cf. Bandura, 1985, 1987). Due to the central role of self-attitudes in human life and their influence on well-being, many psychosocial intervention programs include some form of self-image management in their work with patients (Bos-Branolte, 1987) and many epidemiological studies measure self-esteem and similar self-attitudes as predictors of outcomes (de Haes, 1988).

Another aspect of coping is aimed at increasing positive feeling states, such as joy, optimism, a sense of verve and high spirits, as well as the gratification of needs for doing things and being with

other people. Cancer triggers off a syndrome encompassing a sharp rise in dysphoric feeling states (such as fear or depressed mood) and a curtailment of previous sources of self-gratification and well-being. Effective coping in relation to the enhancement of QOL means the reversal of this process (Cohen, 1982).
Many patients who have *coped with cancer* report greater well-being post-illness than prior to the onset of their disorder. Even terminal patients frequently appear to have achieved a reasonable QOL in spite of somatic status (Morris & Sherwood, 1987).
Psychosocial morbidity (PM) refers to the social and psychological after-effects or repercussions of the somatic morbidity of cancer (Cohen, 1982). A most important component of PM is the threat of cancer to the physical and psychological integrity of the individual and *anxiety*. Hopelessness/helplessness and depressed mood (Endicott, 1984) are a second aspect of PM, which may take the form either of a complete breakdown of defense mechanisms or of an extreme repression of depressive affect (Levy, 1985; Jensen, 1984). Finally, cancer poses a massive threat to the self-concept system: body image, sexual identity, self-esteem, and feelings of self-efficacy (Bos-Branolte, 1987; Mantell, 1982; Schain, 1980; Meyerowitz, 1980; Polivy, 1977).
Social aspects of PM include withdrawal from one's interpersonal network of family, friends and relatives, loneliness, and the loss of interpersonal sources of social gratification and recognition at work or in the larger community (Wortman & Dunkel-Schetter, 1982; Wortman & Conway, 1985).
Health promotion strategies can be directed towards both the psychological and social aspects of PM, since both are preconditions of normalization and attainment of QOL after cancer. Similarly, these factors appear related to risk of metastasizing and premature death, as well as to immune function (Kiecolt-Glaser et al, 1987; Jensen, 1984; Levy, 1985).
Social support refers to the provisions of interpersonal relationships which have a beneficial effect on coping with PM, on the ability to achieve or maintain QOL, and on the capacity to influence the clinical course of the disease and survive cancer (Wortman & Conway, 1985; Levy, 1985; Taylor et al, 1982; Dyk & Sutherland, 1956).
Four types of social supports have been described in the literature (Schaefer et al, 1981; Cobb, 1976):

- emotional support;
- esteem support;
- information support; and
- tangible support, including financial help and the provision of goods and services.

Most importantly, the concept encompasses lay activities of a psychotherapeutic nature, such as confiding one's fears and concerns, receiving advice and encouragement, and being instilled with optimism and a sense of confidence. Major sources of social support after cancer are doctors and nurses, one's immediate family, former cancer patients serving as lay visitors, professional providers of social support to cancer patients, and one's extended social network at work and in the community. For many ex-patients cancer self-help groups are a major source of emotional and esteem support (Schafft in Badura, 1981).
Coping refers to intrapsychic and other activities of the individual for coming to terms with her/his illness (Cohen & Lazarus, 1979). For this reason, health promotion is closely associated with the promotion of effective coping behavior (Weisman & Sobel, 1979). At the cognitive level, coping activities include the major task of appraising one's life situation after the diagnosis of cancer or, in the terminology of Lazarus, *primary* and *secondary appraisal processes:* i.e. what has happened and what can be done? Optimism and a fighting spirit would appear to be important coping outcomes in regard to these appraisal processes (Greer & Watson, 1985; Levy, 1985).
It is speculated that a large proportion of cancer patients must learn to perceive their own basic needs and must alter their pre-illness social environment in order to have these needs gratified (Baltrush & Waltz, 1986). Many types of behavioral and psychotherapy interventions — such as the psychotherapy approach of Renneker (1981), Schnurre's gestalt and marital therapy (see p. 268) or Bos-Branolte's group sessions (1987) are directed towards this *typical* coping problem of cancer patients. This form of coping differs from intrapsychic coping where the individual attempts to overcome the PM triggered off by the diagnosis of cancer and its after-effects. While one type of coping is aimed at changing the patient's environment and lifestyle in order to stay alive, the other type is aimed at the emotional management of the stress of illness. A reduction of anxiety or depressive affect, as well as an increase in feelings of self-

efficacy and personal control, may be viewed as indicators of the effectiveness of both types of coping behavior (Cohen & Lazarus, 1979; Lazarus & Folkman, 1984). We are currently being drawn closer to the viewpoint *that effective copers stay alive longer* and that behavioral intervention programs can aid cancer patients in becoming good copers. Such interventions – e.g. the teaching program resulting from the findings of Project Omega at Harvard (Weisman & Worden, 1977; Weisman & Sobel, 1979; Weisman et al, 1980) – facilitate the development and use of effective coping strategies by the patient and should be predictive of favorable outcomes, both hard and soft.

Physical well-being after cancer is related to the mobilization of the organism's antitumor resistance resources – e.g. elements of the immune system such as sick cells – the prevention of metastasizing, the prolongation of the disease-free period after medical cure, and survival. We have currently very little hard-nosed scientific knowledge on how to bring about or how to ensure physical well-being after cancer, but a body of speculative thinking does exist concerning the ability to influence the clinical course of cancer by means of behavioral interventions (Cunningham, 1984). It seems that most psychosocial oncologists appear to view this as the major aim of their health promotion activities. Clinical experience in psychosocial oncology, a body of case studies on the spontaneous cure of tumors at various sites, and more recently, hard-nosed empirical findings are supportive of this type of speculative thinking and corresponding behavioral intervention programs (Kiecolt-Glaser & Glaser, 1985; Levy, 1985; Cunningham, 1984; Spector, 1985; Institute for the Advancement of Health, 1984-1988).

Psychosocial interventions. Cunningham (1984) has drawn attention to the congruence of evidence indicating that psychosocial interventions "may increase the longevity of cancer patients". Underlying this statement is the evidence that the mind can affect the body in precise ways, as shown by the placebo effect, biofeedback, hypnosis research and psychological conditioning of immune responses (Spector, 1985; Institute for the Advancement of Health, 1984). Furthermore, patients who have recovered from cancer show certain common characteristics, including high egostrength and a strong will to live, "coupled with a sense of responsibility for their own healing and a belief that healing can occur" (Cunningham, 1984). Other characteristics include favorable changes in the individual's environment and the adoption of healthy lifestyles. Many cancer centers have programs (see article by Schnurre, p. 268) aimed at the very points discussed above by Cunningham in his plea for a psychotherapy of cancer patients to promote survival, e.g. a sense of optimism and self-efficacy, a fighting spirit and will to live.

Speculative writings (Renneker, 1981) and recent empirical findings (Levy, 1982, 1985) suggest that psychosocial interventions which are geared to enhancing the quality of life may at the same time be supportive of medical modes of treatment and directtly influence the mobilization of the organism's antitumor resources. Clinical experience, as well as empirical research guided by the biopsychosocial paradigm, are supportive of this type of speculative thinking and corresponding intervention.

One innovative research design with mammacarcinoma patients based on this approach showed joy, optimism, the absence of helplessness/hopelessness, and social support to be associated with differences in the risk of metastasizing and survival of metastatic breast patients (Levy, 1985). It is uncertain to what extent these findings may be generalized to cancers at other sites, but they do suggest that it might be useful to continue exploring such health promotion strategies (Temoshok & Fox, 1984; Temoshok & Heller, 1984; Rogentine et al, 1979); Jensen, 1984).

Type-C behavior. Similarly, characteristics of this pattern of behavior have been shown to predict differences in survival in studies of patients with malignant melanoma and mammacarcinoma (Greer, 1985). It is speculated at present that the Type-C pattern is a psychophysiological pattern of response to environmental conditions or demands, possibly linked to adverse patterns of neuroimmunomodulation (Baltrush et al, 1988). Solomon (1985) has termed it an *immunosuppressive personality pattern*. It emcompasses severe repression of negative cognitions and affect, a lack of emotional outlets, disturbed interpersonal relationships, harmonizing behavior and niceness, a basic mistrust of others, self-derogation, and vulnerability for depression, particularly of a covert nature (Baltrush & Waltz, 1986; Greer, 1985). At the physiological level, it may be related to *"hyperadaptosis"* to chronic stress and increased risk of developing cancer, as well as an unfavorable clinical course of disease (Dilman, 1983, 1984).

Just as in cardiac rehabilitation, programs geared to altering pathological styles of coping with stress could constitute an important type of health promotion with regard to the goals of QOL and physical health.

Cancer care. This is a broad umbrella term which is used in preference to rehabilitation or similar terms as it covers all stages of the illness – including the terminal stage – and all the categories of people who provide such care, whether professional or lay.

4. A categorization of target groups for health promotion

Prior to discussing current health promotion activities on behalf of patient and non-patient target groups, a categorization scheme of these groups will be discussed. Its purpose is to identify areas of urgent needs and major deficits, as well as specific needs related to the age dimension and to the various phases of the illness.

4.1 Patient target groups

4.1.1 The curative/palliative dimension

Medical oncologists have made great progress over the past several decades in developing curative therapies for certain types of cancers and for extending the illness-free period of a large and increasing number of individuals. The fact that many individuals survive the first phase of the illness and must learn to confront a "life with cancer" has led to the emergence of the field of psychosocial oncology as a much needed adjunct to medical oncology.

Professionals and laymen working in this relatively new field of health promotion are concerned with helping individuals to adjust successfully to a "life with cancer". Their endeavors are focused on mobilizing the patient's physical, social, and psychological resources *to stay alive* and to maintain/achieve a reasonable level of *life quality*. This section deals mainly with this major target group of individuals who survive, and with innovative health promotion developments concerned with their psychosocial support.

For certain cancers, only palliative forms of medical therapy are currently available. There are also patients who have a poor physical prognosis, i.e. cancer staging. This group of patients constitutes a second focus of psychosocial oncology related to coping with imminent death. Not only the patient, but also his family and the professional caregivers are frequently under extreme psychosocial stress during difficult circumstances (Sobel, 1981; Worden, 1982; Zimmerman, 1981; Corr & Corr, 1983; Cassileth & Donovan, 1983; Day, 1986).

4.1.2 The age dimension

Unlike other chronic diseases associated with aging in modern industrial societies, cancer encompasses disorders which strike individuals in childhood/early youth, or when they are young adults. In addition, like the major cardiovascular disorders, some cancers may also be viewed as stress diseases linked to the aging process, a decrease in immuno-competence, physiopathological changes in body metabolism and in other systems of the organism, as well as other psychophysiological reactions to chronic forms of stress (Dilman & Ostroumova, 1984). Cancer has been shown to be linked to stressful conditions, such as unemployment in a prospective English study (Moser et al, 1984), to depressed mood in the Westinghouse study (Shekelle et al, 1980) and to adverse socio-environmental situations in childhood and adult life in several studies (Baltrush & Waltz, 1986; Thomas et al, 1979; Jenkins, 1983; Joseph & Syme, 1982).

Epidemiological data on cancers point out that some cancers primarily affect one age group (e.g. young adults), whereas others have a bimodal distribution as disorders of the middle-aged and of the elderly, occurring over several decades of the lifespan (Schottenfeld & Fraumeni, 1982). Depending on the age of the patient, psychological morbidity may differ considerably, being determined by the life situation of the individual concerned.

Childhood cancer patients are in the process of learning for their future social roles and of personality development, and illness may hinder further schooling or apprenticeship training (Spinetta & Deasy-Spinetta, 1981; Van Donger & Sanders-Woudstra, 1986). Young adults are beginning their job careers, searching for the right marital partner, and founding their families of adulthood. Elderly patients have these segments of the life cycle behind them and are either satisfied or dissatisfied with what they have achieved in marriage, work, etc. The same disease may, therefore, have very different effects depending on the position of the patient in the lifespan.

4.1.3 The changing needs for health promotion at various points of the "patient career"

We assume that the needs of cancer patients will vary over time and that corresponding health promotion activities and their providers will similarly be changing.

The first critical point in what sociologists have termed "the career of the cancer patient" is the time prior to and post-diagnosis (Morris & Sherwood, 1987; Rainey et al, 1983; Schnurre, see p. 268). This critical period includes the first suspicions concerning the possibility of a tumor and the decision to consult a physician. The psychological reactions of the patient to a diagnosis of cancer include despair, anxiety, feelings of helplessness/hopelessness, and repressed or open depression. These reactions may be viewed in themselves as a massive reduction of previous psychological well-being and may have an adverse effect on the resistance resources of the organism through well-known *neuro-endocrine pathways.*

The salience of this critical period is little recognized by medical professionals, and resistance to health promotion activities at the time of diagnosis is probably considerable. Empirical research findings are needed to demonstrate differences in the psychophysiological response to the diagnosis of cancer in supportive and non-supportive medical settings. Cancer patients themselves frequently report that this period is highly distressing and disconcerting, so that psychosocial intervention programs appear very much needed.

A *second critical point* is the time prior to and post-surgery. Various types of intervention programs have been developed at this point of the "patient career", based on established psychological theories and therapy concepts. These include anticipatory grief work (Siegel & Weinstein, 1983; Janis, 1979), coping techniques (Weisman & Sobel, 1979) and relaxation training (Vachon, 1986; Burish & Lyle, 1981).

Quite important are *lay visitor programs,* which have proven to be effective in other areas of health promotion, e.g. in the widow-to-widow visitor programs after bereavement (Vachon, 1976; Walker, 1977) or the patient-visitor programs prior to open-heart surgery. Lay visitors appear particularly effective in helping maintain subjective well-being, providing adequate role models for coping with the physical and psychosocial morbidity, and strengthen the biological resources of the individual (this subject is further developed under 5.1.2).

Interventions of professional psychosocial oncologists at the time of diagnosis and surgery (cf article by Schnurre, p. 268, on the Moabit Hospital in Berlin) would appear to have the same aims as those of lay visitors. The resistance of hospital administrators and medical professionals to this type of health promotion could be broken down, if we were in possession of hard-nosed research findings from controlled studies in respect to rate of metastasis, disease-free interval following surgery, and long-term survival rates. The medical professionals and the family of the patient constitute important sources of social support at this critical time point. The anecdotal literature and epidemiological findings suggest, however, that many patients are dissatisfied with the informational and emotional support provided by their physician and/or spouse (Lewis & Bloom, 1979). In addition, many patients lack a supportive social network during this difficult period of emotional management of cancer. Extensive programs of training and further education are needed in respect to health professionals as potential sources of health promoting support. The same is true for mobilizing the supportive potential of the family and the natural support network of the patient during this early phase of adjusting to a "life with cancer".

With post-surgery medical treatment the patient enters into *the third phase* of his "patient career" and faces new problems and needs (Chang, 1981; Burish & Lyle, 1981; Morrow et al, 1981, 1982, 1988). Adjuvant chemo-and radiotherapy may have wide-reaching physical and psychosocial after-effects for patients. We speculate that appropriate supportive interventions, just as those already discussed, could have a positive influence on the *therapeutic effectiveness* of such adjuvant measures. In addition, they would probably also decrease adverse psychological reactions regarding body image, self-esteem, or feelings of low personal competence. As regards adverse physical reactions, including nausea and vomiting, which are a major problem for many patients, numerous centers are exploring the use of relaxation techniques and psychotherapy (Scott et al, 1983; Bos-Branolte, 1987). Intervention techniques in adjuvant therapy are fairly well standardized but can only be used if professionals are aware that these techniques can help patients (Morrow & Dobkin, 1988).

The fourth phase, which starts after post-surgery medical treatment, is one of gradual normalization and social reintegration. The patients must cope with the more physical sequellae of their illness (e.g. physical disfigurement, pain, tiredness, etc.), as well as with cancer's wide-reaching effects on their pre-illness life-space and assumptive world. This segment of the "patient career" can be viewed as a *period of psychosocial transition*. Ideally, comprehensive long-term support for cancer patients, extending from 2-10 years after diagnosis, should be part of the lay system of support, with medical professionals playing an ancillary role.

The two pillars of health promotion include cancer mutual aid or *self-help groups* and the *natural support network* of the individual, which is comprised of the spouses of married adults and the parents of childhood patients, as well as their larger social networks at work, at school, and in the community. Programs facilitating the return to work or school and general social reintegration after cancer have been neglected. Yet, they are necessary for the maintenance of pre-illness social networks and for the promotion of social well-being and positive mental health. These social networks gratify needs for socializing and personal recognition and can, in addition, be major sources of social support in stressful life situations. Socio-emotional isolation, an inability to cope with problems-in-living (work, marriage, etc.), and a lack of positive mental health appear linked to immuno-suppression and the possible long-term weakening of antitumor biological resources (Kiecolt-Glaser et al, 1987, 1985, 1984; Locke et al, 1984; Levy, 1985).

Long-term remissions of cancer and longevity appear on the other hand to be promoted by the provision of social support at *critical points* of the "patient career", e.g. in connexion with life events such as widowhood, retirement, job loss and other disruptive situations. Just as cancer patients need long-term medication and medical surveillance, they also need adequate support for maintaining psychophysiological homeostasis. Marital problems or stressful life events are inimical to homeostasis, whereas marital, job and life satisfaction facilitate it. Patients must be supported in coping with the former and achieving the latter as part of long-term health promotion (Vachon, 1986). Schnurre suggests that facilities be made available to patients for "tanking up psychologically" whenever they feel they are heading for psychological distress or depression.

4.2 Non-patient target groups

A second focus of health promotion may be subsumed under the slogan *"Support the Supporters"*. It recognizes that medical professionals and the natural support system of the patient play an important role in adjustment to a "life with cancer" but are themselves frequently in need of support in order to carry out this role effectively. Health promotion strategies directed at non-patient target groups include programs of various sorts aimed at medical professionals, oncological nurses and professionals in psychosocial oncology (Rainey et al, 1983) or focusing on the family and the social support system of cancer patients (Picard & Scaff, 1988). Behavioral intervention programs are frequently aimed at the chief caregivers, such as the parents of childhood cancer patients, the spouses of young and middle-aged adult patients, or the adult children of elderly individuals. Physicians and chief caregivers can be considered as pivotal target groups in a holistic system of psychosocial adaptation to cancer (Vachon, 1986; Blumberg et al, 1980).

One type of programs is cognitively oriented and aims to sensitize professional and lay persons to the problems and concerns of specific cancer patients (American Cancer Society, 1979; Sullivan et al, 1988) and to teach them how to be effective providers of the social support needed. We assume that the ability to provide various kinds of social support can be learned; physicians and lay caregivers who do not possess this ability can develop skills with the help of handbooks and further education (cf. Blumberg et al, 1980, as example of such an approach; Rainey et al, 1983).

Another type of programs is directed towards the mental and physical health of the supporters and, in particular, towards avoiding their becoming victims of the "burned-out syndrome". The ability to provide support is only possible in the long run if the lay caregivers and medical professionals can maintain their own positive mental health. Health promotion is also directed, therefore, towards helping supporters to cope effectively with the enormous stress of cancer that they themselves experience in caring for their patients and loved ones. This is one aspect of the larger program, "Support the Supporters".

Professionals working in the field of psychosocial oncology, such as social workers and psychotherapists, are also in danger of succumbing to the "burned-out syndrome". In their case, the stress of dealing with sick and dying patients may be aggravated by low social status in the hospital hierarchy, by a lack of recognition and financial resources, and by similar job-related strains. The many professional associations of psychosocial oncologists that now exist at the local, national, European and international levels would seem to be an outcome of the gravity of these *chronic role strains*. Meetings of such associations as the European Society for Psychosocial Oncology (ESPO), the European Working Group for Psychosomatic Cancer Research (EUPSYCA), and the Deutsche Arbeitsgemeinschaft für Psychoonkologie (DAPO), have as their expressed purpose the exchange of experiences and ideas, but they also appear to serve an important, although unexpressed, coping function in "buffering the stress of working in oncology" under the present rather difficult structural and interpersonal conditions. Other fields of rehabilitation do not have such a large number of professional associations and this phenomenon indicates that the problems impeding the work of psychosocial oncologists are in need of greater attention.

4.3 A multidimensional scheme of target groups for health promotion

The purpose of the summary scheme displayed in *Table 1* is to provide a scenario of needs for health promotion interventions as well as an overview of the target groups. The summary table encompasses the curative/palliative dimension, four age groups, and the patient/caregiver dichotomy

Implied in this table is the need to give consideration to the various stages of the cancer patient career - diagnosis, surgery, therapy, recovery and normalization, as well as to the metastasizing and terminal stages - in developing knowledge and support for the patient, his social network and the professional caregivers.

The needs and possible interventions in regard to each target group have been briefly discussed in previous sections. These needs have to varying extents been recognized by health professionals, which has led to first attempts at developing behavioral intervention measures; these measures will be discussed in the next section of this paper. The gap between supply and demand for psychosocial services, as well as current deficits, vary considerably, however, from one cell of the summary scheme to the other. For some target groups very little is being done, and for others fairly effective intervention programs are in the process of being tested and improved in a "learning-by-doing" process.

As a broad generalization, *patient needs are best being met on the short- and medium-term but not at the early stage of cancer nor on a longer term basis; as for non-patient target groups, these constitute a major area of serious deficits.* Resistance of these groups - in particular the medical professionals - to recognize these deficits and the need to take action should be emphasized. There are currently severe hurdles to be overcome in launching intervention strategies aimed at the non-patient target groups, such as self-help for the families.

TABLE 1. A MULTIDIMENSIONAL SCHEME OF TARGET GROUPS FOR HEALTH PROMOTION IN COMPREHENSIVE CANCER CARE

Medical Therapy: curative	The Patient	Social Network	Professional caregivers
childhood/youth	X	parents	X
early adulthood	X	spouse	X
middle age	X	spouse	X
old age	X	adult children	X
Medical Therapy: Palliative			
terminal patients	X	XX	XX
metastasizing tumors	XX	X	X

5. Current intervention projects as models of health promotion for the future

The previous sections reflect at a fairly high level of abstraction the many ideas I have derived over the past four years as a result of two types of inputs: interviews with some hundred experts and individuals with broad clinical experience in diverse areas and working in various countries; and my participation in local, national, European and international assemblies of professional associations involved in meeting the needs of cancer patients. I have thus gradually developed a picture of the current situation in health promotion in cancer care. This picture takes into consideration current developments in *psychosocial* and *biobehavioral cancer research*, in particular the findings of such empirical research as the Göteborg Study for identifying the needs and concerns of cancer patients in Sweden (Sullivan & Cohen, 1988) as well as *promising research* on possible behavioral interventions for promoting and enhancing subjective well-being and survival which represent important and necessary adjuncts to clinical experience (Levy, 1985).

The following sections will provide an overview of concrete developments embodying health promotion concepts in interventions which aim:

1. to meet the specific needs associated with the "cancer patient career";

2. to provide adequate support to professional and lay caregivers.

5.1 Interventions aimed at the cancer patient

This section will deal with:

- the two main approaches used in support programs;

- the role of the lay visitor in the early phase of the illness;

- health promotion in relation to short-, medium- and long-term patient needs.

5.1.1. Support of the patient: two main approaches

The first approach is based on a growing recognition of the manifold problems and concerns triggered by cancer and its medical treatment and has resulted in a large number of innovative psychosocial support programs which are evolving in hundreds of cancer centers and local health services all over Europe. These programs involve professionals, mutual aid groups and ex-patient visitors, and are aimed both at meeting the *general needs* of different patient target groups and at dealing with *specific problem areas*, such as psychosexual problems (Mantell, 1982) or social reintegration in the family and at the workplace (Feldman, 1982). Using a term coined by Mendelsohn (1979), this approach to health promotion will be called the *somatopsychic approach*. In this perspective, cancer is seen as the somatic trigger of major changes in social and psychological functioning, in values and beliefs, and in views about oneself and one's assumptive world or psychological future. Health promotion here means the promotion of effective coping with these sequellae of the somatic morbidity of cancer (Baltrush & Waltz, 1987; Cohen, 1982; Mantell, 1982; Mendelsohn, 1979; Pruyn et al, 1981; Schain, 1980).

In contrast, a second approach may be termed the *psychosomatic approach*. The overriding idea behind this type of intervention strategy is weakly related to traditional psychodynamic theories and therapy concepts but more strongly linked to etiological research on the role of certain psychosocial factors in the onset and development of cancer. These etiological factors, which are considered as being associated with survival and the modulation of disease processes, have recently been subsumed under the concept of a *Type-C* or *cancer prone behavior pattern* (see page 70). A major aim of this type of psychosocial intervention is to change the Type-C pattern.

Coping success according to this approach is indicated by patients making changes in their social environments and their manner of interacting with others, in particular the recognition and gratification of their basic needs and the development of emotional outlets. At the biological level, it is thought that these coping successes will be health-enhancing by mobilizing the antitumor resistance resources of the organism. Hypnosis, meditation, relaxation training, music and gestalt therapy, as well as many other methods may be used to support the patient in his/her struggle for survival. A certain proportion of cancer patients display this Type-C pattern in many or all its aspects, and success in altering it and in subsequent patient survival are indicative of its role in cancer (Jensen, 1984; Renneker, 1981; Rogentine et al, 1979).

Most cancer centers use some mixture of the somatopsychic and psychosomatic approaches in their support programs. Experimental and epidemiological research findings in biobehavioral oncology, psychoneuroimmunology, and allied disciplines are suggestive of an impact of both types of intervention strategies on various systems of the organism and, therefore, possibly on the clinical course of some or all malignant disorders (Watson, 1988; Bandura, 1985, 1987; Balitsky & Shmalko, 1987; Pettingale, 1985; Solomon, 1985; Fox & Newberry, 1984, 1982; Dilman, 1983; Herberman, 1982, 1979; Solomon & Amkraut, 1979; Rogers et al, 1979; Sklar & Anisman, 1979).

5.1.2. The lay visitor or patient-to-patient movement in the early phase of the "cancer patient career"

In the Federal Republic of Germany it is estimated that there are some 700,000 cancer patients. In other European countries, an equally large proportion of the population consists of persons who have been diagnosed as having cancer and who have learned to cope more or less effectively with this knowledge and its meaning to them. In this large and growing group of people who, in German, are called *Betroffene* or "fellow-sufferers", there are many individuals gifted in coping with life after cancer and who would be able to teach newly diagnosed patients their "know-how" or set off effective coping strategies (Weisman, 1979). This "know-how" dissemination is what behavioral scientists term *information support* (Schaefer et al, 1981).

Persons who have experience in the "cancer patient career" *alone* can say the magic words, "I had cancer", thereby breaking down the wall of silence and the socio-emotional loneliness many new cancer patients experience. Confiding is a traditional form of lay psychotherapeutic activity, which aims to decrease the intrapsychic pressure to deny the implications of cancer, to bring the patient's concerns out into the open, and to "de-anxietyze" negative cognitions that cancer patients would like to deny. Gifted ex-patient visitors can initiate this confiding process, which should have, as recent research suggests, salient psychological and biological after-effects.

Extensive behavioral literature on stress and surgery suggests indeed that social support may decrease adverse psychophysiological reactions to surgical measures, including subsequent medical complications and the need for extensive medication (Lazarus, 1974). Most important, such support may strengthen the biological resources of the patient at a time when the stress of surgery is closely correlated with an increased risk of metastasizing of the tumor to be surgically removed (Balitsky et al, 1987).

The moral support provided by ex-patient lay visitors is associated with two major goals: instilling optimism in the patient and triggering off anger and a fighting spirit to vanquish the threat of cancer. Behavioral scientists have coined this type of activity *emotional support* (Cobb, 1976).

Lay visitors usually provide as well two other types of support, *esteem support* and *tangible support*. As role models they can instill a sense of self-efficacy and personal control in the newly diagnosed patient: "This person has had cancer and has beat it, and I can too!" Feelings of being helpless and of having no value as a person after diagnosis and treatment can be shown to be groundless, unrealistic self-cognitions and self-appraisals.

A function of lay visitors, sometimes used as a front to begin providing other social supports, but one which is nevertheless very important, is the conveying of technical knowledge and tips about everyday living with cancer at particular sites. Ex-patients who have been laryngectomized or mastectomized, or who must wear a stoma, possess a wealth of personal experiences and technical know-how, which can be offered to persons just beginning their "cancer patient career". But lay visiting has still another function: the lay visitor not only provides the newly diagnosed patient with the four types of social support discussed above but possibly also insures his/her own positive mental health and enhances longevity by helping others (Gartner & Riesmann, 1977).

The World Health Organization, the Council of Europe and other bodies have recommended to health policy makers to consider ways and means of utilizing this enormous potential for health promotion in cancer care; these bodies have also outlined practical steps to be taken to achieve this objective. Several countries (e.g. Belgium, the Federal Republic of Germany and the United Kingdom, have adopted policies on self-help (Branckaerts & Richardson, 1988).

A first task is the removal of hurdles and barriers currently hindering the work of cancer mutual aid groups which would like to begin providing ex-patient visitor services. In the Federal Republic of Germany, for example, only ILCO (Ilostomy-Colostomy) and groups of laryngectomized ex-patients are permitted access to hospitals and rehabilitation clinics. In contrast, mastectomized patient groups experience extreme difficulties in persuading medical professionals and hospital authorities to grant them permission to launch health promotion activities.

As Holland & Rowland (1981) from the Memorial Sloane-Kettering Tumor Center in New York noted in their historical review: "Oncology has been *cautious* in accepting the 'fellow',patient concept of employing contemporary patients in the cancer treatment process to help one another; this *caution*, however, is diminishing." This positive development on the American Continent cannot yet be confirmed in respect to Europe and in particular to Central Europe. The caution and reticence of the medical profession here is probably linked to apprehensions about the possible loss of control over their patients. It may be feared that lay visitors could trigger off psychosocial processes leading to cancer patients discarding the Type-C pattern of being superficially nice, cheerful, and docile and becoming "difficult" or "emotional".

In the Netherlands, the situation is somewhat more optimistic; eight national organizations have volunteer ex-patient visitor programs, including those for Hodgkins Disease and mammacarcinoma. But even in the Netherlands, a study of 146 hospitals found "some negative reactions from professional caregivers" and difficulties in cooperation between lay visitors and professionals (Van den Borne et al, 1986). The authors summarized the findings from their unique empirical research as follows: "...there is still a relatively large group of patients who experience important barriers to getting in contact with a fellow-sufferer. Most important among these barriers is the fact that *one does not know* any fellow-sufferers. Patients ascribe different *positive effects* to their contacts with fellow-sufferers, and *few negative reactions* are reported" (see article p. 287). The study confirmed the speculative ideas about the value of lay visitor programs and extensive discussions of the author with German groups allowed access to hospital settings, such as ILCO, confirmed these difficulties but also positive effects.

Before concluding the discussion of this highly promising potential for health promotion, certain practical problems of mobilizing patient-to-patient mutual aid activities should be noted. First of all, not every ex-patient is suited for working as a lay visitor. This can be due to the personality make-up of the person or to his/her lack of social competence and communication skills. Programs are needed to select the right ex-patients. Secondly, ex-patients, who are "average" may have less knowledge and know-how than certain "exceptional" or "gifted" ex-patients, and brief training programs may be useful for transferring know-how and increasing the effectiveness of beginners and of the less-skilled ex-patients. The Widow-to-Widow Movement (Vachon, 1976) may be viewed as providing a model and a wealth of practical experience in developing selection and training programs. Another valuable source is found in Project Omega at Harvard, which uses training manuals and cassettes for teaching cancer patients effective coping skills (Weisman & Worden, 1977). It may also be worthwhile to turn skilled ex-patients into full-time professional members of the hospital or general practice cancer team, so that they are available at the critical points between the time of diagnosis and surgery. The Moabit experience speaks for itself (see article p. 268). Finally, empirical research, such as the Dutch study cited above is needed for convincing health authorities and the heads of cancer clinics that patient-to-patient visitor programs have positive psychological and biomedical effects *that can be measured* (e.g. quality of life, survival rates and the effectiveness of medical treatment protocols, such as adjuvant chemiotherapy).

Many cancer patients are capable of providing to varying extents the services and support discussed above. Moreover, it should not be extremely difficult to solve the current problem of many newly diagnosed cancer patients who complain that *they do not know any fellow-sufferer.* The statement, "I had cancer" – which can only be made by a *Betroffener* or fellow-sufferer – starts off a *supported* cancer patient career which means that the patient is not being left alone with the diagnosis of cancer. This *early period of health promotion* after cancer is currently, *along with longer term support* in the fourth stage, *the most important area of deficits* in regard to patient target groups, but one for which the lay visitor offers a viable solution.

5.1.3. Health promotion in relation to short-, medium- and long-term patient needs

In contrast to the early period of the cancer patient career, the short- and medium range needs of patients are currently being well met by innovative interventions at many cancer centers in metropolitan areas (Bos-Branolte, 1987). Other centers, however, are understaffed, have no adequate financial resources or may be using therapeutic approaches from psychiatry not suited to the needs of the chronically ill, not to speak of the lack of social status of the cancer team. Some specific problem areas, such as sexuality and occupational reintegration, are still not receiving the attention they deserve. This is the case at the level both of clinical practice and of behavioral research focused on identifying the concerns and worries of cancer patients. Too little is known about the extent of patient problems or about ways to develop promising intervention programs in these areas (Sullivan et al, 1988).

a) Comprehensive psychosocial cancer care: the Berlin model

The Moabit Hospital project in West Berlin may be described as a comprehensive answer to the needs of cancer patients during the first two years. It parallels stationary and ambulatory medical treatment and uses individual and group therapy, as well as skilled ex-patient professionals and a dense network of mutual aid activities. Guided by an ex-patient professional therapist and a psychologist, a flexible program of behavioral interventions has gradually evolved over the years and the architects of the project now have long-term health promotion as their next goal. A paper describing this project in detail is published on page 268.

b) A mutual aid project in a rural area of northwest Germany

In contrast to the fairly favorable situation in West Berlin, an economically-depressed, rural area in northwest Germany is characterized by a high level of needs for health promotion, the isolated situation of cancer patients in numerous small villages spread over a wide area, and an almost complete lack of personnel and financial resources for beginning to meet these needs. The development of a lay mutual aid movement appears to be the most effective means of altering the present deficitary state of affairs.
A project was initiated accordingly, with the aim to build on existing cancer self-help groups and gradually create a network of lay mutual help activities in the region. In this perspective, existing social networks can serve as vehicles and particular persons and groups can act as catalyzers for spreading the self-help idea among rural cancer patients. These catalyzers are traditional opinion leaders and gate keepers, such as clergymen, the farm women associations, and ex-patients. Medical professionals can also constitute important gate keepers once convinced of the usefulness of such a project.
A study is currently being carried out by a group of medical sociologists and anthropologists to collect data on the situation of rural cancer patients in various regions of the Federal Republic of Germany. The results of the study, which is funded by the Ministry of Research (BMFT) should be available in 1990 and provide important data on the needs and the situation of rural patients.

c) Special problems of particular patient target groups

The behavioral intervention program at the Leiden University Hospital in the Netherlands, is aimed at developing psychotherapy for a major problem facing many chronically ill persons, and in particular patients with cancers at certain sites (Mantell, 1982; Schain, 1980). Many women with gynecological cancer, for instance, have considerable psychosexual problems. A goal of the program is the improvement of sexual functioning after surgery and other modes of treatment, as well as the achievement of satisfaction and well-being in the important area of marriage and partnership (Aaronson, 1987). Psychotherapy is focused on:

1) the problem many patients may have had prior to diagnosis and treatment in the marital-sexual sphere, including the body image and sexual identity;

2) the after-effects of surgical mutilation and of the removal of parts of the sexual organs on coital behavior and intimacy; the patient is encouraged to have needs for physical closeness, trust and warmth gratified in the partnership relationship;

3) the therapy of other psychological problems related to the cancer and its impact on sexuality, such as feminine self-esteem.

At the Central Institute for Tumors and Allied Diseases in Zagreb, Yugoslavia, a program of comprehensive care has been developed for mastectomized patients (Sabel, 1987). Women treated for breast cancer are predominantly middle-aged and they often come to the hospital with the preconceived idea that cancer is incurable. A major objective of the cancer team is, therefore, to influence attitudes and revive positive feelings by providing correct information, listening to patients express their feelings, and giving them social support. This is done through personal interviews as well as in group discussions aimed at mobilizing the patient's psychological resources and capacity to communicate with her spouse. The cancer team starts its supportive work from the moment the patient enters hospital and follows through to the end of the stay, including advice on plastic implants and help with prothesis, or the provision of wigs for patients who are temporarily losing their hair following treatment.

As several researchers have noted, psychosexual problems are not the exclusivity of gynecological and breast patients; this is in fact an important area of behavioral intervention which has received too little attention in health promotion of the chronically ill (Mantell, 1982; Schain, 1980). At the same time, social well-being in sexuality and marriage – "not only the quantity but also the quality" as Bos-Branolte (1987) phrased it – is known to be one of the most important determinants of the quality of life and of general well-being.

d) Reintegration into work

In contrast to the United States (Feldman, 1982) and other countries that do not have a system of social insurance, cancer patients in countries with a social welfare system encounter numerous obstacles and disincentives in respect to occupational reintegration (Sullivan et al, 1988). The data are sparse, but available statistics (Scharf, 1980; BMAS, 1982) in the Federal Republic of Germany suggest that patients are frequently being rehabilitated into forced retirement; fewer return to their former workplace, retirement rates are higher, and the period of extended sick leave is significantly longer than in the United States, for instance. Lehmann (Badura, 1987) has pointed out the same contrasting situation in the case of cardiac rehabilitation and has delineated the structural obstacles to the return to work of former cardiac patients.

A pilot study with young male testicular patients in the Weser-Ems Tumor Center, an economically depressed area, by Galuska and associates (Waltz et al, 1988), has shown that social reintegration at the workplace and in marriage is closely linked to normalization and quality of life in general. Data on the clinical course of disease and survival rate differentials between retired and employed cancer patients are not yet available, but it can be speculated that the fact of returning to work or not will show different "hard" medical outcomes. Higher social status and educational background appeared to be predictive of successful reintegration in the working world, and the latter was correlated with quantitative measures of psychological well-being. Schott & Pfaff (1987) have come to similar conclusions in a five-year prospective study of cardiac patients.

The rehabilitation of the chronically ill into forced retirement and concomitant psychological ill-being is an inherent tendency of health systems with a well developed social welfare system, particularly in periods of recession or in economically depressed regions.

This is particularly the case for the younger (20-30) and older (50-60) age groups of cancer patients. Incentives to return to work after treatment for cancer appear to be low in many such health systems, and, in addition, there are numerous obstacles for patients who wish to find gainful employment (Sullivan et al, 1988; Schraub, 1986). These disincentives apply not only to the ex-patient but also to his/her family, entrepreneurs in the private sector and government employers. Many European countries have regulations prohibiting the recruitment of former cancer patients into government positions and appointment as civil servants. This was the case in France until 1983, when the National Cancer League (LNCC) was able to put pressure on the government for a change in legislation (Schraub, 1986, p. 151-6). Existing laws are particularly discriminating with regard to younger ex-patients for whom the civil service is the major or only employer of individuals with their training or professional specialization (e.g. teachers, law students, or social workers. Similarly, in the Federal Republic of Germany, former patients with a "certification of disability" are pro-

tected in the private sector if they already have a job, but they encounter difficulties if they want to find employment or change jobs. One positive development is the Hamburg Model (originally set up for cardiac patients), whereby cancer patients can work half-time during the initial period of recovery/reintegration but receive their full previous pay.
My impression from a group of middle-aged female cancer patients in West Berlin currently under therapy is that they all place a high priority on returning to work as soon as physical recovery will allow. Occupational reintegration is closely linked to adaptation and overcoming depression and other psychosocial morbidity. In contrast, delay in going back to work due to bureaucratic obstacles or unemployment would appear to aggravate previous psychosocial morbidity. Even terminal cases and those with metastasizing tumors try to work as long as their physical status enables them to do so. These impressions are from a small sample, but they may be generalizable to larger groups of patients in many settings.
For its part, the Regional Cancer Center of Besançon, France, has been successful in raising the rate of reemployment among ex-patients treated at their facilities. The intervention programs being developed are based on the recognition that return to gainful employment is salient for rehabilitation and aim at overcoming various obstacles and motivating the patient to seek employment. At the same time, the Center has developed brief questionnaires for monitoring quality of life and quantifying the results of their behavioral interventions (Aaronson, 1987).

5.2 Intervention projects aimed at the professional and lay supporters of cancer patients

As emphasized in several previous sections, *indirect* health promotion for cancer patients as mediated by the support given to professional and lay caregivers should still be considered as being in its infancy. The pressing need to support the supporters is only gradually being recognized — and may still encounter resistance from particular groups, although medical and other health professionals seem open for supportive programs, and the demand is rising as indicated by the attendance at further education seminars. Seminal programs are being tried out and appear to be a major avenue of health promotion in the future.

Programs that have come to my attention may not be representative of the whole field, but include the following:

- the training program for oncological nurses and community nurses in Slovenia at the Cancer Center of Ljubljana (Vegelj-Pirc & Ravnikar, 1988);

- Balint groups, group therapy, and relaxation training for medical oncologists and cancer nurses in several centers;

- weekend seminars on the problems and psychosomatics of malignant disorders for physicians, nurses, and social workers in Northrhine-Westphalia, Federal Republic of Germany, sponsored by GBK (Gesellschaft zur Bekämpfung des Krebs);

- handbooks on providing social support to cancer patients, especially developed for medical professionals;

- the supervision and support program for social workers in oncology at St Josephziekenhuis in Eindhoven, the Netherlands;

- group sessions and mutual aid groups for the parents of young cancer patients, including grief work for terminal cases;

- group therapy and self-help for family members of adult cancer patients;

- the hospice movement in the United Kingdom, which provides tangible and emotional support to the lay caregivers of elderly and frequently terminal cancer patients for preventing symptoms of "burned-outness".

Frequently, social support is provided to caregivers in a sporadic, *ad hoc* fashion by professionals whose main area of work is the patient. These professionals have recognized that they can help the patient by helping his significant others, but this work is an additional demand on the already meager personnel resources allocated to psychosocial oncology at cancer centers and in the community.

6. Concluding remarks

An encouraging break-through in health promotion and cancer care has been achieved by a number of innovative approaches and interventions aimed at improving the quality of life of cancer patients and at influencing the clinical course of the disease. There are, however, some serious deficits in regard to the provision of adequate support to patients as well as to professional and lay caregivers. The following highlights these deficit areas and the steps needed for further progress.

6.1. Meeting the needs of cancer patients

- Cancer care centers as well as local or regional health care units which are currently not tackling the needs of cancer patients and psychosocial morbidity after cancer must begin allocating sufficient human and financial resources for developing a comprehensive, short-, medium-, and long-range system of professional and self-help strategies to support cancer patients from the point of diagnosis onwards. Programs of behavioral interventions should cover a wide range of patient needs and concerns, such as that evolving in West Berlin and elsewhere.

- Neglected problem areas, such as sexuality and social reintegration after cancer, should receive greater attention.

- A particular problem area is job rehabilitation and the low rate of return to employment of cancer patients. Legal, institutional, and other barriers should be removed, and the central role of the workplace in cancer rehabilitation should be given greater emphasis, instead of the current "rehabilitation-into-forced-retirement" policy.

- Strategies should be developed for an effective transfer of know-how (i.e. clinical experience from promising projects and the latest findings in the field of biobehavioral cancer research) from the source to the many target groups of users.

- The funding of basic and applied research on the links between behavioral factors and cancer-related biological processes should be increased (e.g. psychoneuroimmunology). The same is true of research on the effectiveness of behavioral interventions (quality of life, impact on the effectiveness of medical therapies, risk of metastasizing and survival as outcomes). Research should be aimed at providing knowledge related to the development of interventions and serve to persuade medical professionals about their utility.

- Ways and means should be found for promoting the further extension of the patient-to-patient and self-help movements. This means the preserving of their democratic, grass-roots character and avoiding tendencies towards bureaucratization and subsequent loss of effectiveness.

- The dissemination of knowledge about the needs of cancer patients and how to meet these needs should be increased via the utilization of particular media (videofilms, handbooks, cassettes), as well as via further education seminars and improved curricula for medical schools and nurse training programs.

6.2. Providing support to the supporters

- Group sessions (e.g. Balint groups) and self-help groups for professionals and laymen should be encouraged in order to decrease the psychological and physiological stress that caregivers of cancer patients encounter, such as grief work for professional and lay caregivers of terminal patients.

- Programs focused on the further education, supervision, and emotional support of social workers, psychotherapists, and other professionals in the field of psychosocial oncology is a much neglected area and should be promoted for indirectly enhancing health promotion for patient target groups.

- Means of decreasing the mental and physical health burden placed on the family as principal caregivers of cancer patients, especially terminal cases, should be developed. This should include tangible support to the family, such as housework services, community nurses, the opportunity for leisure and vacation , for "tanking-up" psychologically, as well as information and emotional support programs. Keeping cancer patients in their familiar home surroundings is the most humane solution — as well as being less costly — but the family caregivers must be better supported in several areas. Geriatric oncology should be a particular focus of the development of adequate behavioral intervention programs, as well as the care of childhood cancer patients in the family.

The "Ten-point Plan for Carers" that has been developed by a group of organizations in Great Britain should be largely made known. It provides a set of principles and practical guidelines on how local services can help caregivers and provide them with the support needed (see article by Ann Richardson on p.165).

These, then, are some of the deficits that need to be corrected if we are to progress further towards achieving the goals of health promotion with regard to cancer patients and those who care for them.

EMERGING FORCES IN CANCER CARE

by Michael Lerner

Abstract

The mainstream of scientific research is moving towards increasing recognition of the limits of conventional therapies and cautious optimism about the potential for new biological therapies. This situation has given rise to a social phenomenon among cancer patients. Today, in many parts of the world, a significant minority has chosen to engage actively in the fight for recovery. This minority searches for an intelligent integration of efficacious conventional therapies and complementary therapies involving personal trials of intensive health promotion. These trials cover nutritional, psychological, and immuno-modulating approaches to supporting general health. It appears that 10% among those patients achieve exceptional results, another 10% fail, and 80% become "healthy" cancer patients. While these experiences raise many interesting clinical, scientific and policy questions, they have provided a growing body of evidence that a great deal can be done with behavioral approaches, not in terms of sweeping cures but possibly for some gains in life extension and certainly for great gains in the human experience of being healed (or "becoming whole" with cancer).

The debate over conventional cancer therapies

There is a great debate going on within the cancer research community as to whether the major conventional modalities of cancer treatment – chemotherapy, radiation therapy, and surgery – are reaching a plateau in terms of curative and palliative potential, or whether important progress continues to be made. Bailar & Cairns have argued that progress in cancer therapy over the past decades has been overstated. Their view has been contested in a vigorous debate that has continued in the letters column of the *New England Journal of Medicine* (Bailar & Smith, 1986; Cairns, 1985).

In March 1987, the United States General Accounting Office (GAO) entered the debate with a report on the controversy entitled "Cancer Patient Survival: What Progress Has Been Made?" The report concluded that "the extent of improvement in survival for specific cancers is often not as great as that reported" and blamed "biases that artificially inflate the amount of 'true' progress". GAO also concluded that "improvements in patient survival have been most dramatic for the rarer forms of cancer... As a result, even though the absolute number of lives extended is considerable, this number remains small relative to all cancer patients" (US General Accounting Office, 1987).

While large sectors of the scientific community are concluding that progress in cancer treatment has been overestimated, that does not mean progress in cancer research has reached a standstill. There is excitement about progress in unravelling the innermost mechanisms of cancer. There is also legitimate excitement about the prospects for biological therapies for cancer. In the next ten years, there is a possibility that biological therapies will yield the quantum leap forward in cancer treatment that radiation therapy and chemotherapy have not been able to achieve.

The research community pays lip service to prevention, which in fact is widely recognized as holding the greatest potential for cost-effective reduction in cancer mortality. But little, beyond the anti-smoking campaign and a modest effort to promote anti-cancer diet, has been done to forward public policies that would have a real impact on public health (Cairns, 1985).

Like cancer prevention, behavioral approaches to cancer have not received the recognition that they merit. There is a growing body of scientific evidence that a great deal could be done with behavioral approaches to cancer treatment and care. The hope is not for sweeping cures, but

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for great gains in the human experience of healing with cancer, and possibly for some gains in life extension.

There is, for example, a behavioral research literature demonstrating that acute stress causes immunosuppression and facilitates rapid tumor growth in animals. "The accumulated data for humans, although not so extensively documented, are similar and suggest that acute stressors result in immunosuppression or tumor facilitation in humans." Brown & Fromm (1987) have published one of the best summaries of the role of stress in cancer and the theoretical basis for hypnosis and other behavioral interventions. This suggests that efforts to reduce the stress of the cancer experience from diagnosis through treatment might sometimes slow the rate of cancer development or decrease the incidence of cancer recurrence following treatment.

There are also clinical studies that strongly suggest, although they do not prove, that many different systems of profound stress reduction, including imagery, hypnosis, psychotherapy and other psychological techniques, may modulate tumor growth in humans under clinical conditions (Gravitz, 1982-83); Locke, 1986; Rossi, 1986). Other studies indicate that relaxation, imagery, and hypnosis can diminish nausea, vomiting, fatigue, insomnia, and eating problems related to cancer and cancer treatment (Gravitz, 1982-83). Behavioral techniques have also been reported to diminish anxiety and pain, reduce recovery time after surgery, and greatly improve the quality of life and the experience of death.

Locke has published a bibliography (1986) which is a treasure trove of the most interesting psychological and behavioral approaches to cancer and other immune-related disorders. Rossi, for his part, has written a book which is considered by many researchers and clinicians as one of the best overviews of the emerging field of mindbody healing; the section on cancer (pp. 158-66) is particularly interesting. The striking fact is that these accessible mindbody techniques, which offer such great potential to improve the human experience of cancer, are so undervalued and underused in conventional cancer treatment and cancer care.

The emergence of exceptional cancer patients as a social phenomenon

In the 1950s and 1960s, most people with cancer placed their hopes in the promise of biomedicine alone. In the 1970s and 1980s, a new phenomenon among cancer patients has emerged. In many parts of the world, what can only be described as a social movement among "exceptional cancer patients" who engage actively in the fight for recovery and for a better quality of life is growing larger with every passing year.

The term "exceptional cancer patients", popularized by Bernard Siegel (1986) is in some respects an unfortunate one since it suggests that other people with cancer are "less exceptional". No-one who uses the term wants to imply this. There are many good reasons why people choose simply to accept the diagnosis, the prognosis, and the best efforts of their physicians without any special interest in what they might do themselves to improve the quality of their lives or the possibilities for survival. But no-one has proposed a better phrase for that significant minority of people with cancer who choose to engage with their illness in a real effort to make the best of their time and, if possible, to extend their lives or even completely reverse the cancer. The means that patients choose for this intensive effort are varied. Some patients use only conventional therapies. Some supplement conventional therapies with lifestyle changes and complementary cancer therapies that make sense to them. (The term "complementary cancer therapies" refers to the enormous range of alternative and adjunctive approaches to cancer that exceptional patients have popularized. These approaches are described on page 86 and following.)

It should be emphasized at the outset that there is more than a search for "cure" taking place among many exceptional cancer patients who elect to explore complementary cancer therapies. Many of these patients believe that what they are seeking is *to heal*. Healing overlaps with, but is distinct from, being cured. A cure is generally understood as an external medical intervention that eliminates the disease process in the patient with some degree of reliability. Healing, by contrast, is a process emerging from the inner resources of the individual. Healing describes a psychobiological process of becoming whole. Healing can take place at physical, mental, emotional and spiritual levels. There is a growing consensus that psychological healing may sometimes stimulate physical healing (Borysenko, 1987; Locke & Colligan, 1986). At the same time, psychological and spiritual healing can proceed even if the struggle for physical

recovery is being lost. Profound experiences of healing can take place during the dying process. Some early cultures even referred to death as "the great healing". Many exceptional cancer patients consciously seek a "healing" as well as an enhanced prospect for cure.
I will propose in this paper that the exceptional cancer patients who choose (not all do) to explore the integration of the best of conventional cancer therapies and the best of complementary approaches to cancer are changing the nature of the vituperative debate over complementary cancer therapies that has distorted rational consideration of this subject over the past decades. These exceptional cancer patients, I suggest, are extracting reasonable personal strategies for intensive health promotion from the complex strands of ethical and questionable practice in the complementary cancer therapy field. Their search for intelligent integration of efficacious conventional therapies and personalized forms of intensive health promotion derived from complementary therapies may constitute a major force in shaping the development of humane integral cancer therapies in the coming years.

Exceptional cancer patients and the cancer self-help movement

One of the most obvious indices of the growth of the social phenomenon of exceptional cancer patients is the growth of a wide range of self-help groups with such patients. In a broader context, the cancer self-help movement is part of a proliferation of self-help and self-care groups for an astonishing range of health-related problems. The cancer self-help movement, specifically, is a very diverse social phenomenon with a continuum that extends from support groups (sponsored in the United States by the American Cancer Society) to self-help groups that strongly advocate alternative cancer therapies. But the most interesting area of growth has been neither in the pro-establishment self-help groups nor in the pro-alternative self-help groups. Rather, the leading edge of the self-help movement growth appears to be in autonomous self-help groups and oganizations where people with cancer and those who care about them gather to ask: "What can motivated cancer patients do for themselves to improve quality of life and survival potential?" The cancer self-help movement can be seen as deeply influenced by strong cultural trends in virtually all advanced Western technological societies. These trends include cultural shifts towards healthier lifestyles, interest in human consciousness and human potential, awareness of mindbody interactions and renewed interest in spiritual aspects of human experience. No less important are the developments of research in psychoneuroimmunology, caution about the unintended consequences and tradeoffs of technological interventions, greater acceptance of the positive values of pluralistic medical systems in many cultures, as well as growing tolerance for many forms of complementary health care and increasing consumer sophistication. All these aspects are part of the environment in which the eclectically oriented, informed and pragmatic cancer patient, independent of orthodoxies of the medical establishment and of the medical counterculture, has emerged as a growing force.

The Wellness Community in Santa Monica, California, founded by Harold H. Benjamin, an attorney who has devoted himself to cancer support work, is one of the largest and most successful of the autonomous cancer self-help centers. It offers a wide range of classes and activities for people with cancer. The April 1987 calendar for the Wellness Community announced classes in art therapy, in parenting and cancer, and in psychological self-exploration. There were also announcements of an advisory group meeting to discuss the policies and philosophy of the Wellness Community, and for an alumni meeting where "former participants who have 'graduated' gather to devise ways to provide support for current community members, while enjoying the company of fellow 'victors' and family group alumni". The Wellness Community supports psychological approaches to self-care. It carefully and emphatically dissassociates itself from any involvement in complementary therapies that go beyond this approach. Its emergence as a major patient resource in the Los Angeles area, with strong support from many oncologists and other physicians, is a sign of the times.

The National Coalition for Cancer Survivorship (NCCS), founded by Dr Fitzhugh Mullan of the Johns Hopkins School of Public Health – himself a cancer survivor – is another reflexion of the growing interest that exists among health professionals for cancer hotline and information groups and the cancer self-help movement. Like the Wellness Community, NCCS focuses primarily on psychological and social issues of cancer survivorship. But the development of a national coalition seeking to identify cancer survivors as a specific group with common interests and perspectives is very significant.

ECaP, or Exceptional Cancer Patients is a group founded by Dr Bernard Siegel, a surgeon and faculty member of the University of Yale. ECaP is a vivid example of the primarily psychologically oriented approach to self-help that increasing numbers of people with cancer seek to explore. Siegel's book, *Love, Medicine and Miracles* (1986), was on the list of non-fiction best-sellers within a year – a rare event for a book about cancer. It is an outspoken book describing the ways in which exceptional patients engage with the cancer experience. Its popularity is another sign of the growing cultural phenomenon of the self-help approach.

The Australian Cancer Patients Foundation is an example from the other side of the globe of a thriving self-help group for exceptional cancer patients that goes well beyond interest in psychological and social issues of cancer survivorship. It is by no means hostile to conventional therapies, but has a strong emphasis on complementary (alternative and adjunctive) cancer therapies that include psychological, nutritional, spiritual, and alternative immunotherapies. In his book, *You Can Conquer Cancer* (1984), Gawler, one of the founders of the group, gives a remarkable account of an exceptional cancer recovery, using complementary cancer therapies.

In England, *the Bristol Cancer Help Centre* is an adjunctive cancer therapy center that vigorously utilizes nutritional, psychological, and spiritual support for cancer patients in an integrated program. The new facility for the Centre was opened by Prince Charles. The Centre was approvingly described in a series on BBC television and it receives referrals from many physicians throughout England. It has had a profound influence on many cancer self-help groups across Canada and the United States (Lerner, 1987a).

In Switzerland, the *Lukas Klinik* is the best known of the central European anthroposophical hospitals dealing with cancer. The Lukas Klinik is operated on principles set forward by the founder of anthroposophy, Rudolf Steiner. It draws on all established medical therapies for cancer, but it also uses a wide range of remedies recommended by Steiner from the great European naturopathic tradition. Art, movement and other approaches to creative expression are given a key role in the treatment, from a perspective on the interrelationship of healing and creativity that closely parallels that of humanistic psychology in the United States. Patients come from around the world to experience what many regard as a model of integration of humane established and complementary cancer therapies (Lerner, 1987a).

There are literally hundreds of other self-help groups, support organizations and health centers for exceptional cancer patients in many countries around the world. Some are self-help groups in the strict sense of the term; others are psychosocial support groups founded to create an environment in which people with cancer can be helped professionally and can help each other; still others are medical centers with an orientation towards self-help and towards the kind of care many exceptional cancer patients are seeking.

Socio-cultural perspectives on complementary cancer therapies

When confronted with the need to clarify the relationship among the diverse and complex perspectives of those who offer and utilize conventional and complementary cancer therapies, most people initially see the problem as a scientific one. They simply want to know, with some urgency, who is right. If they study conventional and complementary cancer therapies further, they often conclude that the problem is less scientific than political. They may become very exercised against one position or the other. My own view is that a socio-cultural analysis of the cultures and subcultures of both conventional and complementary cancer therapies sheds the most light on how best to pose both scientific and clinical questions.
But before we undertake this analysis, it is vitally important to distinguish among the several approaches used in the adjunctive and alternative therapies which form the two major groups of complementary therapies.

First, there is the use of psychological approaches such as counseling, imagery, relaxation and meditation to improve quality of life, help control pain, diminish side-effects of conventional therapies, or lower resistance to medical treatment.
Second, there is the use of psychological approaches with the objective of affecting

the course of the illness and extending life. *Third,* there is the use of improved general health practices– diet, exercise, recreation, positive thinking – both for quality of life and, some would argue, for possible life extension.

This is the point at which, culturally, in the United States, the dividing line is roughly drawn between adjunctive/lifestyle approaches (the first three above) and alternative cancer therapies.

The *fourth* approach in complementary cancer therapies – and the first among alternative therapies – comprises the wide variety of schools of intensive health promotion that make claims for life extension with cancer. For example, the Macrobiotic diet and life change program (Kushi, 1983), the Gerson therapy (Gerson, 1977) and the Hippocrates Institute wheatgrass and raw food diet are examples of these schools of intensive health promotion; whether or under what circumstances they actually promote health is not under consideration here (Lerner, 1987a). The *fifth* approach derives from one or the other of the "traditional medicines" described by the World Health Organization. Acupuncture, naturopathic medicine and homeopathy are all well-established traditional therapies that have a great deal to offer with regard to the treatment of cancer.

Sixth, and most difficult of all to evaluate, are the alternative cancer therapies with some secret or indecipherably complex or esoteric component that results in the therapy being partially closed to ready scientific evaluation. Dr Lawrence Burton in the Bahamas, Dr Emmanuel Revici in New York, Dr Hans Nieper in Hannover, Federal Republic of Germany, Dr Virginia Livingston-Wheeler in San Diego (*The Conquest of Cancer, Vaccines and Diets,* 1984), and Dr Stanislaw Burzynski in Stafford, Texas, are among the most widely recognized of those who either utilize a system that is too complex for any other practitioner to understand fully, or who keep some component of their system as a proprietary secret (Lerner, 1987a; 1987b). It is important to note that this significant category includes a number of the most highly respected (in the culture of alternative cancer therapies) cancer researchers and clinicians in the Western world. There are many others who enjoy lesser esteem among their peers in the field.

Other components often found in complementary cancer therapies, on which we will not elaborate here, include herbal therapies, electromagnetic therapies, such as that of Bjorn Nordenstrom in Sweden (Nordenstrom, 1983), the unorthodox use of established therapies, such as that of the Janker Klinik in the Federal Republic of Germany (Lerner, 1987a), the use of experimental therapies from mainstream research programs for individual patients on a private payment basis, such as that of Biotherapeutics in Franklin, Tennessee, and spiritual healing. Consideration of these categories is less relevant to an analysis focused primarily on the role of health promotion in complementary cancer therapies.

The point is that any perspective that labels all these very divergent trends as "cancer quackery" is not optimally informative for either the health care practitioner or the cancer patient.

The subcultures of cancer care

Health professionals, for their part – at least in the United States – have extraordinarily refined systems for recognizing and differentiating the subcultures of cancer care to which they respectively belong, whether they are engaged in behavioral approaches to cancer in mainstream institutions, promote psychosocial support services or programs in the community, or advocate adjunctive or alternative therapies.

A psychiatrist at a major cancer hospital, for instance, will often support the use of relaxation and imagery to minimize resistance to treatment and side-effects, but he will vigorously differentiate himself from those who believe that these therapies may directly affect the cancer or extend life. At best, this is regarded as an interesting but unproven hypothesis. Similarly, the therapist in private practice who uses psychotherapy, relaxation and imagery with the purpose of directly attacking the cancer and extending life may no less vigorously differentiate himself from those who believe that improved nutrition or some alternative cancer diet could also affect the cancer and survival. The point is that, in this highly charged frontier area, there are very elaborate sociocultural rules concerning what one can and cannot espouse. Health professionals with career stakes in the field are usually exquisitely sensitive to what they can and cannot say about the role of any intervention beyond conventional medical treatment in cancer survival. The sociocultural agreement on what is legitimate within different cancer therapy subcultures is in a process of rapid evolution, so the specific positions are changing; but the care with which professionals locate themselves territorially in this field, and with which they differentiate themselves from each other, remains constant.

As scientific evidence and scientific opinion regarding behavioral interventions, dietary interventions, and health promotion in cancer treatment move towards cautious embrace of these once scorned options, the territorial lines that were so firmly fixed between conventional and complementary approaches have entered a period of rapid and disconcerting flux. In the "war over cancer therapies" that was widely publicized by the American media for the past decade, both sides often described the opposition as a malevolent monolith. Thus the cancer establishment characterized the alternative and adjunctive cancer therapies as the work of quacks preying on desperate and credulous cancer victims, while the proponents of complementary approaches depicted conventional treatment as the "cut, burn and poison" therapies of a cynical and profit-driven conspiracy. These stereotypes are, from a sociological perspective, familiar to anyone who has studied the phenomenon of propaganda in conflict situations. Each side in the cancer therapy controversy accuses the other of being profit motivated, of cynically suppressing or ignoring therapies that could be beneficial, and of representing an organized conspiracy to thwart progress in cancer.

Some legitimate causes of concern

This antagonism between important elements in both established and complementary cancer therapies continues. There are, indeed, legitimate causes for concern on both sides. Alternative therapies in the United States represent an unregulated field, frequently operating under black-market conditions because of laws and regulations designed to protect the consumer from medical fraud. Whether these laws and regulations have struck the right balance between consumer protection and consumer choice is a warmly debated issue. At present, in these unregulated markets, unethical practices do in fact flourish alongside ethically motivated efforts to provide therapies that practitioners and many patients believe in.

Conversely, the excesses and abuses of conventional cancer therapies have been extensively documented by critics within the cancer establishment as well as opponents outside the system (US Senate, 1982). Some of the most common concerns of cancer patients include the following: their physicians did not consider their feelings and their personal dignity in interactions; they were not given sufficient information to make informed judgments about options among conventional therapies; they were not made sufficiently aware of the side-effects or unintended consequences of treatment; they were insensitively informed of their diagnosis and prognosis; and their physicians were actively hostile to any suggestion of interest in complementary approaches to cancer care.

The situation with respect to complementary therapies differs markedly according to countries. Hostility is least apparent in cultures characterized by broader acceptance of pluralistic medical systems. China, Great Britain, India, Japan, and Switzerland are examples of societies where diverse systems of medicine coexist. The coexistence is not always friendly, but no single system has established absolute hegemony. As a result, a broader range of cancer therapies tends to be accepted in these and other medically pluralistic countries. Opposition is more pronounced in countries such as the United States, where allopathic medicine has established stronger hegemony. When the World Health Organization espoused the use of "traditional" (non-allopathic) systems of medicine around the world to achieve its goals of health for all, it increased international awareness of the potential contribution of pluralistic medical systems to health care. Some complementary cancer therapies fit clearly within the framework of the "traditional" systems of medicine supported by the World Health Organization.

The important point is that, today, exceptional cancer patients in the United States tend to be relatively unengaged in the old rigid controversies between advocates of conventional and complementary cancer therapies. Nor are they greatly interested by the elaborate rituals with which health professionals differentiate their respective positions of adjunctive and alternative cancer therapies. They have, in effect, adopted a pluralistic and pragmatic perspective and frequently hold the view that neither established nor complementary cancer therapies are monoliths. As "informed consumers" they realize that there are widely divergent tendencies within both cultures and characteristically utilize all efficacious established therapies. They almost always stay under the care of an oncologist, internist, or family practitioner. Using efficacious conventional treatment as a base of departure, they range widely through the complementary approaches to cancer therapy and self-care.

Findings on complementary cancer therapies

I have studied complementary cancer therapies, lifestyle changes and self-care systems for five years, visiting over fifty centers, talking with hundreds of physicians and well over a thousand patients. I have also spent fifteen weeks over the past two years in week-long residential retreats with exceptional cancer patients, exploring their experience with a wide range of complementary cancer therapies (Lerner & Remen, 1985; Lerner, 1985; 1987a). I have looked at nutritional and psychological therapies, I have looked at high-pack, immuno-modulating alternative cancer therapies, I have looked at spiritual therapies and at the unconventional use of conventional therapies, I have looked at herbal therapies, at traditional medicine including acupuncture, at a special form of yoga that is said to have effect on lung cancer in China, and at many other therapies. And through those five years of study I developed conclusions that have changed very little.

First of all, I have not seen a reliable cure for cancer among any of the complementary cancer therapies. This is very important to say because some enthusiasts will claim that somewhere, out there, a wonderful cure for cancer is available and that it is being suppressed by the medical establishment. This has not been my experience. The medical establishment may be hostile to complementary cancer therapies but it is not suppressing a cure.

Secondly, I found little scientific evidence on which to evaluate the really key question: "Do some people do well on complementary cancer therapies and if so, what are the conditions under which some people do well?"

Thirdly, I found very strong anecdotal evidence that some people, in fact, do well while using these therapies. Whether there is a causal link between these therapies and their improved health is another matter. But while they are using these therapies, some people do very well indeed.

Fourthly, I found throughout a convergence between some of the best thinking in complementary cancer therapies and the best thinking in established cancer therapies, particularly in areas that include nutritional, psychological and immunomodulating approaches, or in the use of traditional systems of medicine, Chinese acupuncture, and a variety of other approaches to supporting the general health of the cancer patient.

I also found, as did Barrie Cassileth (1984), that the old stereotypes of the typical provider of complementary therapies as an untrained "quack" and the typical consumer as a desperate, credulous, end-stage cancer patient, are largely untrue. Many providers are trained medical doctors, fully aware of the benefits and limitations of established therapies. Many patients who seek out these therapies are above average in their information levels, their sense of personal efficacy, the competence with which they navigate through the medical field, their belief that it is possible to effect change in their lives, and their will to live. Although there is no scientific evidence about the efficacy of complementary cancer therapies, when you talk to the really informed people who have been watching this field for many years, you find that there is something of an outcome curve that they have come to expect.

At one end of the curve there are, perhaps, 10% of the people who are hurt by these therapies. These are, characteristically, desperate and frightened people who had an operable cancer and ran away from surgery in the hope of finding a cure that would not involve physical mutilation. They undertook a complementary cancer therapy and returned later with the tumor beyond surgical removal. This does not happen to lots of people, but it definitely happens. There is a book on "psychic surgery" in the Philippines which relates in some detail the experience of an American surgeon who went with an open

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A personal life event is at the origin of Professor Lerner's involvement in cancer care. "I was always interested in what people did when they learned they had cancer, he recalls. I had been reading about it for years, but I had never actually done anything in the field until my father was diagnosed as having non-Hodgkins lymphoma. When my father got cancer it really crystalized my interest. I decided to visit the best complementary cancer centers throughout the world. I wanted to be able to tell him what was available. But as we got into it, the project grew into a much broader study."

mind to look at the "psychic surgeons" in the Philippines and followed up the cases they had treated. These were people who had been told they had breast cancer that could be removed surgically, but who went to the Philippines for "psychic surgery". They were convinced that the "psychic surgeon" had in fact taken the tumor out. They returned home and three months later the cancer was no longer removable and they died. One cause of casualties in the use of complementary cancer therapies is this loss of opportunity to use conventional therapies that really could have made a great difference.

Another source is that there are some very unethical quack practitioners who are using very dubious therapies in very unhygenic environments. People get sick and die from the unwise use of poor therapies under horrible conditions. There are casualties, there is no question about it. But I think they represent about 10% of the people who use complementary cancer therapies.

At the other end of the continuum, there is another *10% who use these therapies and have exceptional stories to tell*. These people undertook complementary cancer therapies, and they got better and began to live effectively with their cancer; some report a long-term remission or even that their cancer disappeared. These stories have been documented. The Institute of Noetic Sciences in the United States has published a bibliography (1985) which is the outcome of a study of all the reports on spontaneous, unexplained remissions from cancer published in scientific literature. This is the first time that one can have an easy access to these hundreds of reports, which show the extraordinarily different conditions under which people recovered from cancer. For example, in Japan, there are many reports in the medical literature of people who simply could not afford the medical treatment for their cancer. So they went home and said: "Well, I have lived my life in God's hands and I just give myself up to God. Whenever He wants to take me, He will." And they lived on and on and on, and finally somebody wrote an article about it. There is another case reported by the Association for Humanistic Psychology which is just as intriguing. It is about a man in the United States who had advanced lung cancer and was given a few weeks to live. The interview published took place 10 years later! "When the doctor told me that I had just a couple of weeks to live, I decided that I was going to give that cancer something to eat on before it ate me. So when I got in the hospital I began to order three helpings of everything. And as I was pretty nervous, I had a couple of pints of beer smuggled to my room every day. When I got out of hospital, I just kept on eating and I put on about 50 pounds. I know I should have given up smoking with lung cancer but I just couldn't!" And 10 years later the man was alive and well.

This clearly shows that the conditions under which an individual heals may be very different. Experience indicates that different people with the same cancer will do well on very different therapies and that the people who do well, do well to a surprising degree irrespective of the extent of the disease, whereas other people, who started early and made every effort, do not progress at all. The psychological literature on internal locus of control suggests that there are 10, 15 or 20% of the population as a whole who believe that it is possible to make a difference in one's own life. Exceptional cancer patients probably represent that very 10 or 20% among the people who get cancer.

Then, in between these two 10% who are at the extremes and who either succeed or fail, you find 80% of the cancer patients who, on the one hand, did not get hurt but who, on the other hand, did not have an extraordinary remission. They undertook a therapy that made sense to them and became what Dr Alec Forbes of the Bristol Cancer Health Centre calls *"healthy cancer patients"*. And these healthy cancer patients have very interesting outcomes. They tend to do better on all established therapies because they have greater strength and resilience; they tend to have better morale, to feel less pain, and their quality of life tends to improve.

The significance of health promotion in complementary cancer therapies

What is really interesting, as one explores complementary cancer therapies in depth, is that so many of them are, in part or in whole, systems of intensive health promotion. *I would define the ideal system of intensive health promotion for an exceptional cancer patient as a multimodal approach to enhancing physical, mental, emotional and spiritual well-being tailored to the specific needs, beliefs, goals, situation, resources, preferences, and psychophysiological responses of the individual.*

In this ideal-type definition, I would further emphasize the importance of the dictum that *it is more important to know what kind of patient has the disease than what kind of disease the patient has.* This is literally true because the goal of intensive health promotion is to create conditions that optimize the healing process for each unique individual. While there are certain practices that commonly promote health and create conditions of healing, the particular configuration that will optimally release inner healing resources for an individual requires sensitive exploration. In this ideal case, the patient/investigator, with the help of his physician, would carefully monitor his response to the multimodal system he has chosen, modifying it as suggested by subjective experience or by objective indices of health and by the disease process.

Although some enthusiasts or promoters may identify complementary cancer therapies as "cancer cures", they are not "cures" in the sense of medical interventions that regularly and reliably cure a disease. Rather, the primary purpose of many of these therapies is to improve the inner and outer conditions that will enable whatever natural healing is possible to take place. That is why these therapies are best entered into as complements to the sensitive (and also personalized) use of conventional therapies. The goals of the health promoting complementary therapies are, then, to enhance general immune function, morale, general strength, vitality, and other host resilience factors.

The complementary therapies that can be considered systems of health promotion propose some combination of diet, supplements, exercise, relaxation, meditation, imagery, prayer, will to live, improved family and work environments, changes in life work, new perspectives on what is meaningful in life and other forms of self-exploration or health enhancement. Many of these therapies, in addition to being intensive forms of health promotion, place a profound emphasis on stress reduction. It would seem reasonable, therefore, to assume that people may experience a longer life simply because the tumor facilitating effect of stress is eliminated. Thus, if stress reduction and intensive health promotion enhance each other, is it not likely that there would be a change in the whole *psychobiological milieu* that was favorable to cancer growth?

It is appropriate, here, to mention the studies on multiple personalities (Institute of Noetic Sciences, 1985). These are people who were severely abused as children and their personalities sort of fractured; as a result, they developed within themselves 5, 10, 15 or 20 different personalities, all of which are unconscious of each other most of the time and take control of consciousness serially. As the field of psychoneuroimmunology has developed, scientists began to look at this phenomenon, realizing what an incredible laboratory a multiple personality constitutes. They have traced what happens to different psychoneuroimmune parameters as the personalities change. And they found extraordinary changes in physiology. One personality will be allergic and another one will not. One personality may be diabetic and another one will not. One will be short-sighted and another one will not. So that there are extraordinary changes in personality in these "multiples".

Similarly, one of the things that happens with exceptional cancer patients who undertake to engage with their illness in a really deep way is that *they become a different person from the person who developed the cancer.* This is absolutely true. They are not multiple personalities, but all of us have sub-personalities. And so, characteristically, you find that persons who developed a cancer were severely stressed, rather depressive, smothered anger and did not really act out their lives. And when they became ill some kind of inner dialogue went on like this: "Well, Charly, you have been running this ship for a long time and you did as best as you could in coping, but George over here is better at the kind of heavy-weather sailing we have. He is a better prime minister in times of war. So we are going to put you on the opposition bench for a while and bring George in, because George has the kind of personality that is needed for the fight we are going to make for our lives." And the whole personality changes. *You can see it.* There is no question about it. You know it is really a profound personality change. And if you combine that personality change with a great effort to clean up diet and get exercise – which is in itself an anti-depressive – and with many other steps, then there must be a change in the psychobiological milieu in which the cancer was developing.

From this perspective, one may indeed wonder why cancer patients are often tacitly discouraged from making vigorous efforts to improve, to the greatest extent possible, their general health in the face of a cancer diagnosis. Physicians usually consider general health, morale, and functional status significant predictors of outcome for people with cancer. A person in good health is able to withstand both the disease and the treatment better than a person in poor health. Some cancers move sufficiently slowly that the patient has ample time to explore and engage in a system of vigorous health promotion which, to his view, will improve his physical health and his psychological state, regardless of whether it affects the progress of the cancer.

The situation that a cancer patient in search of an ethical system of intensive health promotion finds is complex. The fact that many complementary cancer therapies represent different schools of thought on how to regain health certainly does not facilitate choice. Furthermore, as we saw, among patients who undertake the recommended lifestyle changes, some succeed in improving their status while others may damage their health. Diets are a case in point. Men characteristically lose more weight than women when they change to a vegetarian diet. This is the common experience of many yoga centers and other places. But in cancer, weight loss is also often associated with cachexia. Thus weight loss may be very frightening to a patient and to his mainstream physician when neither are familiar with the phenomenon of diet-related weight loss in vegetarian men. More than that, the weight loss associated with some of the more stringent vegetarian diets may in fact be unhealthy and unwise, especially for a male cancer patient with low weight reserves at the outset. So the situation is by no means simple, and the physician-patient search is not for an abstract ideal of the optimal therapeutic diet but for a diet that empirically works for the individual patient.

In fact, the very complexity of these questions speaks strongly in favor of pursuing explorations of complementary cancer therapies under the care of a competently trained, nutritionally oriented physician who is also knowledgeable in conventional cancer management. Unfortunately, oncologists, internists and family practitioners with training and experience in guiding cancer patients through informed choices among competing systems of intensive health promotion are a rarity. The entire field of ethical, individualized health promotion for motivated cancer patients is one in great need of development if we are to offer integrated systems of conventional and complementary therapies to people with cancer.

Many unanswered questions require research

There are many components of complementary cancer therapies that should be scientifically investigated. The most obviously important and easily accessible of all is the question: "Do intensive efforts at multimodal health promotion by highly motivated cancer patients have effects that extend beyond an increased sense of personal efficacy and improved quality of life?"

There are many important issues here. First, is it possible for some cancer patients who undertake vigorous programs of physical, mental, emotional and sometimes spiritual development to improve their general health significantly? Conversely, how many damage themselves or achieve nothing in the process? Second, are these regimens of intensive health promotion of value (when they work) for quality of life even if they have no effect on the rate of development of the cancer? Third, does vigorous multimodal health promotion improve resilience to sideeffects of conventional therapies, and therefore possibly improve the efficacy of conventional therapies? Fourth, do vigorous attempts at multimodal health promotion have effect on the cancer process – or on prevention of recurrence – for some cancers, or for some people with some cancers? Fifth, can the effects of individualized systems of intensive health promotion be scientifically estimated and, if so, how?

Many researchers and clinicians look at the complementary systems of intensive health promotion and if they find that a system is not practicable or suitable for all patients with a specific cancer, then they decide that it is not worth pursuing. What is missed are the research opportunities created by exceptional cancer patients who have decided that these health promotion systems are regimens they choose to undertake. What can we learn from monitoring these pioneering personal explorations? What crude patterns would emerge if we looked carefully at the different rates of success of different programs with different cancers and – equally important – with different kinds of people?

One fascinating example is from the literature on breast cancer. Wynder & Rose have suggested that a "Japanese-style" diet might be helpful as an adjuvant therapy for postmenopausal women with breast cancer, but not for premenopausal women, based on an intriguing review of epidemiological literature. They cite reports that postmenopausal Japanese women have twice the ten-year survival rate of American women, while premenopausal Japanese women have a survival rate very close to that of American women. They propose, therefore, clinical trials on the question (Wynder & Rose, 1984). But should the clinical trials be focused on the "average" American postmenopausal breast cancer patient, for whom undertaking a "Japanese-style diet" could be stressful in a way that did not parallel the experience of her Japanese counterpart, or on exceptional cancer patients who want to undertake the program? This is an example of how we may move from the most generalized question – "Does a dietary change known to be associated with lower risk of breast cancer in epidemiological studies affect survival or recurrence rates?" – to much more sophisticated health promotion questions: "Does this dietary change affect survival or recurrence in motivated postmenopausal women?" If it does, the next logical question might be whether placing – surgically or chemically – a motivated premenopausal breast cancer patient in menopause would move her into the group that may achieve greater ten-year survival.

If different diets and different regimens of nutritional supplementation may be selective in their possible effect on life-extension, it may be that behavioral interventions have an effect that is more independent of tumor type. The impact of psychotherapy, meditation, imagery, hypnotherapy and relaxation techniques may depend far more on the psychological make-up of the individual. Meares has done some of the most interesting clinical studies of intensive meditation in Australia, and reports from his clinical series of patients that improvements in the quality of life, and even life extension for some, are achieved independent of cancer type. "The results of treatment with 73 patients with advanced cancer who have been able to attend at least 20 sessions of intensive meditation, indicate that nearly all such patients should expect significant reduction of anxiety and depression, together with much less discomfort and pain. There is reason to expect a 10% chance of quite remarkable slowing of the rate of growth of the tumor." (Locke, 1986).

The effects of psychotherapy on life extension as well as quality of life is greatly deserving of further study. One of the most interesting reviews of the subject is by Cunningham (1984). While recognizing the methodological deficiencies of clinical studies to date, he believes their claims may nonetheless be "both true and very important". He proposes a different standard be used to weigh their findings – one that might be called the principle of cross-study consistency. "Cunningham argues that the results of the clinical studies are consistent with each other and also with the results of prospective studies correlating personality factors with cancer and animal studies investigating the effects of stress on tumor growth." (Locke, 1986).

There are other important questions with regard to intensive health promotion for cancer patients. Many cancer researchers and clinicians now believe that *specific cancers may develop in different patients by different pathways, in other words, have different etiologies.* If this is the case, this may explain why a specific type of intensive health promotion may have markedly differnt effects for people with similar cancers. From a scientific perspective, this makes the question of identification of the most appropriate forms of intensive health promotion a very complex and difficult question. From an evaluation perspective, it creates great difficulties.

The cancer patients who engage in these personal trials of different forms of intensive health promotion have, of course, a different perspective. They carefully monitor their own "subjective" feeling of well-being with different approaches to health promotion. They also monitor reports from their physicians on the progress of the disease. When they find approaches to health promotion that make them feel better and that coincide with objective evidence that they are doing well, they often continue on these programs. When the putative health promotion programs do not make them feel better or do not appear to affect the progress of the illness, they reevaluate their self-care options. They do not, after all, have to solve the question of whether the health promotion system they have adopted would work for everyone with the same cancer. They do not have to assess the differential contributions of the medical treatment and their complementary modalities of self-care. They have a legitimate interest in the simple empirical question of what will work best for them.

Why are we, as a medical scientific community so resistant or uninterested in exploring all these questions? I would submit that it has to do with our prejudices. And one of these prejudices is that we are continuously looking for some kind of high technology therapy that will be equally effective for all people with the same cancer and we only set up methodology that will work under these parameters.

There are still other components of health promotion that could be studied in terms of their differential effects. Is there a kind of "perennial wisdom" about healing that would explain why different people achieve apparent life extension, improved quality of life, or improved passage into death with profoundly different and often mutually contradictory systems of health promotion? Does this suggest that there are certain grand highways that have led many safely to healing but also innumerable byways that proved just as successful for those who seek them out, even if they run counter to the grand highways? Thus, while peace and love are certainly great contributors to healing, it is also true that some have staged extraordinary recoveries fueled by fury and hate.

It may be that the best research, in the future, will take very seriously the observation that *different things are health promoting and healing for different people.* Therefore, to study the optimal effects of intensive health promotion for exceptional cancer patients, we will have to greatly modify our standard methodologies. A most exciting development in this regard is the movement towards marketing a number of different blood tests for cancer progression or regression that are independent of cancer type. One of the greatest needs for research in the field of intensive health promotion in relation to cancer is for some form of "biofeedback" that would feed back to the patient and to the clinician whether the specific regimen of health promotion under trial is having any effect on tumor progression. When these tests come to market at affordable prices, the quest of the exceptional cancer patient for personally efficacious systems of intensive health promotion will be transformed.

A new and important social force in cancer care

The phenomenon of exceptional cancer patients interested in integrating efficacious established therapies with complementary therapies, lifestyle changes and self-care systems that make sense to them represents an important social force in cancer therapy and care. Some of these exceptional cancer patients have developed a pragmatic, pluralistic perspective on the often antagonistic cultures of conventional and complementary cancer therapies. Within complementary cancer therapies, these patients have generally identified a variety of approaches to intensive physical, mental, emotional and spiritual health promotion.

The value of intensive health promotion for motivated cancer patients has not been demonstrated conclusively. But many exceptional cancer patients are engaged in their own personal trials of intensive health promotion, which can be reasonably separated from more speculative and questionable components of alternative cancer therapies.

This phenomenon raises many interesting clinical, scientific, and policy questions and should be studied further. The autonomous self-help groups popularized by these exceptional cancer patients may prove to be a leading indicator of future trends in cancer care. Just as humanistic "birthing centers" have transformed hospital birth practices over the past decade, one can easily envision a powerful consumer interest in humane cancer care that integrates innovative strategies of health promotion and promising complementary cancer therapies with the best of efficacious conventional cancer treatment.

CONCEPTUAL VIEWS ON QUALITY OF LIFE: AN IMPOSSIBLE TASK OR A NECESSARY CHALLENGE?

by Jørn Beckmann & Gert Ditlev

Quality of life can be discussed in many ways. One way is to analyze the empirical quantitative approach to determine whether the research categories are operational, empirically unambiguous, and thematically relevant; progress, in the sense of changing the number of research categories, does not take place through a systematic empiric test but through a modification of the theory of quality of life. The current debate on quality of life has included a conflict between natural science and a humanistic approach. Our view is that quality of life must be defined through the difficult concept of happiness. When cancer threatens happiness, not one, but two, fundamental crises influence quality of life, which we regard as a key concept of a therapeutic method.

Many issues are involved

The issues inherent in the concept "quality of life" are not one, but many. For example, there is the issue of alternative therapeutic modes. Or, there is the issue of empirical research in relation to quality of life, and there is the choice of therapeutic method. In this paper focus will be placed on the issues of empirical research and choice of therapeutic method.

The empirical-quantitative approach to quality of life selects research categories in accordance with two criteria, or theories: (1) categories are selected on the basis of one definite scientific theory, and they must be operationally or empirically unambiguous; and (2) research categories are selected on the basis of a quality of life theory. The scientific theory cannot be the only selection criterion, since it can only determine which terms are operational or "scientific". It cannot address which terms are relevant to quality of life, and it cannot determine when all the relevant terms have been assessed.

These aspects are determined by a theory of quality of life. Every empirical-quantitative analysis of quality of life necessarily presupposes a theory of quality of life (Beckmann et al, 1985).

"Progress" is a central implicit claim in the definition of science. Progress in the empirical-quantitative sense can mean one of two things: advancement in defining the research categories used, or changing (increasing/decreasing) the number of research categories. A theory for the formulation of empirical scientific terms, a norm of exactness, is used to assess the first definition of progress. It is the second definition, progress as changing the number of research categories, that is of more interest. Unlike other empirical research the empirical-quantitative approach to the study of quality of life is not worked out with empirical testing in mind. Progress, then, in the empirical-quantitative approach means exchange of the theory of quality of life. But because this exchange is not clearly scientifically determined, progress becomes identical with arbitrary change (Beckman et al, 1981).

Development of quality of life research confronts at least three questions: (1) Can the empirical-quantitative and the empirical-interpretative approaches be integrated and used together? (2) How are theoretical considerations concerning quality of life assessed? (3) How are theoretical considerations and empirical research combined? These three questions are the most important research problems in the study of quality of life.

Natural science versus a humanistic approach

The popular concept of the quality of life debate focuses on the natural science versus the humanistic approach. If this concept is allowed to remain unchallenged, it will then follow that the debate on quality of life will be nothing more than

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an exchange of preconceived, untenable viewpoints. The two approaches do have one major concept in common: quality of life is defined as happiness. The problem, however, is that happiness is defined differently by each approach.

According to the natural science approach, happiness is defined by pleasure and displeasure. This definition stems from the natural science paradigm, which is based on a biological-mechanical orientation. The human being is seen as part of nature, an antisocial, sensual, mechanical being. Happiness, in the natural science paradigm, is hedonism. According to the humanistic approach, happiness is defined by self-realization and inner peace or harmony. In the humanistic paradigm, the procedure is a dialogue, and the human being is culture, a conscious and social being. Happiness, in the humanistic paradigm, is eudemonism. The quality of life debate becomes, therefore, partly a discussion of the two paradigms. The eudomonic and the hedonistic points of view have equal strengths and weaknesses, and many obvious areas of disagreement.

Many people have given up the debate on quality of life because it is unmanageable; others have begun to measure quality of life without having defined it. Although these groups recognize the need for a definition, they maintain that since the issue deals with invisible quality of life concepts, it is theoretically impossible (Beckmann & Ditlev, 1982).

Quality of life versus quantity of freedom

Since the definition of happiness varies from person to person, it is imperative that each individual be able to choose what he regards as happiness. It is, therefore, futile to try to determine a universally concrete definition of happiness. We, instead, enter into a discussion concerning the conditions for happiness, with the theme being *conditions for quality of life*. The concept of freedom, the ability to choose and realize one's goal becomes the central condition of our new thesis.

In accordance with the natural science paradigm, illness is disharmony with the biological/physical necessity, whereas in the humanistic paradigm, it is a collapse of meaning. But with our new thesis, illness becomes defined as a restraint or reduction of freedom. In addition, the task of treatment in the natural science paradigm is to reestablish the harmony of necessity. In the humanistic paradigm it is to reestablish meaning. In our new thesis the task of treatment becomes the maximizing of freedom. The current view of the debate on quality of life must be abandoned. The concept of illness and the task of treatment must be redefined. The application of the concept of quality of life must be redefined.

Quality of life as a therapeutic method

The concept of quality of life is not only a criterion for decision and choice, it is a key concept as a therapeutic method. This concept is based on a new description of crisis situations, with quality of life as a basic category. Cancer, contrary to many other diseases, releases not one, but two crises. These two crises, the loss of the outer world and the necessary integration of the illness, are interwoven and are, therefore, not immediately recognizable as separate entities. In accordance with the two-crises theory, cancer causes not only a crisis of integration but also a fundamental crisis.

The crisis due to loss of the outside world

The fundamental crisis of cancer is caused by the loss of the outside world. Everyday life collapses. This breakdown causes an "I-" or self-fear, both for the "I" and by the "I". In other words, the person changes from a "human being" to an "I". He drops out of the occupations of everyday life, where life had been perceived as inevitable.

There is an understanding in everyday life that the outside world is eternal or obvious, and that the individual can let himself be absorbed by it. In the crisis of cancer the individual is thrown back upon his own resources. The subject or the ego is shattered, creating a situation in which the individual is confronted with himself, and his lack of self.

This fundamental crisis creates a social restraint that is compounded by the loss of self. The security and confidence of being a human being reveal themselves to be illusion. The fundamental crisis is that the individual must establish himself as a goal-setter instead of giving himself up to his surroundings.

The crisis of integrating the illness

The difficulty of integration of illness is also a crisis that is related to the setting up of goals. If this crisis is treated in isolation, it has three problems:

1) the patient, the presupposed subject for the solution of the conflict, does not exist but is under construction. The integration becomes, therefore, not a combination of new into old, but of new into new. Without this understanding, the result of the therapy is accidental.

2) The individual must solve his fundamental crisis alone, and perhaps it will never be solved.

3) The effort to solve the crisis of integration can eventually block the solution of the fundamental crisis. The physical difficulties of illness increase this possibility. The process of hospitalization, for example, often works contrary to the *individual's process of becoming* a subject by turning him into an object. Patterns governing the individual's everyday life, patterns that make the individual a subject, are replaced by patterns belonging to the hospital. The hospital's values or lack of values may become the new everyday life of the individual. Hospitalization can have the consequence that the process of integration comes to a standstill.

Conclusions

The concept of quality of life is not only a criterion that can help us to choose between alternative treatment modalities, but it also becomes a therapeutic tool in itself. It can be utilized in complex crisis situations, in which the individual consciously or unconsciously drops out of a system of given values which no longer provides usable supports.
It now becomes the task of the individual to construct a system of values for himself, using himself as a basis, and being aware that the validity of the values is a function of himself. The values do not become human being values but "I" values. In this situation the individual becomes both "I-"seeking and values-seeking and is therefore a victim of a new crisis. There are now two possibilities: either the individual will forget himself again, or he will stick to the process of becoming a subject and be supported in it. He thereby develops "I" values, with himself as the basis. In other words, values that the individual has set and chosen himself become the basis of his life, as he works through his fundamental crisis.
We can, therefore, see how the two-crises framework fits together with our new definition of quality of life to give a usable framework for treatment of individuals with cancer.

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CONCLUDING REMARKS

The value of intensive health promotion for cancer patients has not yet been demonstrated conclusively. But many cancer patients are engaged in their own personal trials of intensive health promotion, and have developed autonomous self-help groups which may prove to be a leading indicator of future trends in cancer care.

Just as humanistic "birthing centers" have transformed hospital birth practices over the past decade, powerful consumer interest in cancer care might result in innovative strategies of health promotion where promising complementary cancer therapies and efficacious conventional cancer treatment have both their place.

Many health care centers are precisely attempting such an approach. They are using health promotion to improve the quality of life of cancer patients and influence the course of the illness, while imaginative projects are tackling specific problems. These projects aim to enhance well-being through improved coping skills and reinforced social support.

The search for intelligent integration of conventional therapies and personalized forms of intensive health promotion derived from complementary therapies may indeed constitute a major force in shaping the development of humane integral cancer therapies in the coming years.

4.

CHRONIC PAIN CONDITIONS: A NEW UNDERSTANDING

INTRODUCTORY NOTES

In recent years, our understanding about causation, processing and sensation of pain has advanced considerably. We have begun to accept that the simple cause-and-effect approach is, in most cases, inadequate. The idea of a straightforward correlation – here organic damage and there pain – is today scientifically no longer valid.

During the last two decades, a more differentiated approach to pain conditions has led to a clearer division between two phenomena: acute and chronic pain. Despite the comprehensive scientific literature available, this awareness has remained limited, in the main, to a small group of initiated experts. Even within the medical profession, it is frequently not fully recognized. "Pain remains pain and the best remedy is pills" still appears to be the opinion widely shared by both medical doctors and the public alike. This situation presents a special challenge for everybody concerned with public health education.

This is all the more urgent, since one can say today, with good reason, that to treat chronic pain conditions solely with methods applicable to acute pain therapy, is close to a professional error and thereby a failure to provide adequate help.

The phenomenon of chronic pain underlines the necessity to search for new ways of medical action and health promotion. It makes clear, as hardly any other clinical picture can do, that, for its understanding, we need a holistic, systematic and ecological viewpoint.

H.M.

SITUATION OF PAIN PATIENTS IN THE HEALTH CARE SYSTEM: DEFICITS AND PROPOSALS FOR CHANGE

by Hanne Seemann

1. Introduction

"The sick are more human. They have more spirit. They are more interesting than the healthy ...". This provocative view was expressed by Nietzsche, who claimed that he owed his "higher health" to his long sickness. "I also owe my philosophy to having been ill", he added. Being ill is part of the human condition (Schipperges 1982, p. 145) and pain is a familiar element of human existence. In medicine, however, pain is reduced to a symptom or a diagnostically relevant indication of a disease, while health is defined by the absence of such a symptom. This view results in making people feel that they are sick whenever they have pain.

We have to find a concept of health that allows a person to say: "I have pain, but I feel fine. I am not ill." The concept of the "healthy ill person", who feels "whole" and undamaged despite pain, seems to offer a positive approach in this context (Milz, see article p. 25). First, it gives the possibility to cover a wide range of individual states, and second, it allows the individual to determine this state himself. At the beginning of the century, Groddeck (1913), one of the founders of psychosomatics, emphasized this view. In his treaties, *Natura Sanat, Medicus Curat,* he wrote: "I do not see any way to define the word *ill* scientifically. Therefore I take the liberty of judging myself. To my mind a person is ill when his capacity to perform has suffered, or when he considers himself ill. All others, even if declared ill by science a thousand times, are healthy in my opinion, even if death has grasped them, even if disease has devoured their bodies almost entirely. The doctor has nothing to do with them. They are healthy."

Considering this background, health promotion should aim to identify approaches that society and the health care system can use, as well the social environment of chronic pain patients and the patients themselves in order to reach a satisfactory quality of life and subjective well-being.

In analyzing the situation in respect of this objective, this paper reviews:

- the heterogeneity of the meaning attributed to the term "chronic pain";

- the extent of the problem of chronic pain and the relevance of lifestyle factors;

- the situation of chronic pain patients in the health care system;

- the degree to which diagnostic and therapeutic processes are based on a holistic approach and how much they encourage patients to take on responsibility for improving their health;

- criteria for an integrative pain therapy approach;

- the need for studies on the attitudes and behaviors of the social environment of pain patients;

- and last but not least, suggestions regarding a number of concepts and approaches of value in developing health promotion for chronic pain patients.

2. What is chronic pain?

A definition of pain from the point of view of research has been developed on behalf of the International Association for the Study of Pain (IASP) by a commission consisting of 14 scientists in pain research: "Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage." (IASP, 1979).

The last half of the sentence contains the most interesting part of this definition: "... or described in terms of such dam-

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age". It says in effect that all kinds of pain are experienced as if tissue was destroyed: whether or not a lesion has actually taken place is not relevant for the *experience* of pain. This means that, for example, back pain caused by mental problems will be experienced with the same degree of reality as back pain caused by damaged vertebrae. It would be inaccurate to talk of "real pain" in one case and of "imaginary pain" in the other (Schmidt & Struppler, 1982).

One problem with the IASP definition is that it gives the impression that a close relationship exists between experiencing pain and suffering from pain. This is not always the case: if pain is provoked experimentally, for instance, it will often be *experienced* as a pure sensory feeling without a component of affective aversion, whereas in chronic pain the component of aversion and a crippling feeling very often prevail.

Another weak point of this definition is that it does not explicitly state that acute pain differs essentially from chronic pain; yet, the differences are of central importance with respect to clinical diagnosis and treatment.

Acute pain points to a tissue damage, which is impending or has already occurred; it is usually localized at the site of damage, which can be localized fairly well; it indicates the underlying cause in conjunction with the particular quality and cycles of the pain. Because of the significance of acute pain as a leading or accompanying symptom of certain diseases, it is considered as malpractice in clinical care to suppress pain before it has been evaluated diagnostically.

Acute pain also initiates typical vegetative reactions: the frequency of heart pulsations and blood pressure are increased, breathing becomes deeper, the pupils are enlarged, muscle tonus is increased and the glands in the palm of the hands are activated. The entire sympathetic nervous system is on the alert in the same way as in the case of anxiety. Treatment designed to reduce fear in situations of acute pain will often reduce the subjective intensity of the pain and the extent of vegetative reactions.

Long lasting or permanent pain (e.g. back pain, tumor pain) or recurring pain like migraine, headaches, trigeminus neuralgia, are called chronic when lasting more than half a year. The side-effects of acute pain cannot be defined so clearly in the case of chronic pain, but various kinds of vegetative symptoms also become more prominent. Patients report sleep disorders, loss of appetite, lack of libido, irritation, declining interests, diminishing contacts with relatives and friends and a steadily growing preoccupation with their symptoms. Increasingly, feelings of depression and hopelessness prevail while the patient starts to doubt whether life is worthwhile. These symptoms form what is called the "algogenous psychosyndrome". The intensity of pain experiences on the one hand, and the extent of depressive malfunction on the other hand, seem complementary and tend to magnify each other (Schmidt & Struppler, 1982, p. 23). It is not clear whether the depression is the cause or the result of the chronic pain. However, this question seems superfluous, because a therapy directed at the neurotransmitter level – such as treatment with tryptophan which promotes the presynaptical production of serotonine, and treatment with tricyclical anti-depressives which prevent the decomposition of this substance – may have positive effects on both states. Terenius (1979) came to a similar view on the genesis of pain and depression through his studies in the field of neurophysiology.

In chronic pain, the actual experience of pain frequently becomes clearly detached from the original or permanently underlying physical cause of disablement. Pain then becomes the major cause of disablement. Moreover: "... through pain we experience the rupture of the most natural of all unities, namely the unity of our mental and of our physical being" (Buytendijk, 1948). Or, as Metz expresses it: "Chronic pain is a mode of being in which the body becomes the center of one's life-world." (Vrancken, see article p. ...).

As there is often no distinction in clinical practice between acute and chronic pain, severely crippling pain syndromes often remain untreated for years if the diagnostic tests do not produce a clear result. However, the simple criterium of half a year for distinguishing between acute and chronic pain is not enough evidence to determine the chronicity of pain. Gerbershagen (1986) proposed different stages of chronicity incorporating various factors involved in the chronification of pain and an assessment of therapy resistance and prognosis. This is described in *Table 1.*

TABLE 1. STAGES OF PAIN ACCORDING TO THE STATE OF CHRONICITY

Stage I	Acute-subacute pain without predictable complicating factors or with few such factors. Treatment: monodisciplinary or possibly interdisciplinary (2-3 specialities, e.g. anesthesia, neurology, orthopedics); usually manageable.
Stage II	Non-acute persistent pain with complicating factors, multiple pain syndrome involving various identifiable localizations with different quality and intensity of pain. Repeated change of doctor, frequent unspecified consultations of medical specialists, hospitalization due to pain and surgery, possible drug abuse and drug dependency, moderate psychosomatic and/or personality problems. Treatment: long-term interdisciplinary medical and psychosomatic therapy.
Stage III	Persistent pain, often not clearly localized and spreading to distant parts of the body; multiple pain syndrome with identical quality and intensity of pain. Frequent change of doctor, frequent hospitalization due to pain and surgery, drug abuse over many years, polytoxicomania, marked psychosomatic and/or personality disorders, therapy resistant depression, marked unchangeable psychosocial and environmental factors, marked multimorbidity. Treatment: monodisciplinary or possibly interdisciplinary.

Abbreviated description of stages according to Gerbershagen, 1986.

Certain symptoms may be attributed primarily to stage II, e.g. the early postherpetic and diabetic neuropathies and the Sudeck syndrome. Typical of stage III are manifest postherpetic, alcohol-induced and diabetic neuropathies, and the thalamic pain syndrome.

When isolating a few chronic pain syndromes, it can be noticed that the concept of chronicity has a very different meaning in the various pain contexts. The *postherpetic neuralgia*, for instance, is a severe chronic pain occurring when herpes zoster has not been treated adequately at the acute stage. If several months have elapsed following the occurrence, the pain becomes resistant to the therapeutic means presently available, i.e. it is chronic. *Migraine* and other types of recurrent headaches can also be considered as chronic pain, even if the fits can be alleviated by early medication. Likewise, the term "chronic pain" is used in conjunction with iatrogenic headaches occurring after abuse of analgesics, particularly combination drugs. After successful withdrawal, these headaches often disappear completely. Tension headaches are also regarded as chronic until their individual etiology has been discovered or an effective means of prevention has been found, e.g. through stress or conflict management.

Pain is a persistent companion of *rheumatic diseases* and, likewise, chronic and deteriorating. It is treated in the framework of rheumatic therapy as an accompanying symptom. Symptomatic antirheumatic drugs have a soothing effect on pain and swellings and therefore improve movement and performance. Their capacity to inhibit inflammation and relieve pain is limited to the duration of the treatment.

Similar ideas apply to tumor pain. Even severe tumor pain — which occurs more frequently in late stages than in early stages of cancer (Foley, 1979) — can be reduced completely or at least to tolerable levels when treated adequately, e.g. by the application of opioids peridurally or orally on a time-schedule (WHO, 1986). Pain in late tumor stages can be considered chronic even when persisting less than half a year, because the underlying illness is deteriorating and the pain has to be treated palliatively in a permanent way. In this context the question remains whether the patient, in case of successful pain relief, would still see himself as a pain patient since he continues to be under medication. On the other hand, many patients succeed in repressing pain without the use of drugs, e.g. by concentrating strongly on something else or by using hypnotic dissociative techniques.

Pain is a very personal experience and is not accessible to the treating doctor but only to the patient himself. When there is no evidence detectable medically — which is typical for headaches or unspecific facial aches and is often the case for backaches persisting in spite of various therapies, particularly after surgery — chronic pain is often denigrated by the term "psychogenous", in the sense of a residual category. This dichotomization of "somatogenous vs. psychogenous" can no longer be sustained as we know that *any pain*, in particular chronic pain, *has a* *strong mental and psychosocial component.* Persisting pain, particularly pain that has been treated repeatedly without success, results for many patients in severe mental disorders, hopelessness, depressive indigestion, feelings of bitterness and resignation, amplifying in turn the pain and perpetuating it.

States of pain chronify as a result of psychological and social reasons. Following an accident, for instance, pain may persist because of avoidance behavior due to fear and overtension. When attention is directed towards pain, it may become worse and exclude healthful activities; it may also persist after a lesion has healed if the patient has acquired secondary gains from the illnesss; and pain may remain vivid for a long time as a conversion syndrome, e.g. in the sense of hysteric pain, to help avoid psychological and lifestyle-oriented changes.

A psychological theoretical model on the chronification of pain originates from the "operant" approach of the learning theory (Fordyce, 1974, see p. 124). This approach assumes that pain is frequently prompted by repeated positive responses. Sympathetic reactions of the social environment and the desire to avoid unpleasant activities or situations lead to the pain being maintained for a long time. As the outcome of a social learning process, chronic pain originates when people are not able to obtain the desired social attention or other important gratifications by actions which are not self-destructive. This is particularly important with respect to the learning experiences of children.

In drawing a line between acute and chronic pain, frequently acute pain is viewed as symptomatic while chronic pain is regarded as an illness of its own. This view is useful to point out, first, that chronic pain will generally not fade away by itself and, second, that it must be assessed by careful diagnosis and therapeutic means. This is particularly necessary in cases where no somatic evidence can be found or where the evidence does not match the degree of disablement associated with the pain. However, treating such pain as an illness, in the medical sense, misses the real problem if the conditions leading to chronification originate in the psychological and social environment of the patient. Somatically oriented physicians are seldom able to ask, in a broad context, what causes the pain of the patient. On closer inspection, it appears that many people suffering from chronic pain have encountered some block in the progression of their lives. The pain demands constantly: "Change something!". For Bresler (1979, p. 68-70) "pain may be a warning about other serious problems in your life ... although many of us see pain as an enemy to be conquered, other societies recognize it as a friend that warns you when something is wrong." (See also Bresler's article, p. 139). Beck (1981), too, shows impressively in his book on "Illness as a process of self-healing", that the body uses illness (and how it does it) to mobilize the powers of self-healing.

The heterogeneity states of chronic pain with respect to their etiology, their onset, their responsiveness to therapy and the degree of stress experienced by the patient, makes a comprehensive assessment of chronic pain very difficult.

Therefore, we urgently need improved research — which would be relevant both to prevention and therapy — on the causes of chronic pain. Concepts of etiology which stress typologies of personality, such as the "pain-prone patient" (Engel, 1959), have to be complemented by more practical concepts which are tracing the relevant factors at the somatic, mental and social levels. Longitudinal studies are indispensable in order to compare long pain careers in "pain families" with normal development processes ("health careers").

3. Frequency of chronic pain and the role of lifestyle factors

Acccording to various estimates, nearly one third of the population in industrialized countries suffers from chronic pain. Roughly one half to two-thirds are unable to work for a few days, weeks or months per year (Bonica & Black, 1974). In a report from the National Institute of Health (1979), the costs to the economy of the United States due to pain alone are estimated at 40 to 50 billion dollars per year. More recent estimates give a total of 70 billion dollars per year, if costs for medical treatment, lost working-days and pension are included (Milz, 1985, p. 65). The Nuprin Pain Report (Taylor & Curran, 1985) — the first representative census on the occurrence of pain in the US population — indicates that 4 billion life-days are spent in pain, which means that, on the average, an adult US citizen is disabled by pain in his normal daily life 23 days per year. For all US citizens in full employment, lost working-days total 550 million per year.

3.1 Some indications on frequency and severity

Chronic back pain is not a life threatening disease, but it represents a heavy burden on sufferers and their families, often leading to early pensioning. Back pain is a frequent cause of forced physical inactivity. In many cases it leads to permanent disablement: only 50% of all patients suffering from back pain for more than six months return to work eventually. In the Federal Republic of Germany, no epidemiological studies are available at present. However, in 1981, the statistics of the General Local Health Insurance (AOK) showed 700,000 cases of painful vertebrae syndromes leading to a loss of 13 million working-days per year.

In the case of *rheumatic diseases*, pain is also a predominant and recurring symptom. Half of the 1.2 million polyarthritis patients in the Federal Republic of Germany suffer permanently from severe pain; 37% consider their pain as moderate (Schade, 1987; Raspe & Zeidler, 1982). In the US, 51% of adults suffer from joint pain, occasionally or frequently, and 19% of these suffer more than 100 days per year (Taylor & Curran, 1985); this concerns mostly patients aged 65 and over.

Headaches are the most widespread ailment in modern industrialized countries (Heyck, 1975). Soyka (1984) reports on a study in the canton of Zurich (Angst & Tobler-Mikula, 1983), showing over one year a prevalence of 59% for men and 77% for women, i.e. 68% for both sexes; 23% of the males and 44% of the females had suffered from headaches at least once a month during the entire year preceding the study. Unlike other types of pain, headaches are most prevalent among young people and become less frequent with growing age: 85% of 18 to 24 years old US citizens report suffering from one or several types of headaches in the course of the preceding year, compared to 50% of those aged 65 and over (Taylor & Curran, 1985).

Cancer pain. While detailed morbidity and mortality statistics exist, there are no reliable data on the frequency and intensity of tumor pain in relation to the type and stage of the cancer. Between 55 and 85% of all cancer patients are said to suffer from pain in the more advanced stages of the disease (Wagner, 1984). The difference in estimates results from the fact that many statistics do not specify the type of, or stage, of the cancer. Leukemia is rarely painful while bone metastases very often cause severe pain (Foley, 1979; Twycross & Fairfield, 1982). Such figures are obtained almost exclusively from British hospices, i.e. institutions dedicated to the comprehensive care of terminal cancer patients. In the Federal Republic of Germany, there is still a widespread lack of knowledge about cancer pain in the primary care units. Even general practitioners familiar with the problem do not know how to deal with it.

Chronic pain. A figure of 3 million chronic pain patients is often reported for the Federal Republic of Germany. This figure can be regarded as a realistic estimate if limited to types of pain needing treatment.

In a 1984 study carried out in the Federal Republic of Germany, it was found that 10 to 12% of the patients of general practitioners, internists and neurologists are chronic pain patients; the figure for orthopedists is 31% (Zimmermann & Seemann, 1986). A US study (Margolis et al, 1984) reports 13% of all patients of internists to be chronic pain patients. A Danish study (Tammisto et al, 1983) indicates that 22% of the outpatients of a health care center need treatment for pain; 4% of all patients are extensive users of therapies and half of them can be considered as problem pain patients; the study, however, does not distinguish between acute and chronic pain. The Department of Health in Finland (Tammisto et al, 1983) gives a figure of 2% of all patients of general practitioners as problem pain patients suffering from therapy resistant pain.

If we consider that approximately 25 million patients consult general practitioners yearly in the Federal Republic of

TABLE 2. CHRONIC PAIN PATIENTS IN THE FEDERAL REPUBLIC OF GERMANY
FIGURES PER ANNUM ESTIMATED ON THE BASIS OF QUESTIONNAIRES

Total number of patients of GPs	Patients suffering from chronic pain	Problem pain patients
25 million 100% GPs	3 million ca 12% GPs, specialists	ca 400,000 ca 1.5% pain therapy centers

Germany, these percentages give us a figure of about three million chronic pain patients, of whom there are about 375,000 to 500,000 problem cases (see *Table 2*). This figure matches those 10 to 11% of chronic pain patients mentioned above by general practitioners, internists and neurologists, who would like to refer them to special pain therapy centers according to our 1984 study (Zimmermann & Seemann, 1984).

Pain patients are considered as problem cases when they have already had a long "career" as a patient and if their pain has a strong psychological component.

The data of a practice concerned mainly with pain therapy showed that an unselected sample of patients (910 males, 1549 females) had already been treated for pain for an average of 7.3 years when they came for the first time to the practice. Other pain therapy centers for outpatients also report that their patients have had treatment for about ten years and have consulted, on average, 11 different doctors during that time. It should be noted that roughly 70% of these patients are in an age group fit for work. Obviously there is a group of severe pain patients needing long-term intensive and interdisciplinary treatment because the pain has become chronic since a long time. In comparison with the total number of patients, however, this is a relatively small group of about 1.5%.

We cannot determine the kind of therapies that have been tried for these types of pain, which therapies have helped or failed to help, what factors could have led to therapy resistance and chronicity, nor which people belong to the group of problem patients and what their social conditions are.

The figures concerning the consumption of analgesics demonstrate the extent of pain therapy with drugs. According to data from the German Federal Association of the Pharmaceutical Industry, the turnover for analgesics in 1982 was DM 373.5 million. In recent years consumption of analgesics has remained fairly constant.

According to the April 1980 microcensus, about 9.5% of the population takes medicine for pain and sleep disorders regularly, and 13.5% occasionally. With growing age, consumption increases for males as well as for females.

The use of *anti-rheumatics,* which have in some cases analgesic effects and are taken frequently only for pain relief, is documented by data of the German Federal Bureau of Statistic showing that the female population affected is about 50% higher than the male population, and that drug consumption increases dramatically with growing age.

Self-administration of sleeping pills and analgesic drugs is widespread. In a study of 50 households in the Federal Republic of Germany, by Illy and Jork (1983), more than a quarter of the drugs in the family medicine-chest were self-administered. The most frequent indications for self-therapy are listed in *Table 3*.

TABLE 3. INDICATIONS REGARDING THE SELF-ADMINISTRATION OF DRUGS PERCENTAGES OF INTERVIEWEES TAKING DRUGS

Indications	%
Joint pain	23
Other pain syndromes	15.5
Sleep disorders and psychological problems	9
Constipation	9
General ailments	6.5

Source: Illy & Jork (1983)

In view of the high degree of self-medication for pain, a reliable statement on the occurrence and severity of pain among the general population cannot be derived from the number and type of medical prescriptions.

A socio-economic analysis of the pain problem in the Federal Republic of Germany would necessitate a definition and classification of syndromes by diagnostic identifiers according to the *International Classification of Diseases* (WHO 1977), where pain is a central symptom of illness in the subjective view of the sufferer. Those types of pain which constitute an illness in their own right should be included in the classification in their own category. Then, it would be possible for the General Local Health Insurance, for instance, to register all sick-days and subdivide them according to pain-related disablements.

3.2 The Nuprin Pain Report: what is the relevance of lifestyles?

If figures on pain-related disablement were available, they would provide a rough estimate of the size of the problem from a medical point of view, but they would not enable us to say in which way people suffering from chronic pain are incapacitated in their daily life and in their mental well-being. One step in this direction is the recently published Nuprin Pain Report (Taylor & Curran, 1985). In a representative study, this report examines not only the usual questions about prevalence of pain (type, frequency, severity), but also the social and economic side-effects of pain through demographic profiles. It investigates the extent of use and non-use of medical and other professionals in the treatment of pain, the relation between pain and stress and between pain and the "health locus of control", as well as some relevant lifestyle factors such as life and work satisfaction, alcohol consumption, smoking, sleeping habits, leisure habits etc. Such social epidemiological data may give clues about the social groups needing preventive action and health promotion measures.

The report states,for instance, that young people suffer from pain more frequently than older people. This applies to all types of pain except joint pain, which increases dramatically with growing age. Women suffer from headaches much more often than men, while all other types of pain show only a slightly increased frequency for women. White women suffer clearly less from menstrual pain compared to women from other ethnological backgrounds. Financial status or income respectively do not seem to be related in any way to pain. Rather clearly, however, the family history is related to pain, i.e. the occurrence of pain in succeeding generations.

In many cases there is a clear relationship between pain and lifestyle, e.g. people playing sports for three or more days a week, non-smokers, people drinking moderately and spending little or no time watching TV have less pain than the opposite group. Joggers tend to have more muscle pain (and women more menstrual pain) than non-joggers but they suffer less from back pain and joint pain. Smokers suffer from stomach pain more frequently and more severely than nonsmokers. Those consuming alcohol show an increased prevalence, the intensity of pain and alcohol consumption increasing in proportion; in particular, headaches and stomach aches are more common among drinkers. People who spend a lot of time watching TV display a higher occurrence of pain than those who do not. In all these instances, it is difficult to determine what is the cause and what is the effect. On the whole there is no difference concerning the health behavior of people suffering from pain and the population in general. When pain increases, however, there is a tendency for all sufferers to move less, for smokers to smoke more, and for those consuming alcohol to increase consumption.

Concerning the disabling effect on day-to-day activities and on fitness for work, it would seem that those in low income groups and with poor education feel most disabled, as well as women and persons who experience a lot of daily life stress. On the other hand, individuals who feel responsible for their health, i.e. with an internal locus of control (and also protestants rather than catholics) are less inclined to let pain interfere with their daily life and their work. Back pain accounts by far for the largest number of lost working-days, followed by joint pain, headaches and muscle aches. It is of interest to note that those working full-time lose less working-days because of illness than part-time workers.

There is a clear relationship between pain and stress, not only with respect to direct stressors and frequently occurring stress events in the sense of "life events", but also with respect to the hassles scale which registers "irritating, frustrating and distressing demands that to some degree characterize everyday transactions with the environment". The obvious interconnexion between the degrees of stress and the pain intensity is particularly significant. A striking finding emerging from the research concerns stock traders who are exposed to an above average degree of stress, yet who score very low on the hassles scale and have a very low prevalence of pain; this points to an extraordinary capacity for coping with stress. With reference to these results, Sternbach (1986) points out that hassles might possibly have a better prediction value than unspecific stress and major life events. A study by DeLongis, Folkman and Lazarus (1988) indicates that hassles are more strongly associated with somatic health than life events.

The subjective interpretations of the cause of pain have a remarkable feature. Stress is presumed to be the most important cause by 48% of those suffering from headaches, while two-thirds think stress is partly responsible for their pain; 14% of those suffering from headaches think it is related to work. In contrast, back pain is presumed to have somatic causes in most cases (accidents, lesions).

One-third of those suffering from frequent muscle pain attribute this to overtaxing themselves. Nearly half of those suffering from stomach pain blame unhealthy eating; 35% identify stress as the cause (of which 10% mention work-related stress) and 33% think stress is *the* most important pain trigger. Stress is also seen as a major cause by one-third of women suffering from menstrual pain. The weather is reported as influencing pain by 46% of those who suffer from joint pain and also by 30% of patients with headaches. Muscle and back pain also seem to be related to the weather to a certain degree.

It would be desirable to replicate the Nuprin Pain Report in other countries with respect to methodology and contents. In the Federal Republic of Germany, for example, no such socio-epidemiological data exist.

In particular, we do not know what impact a long-lasting or even life-accompanying pain may have on the person concerned. Neither do we know how it affects his or her mental and social life, to what degree it disables the person, what kind of coping strategies are used and to what degree they are successful or sometimes, destructive.

Epidemiological cross-sectional studies are not very helpful. We need carefully planned longitudinal studies based on a socio-ecological model of pain genesis. The Oldenburg longitudinal study on rehabilitation after a heart attack (Badura et al, 1986) provides a very good model (see article p. 54). Such studies should include mental conflicts, stress coping strategies and variables regarding the personal locus of control. There are some indications that the microsocial life context (structure of the household, social contacts, family cohesion) is more explicative than macrosocial categories (Grünow et al, 1984; Breitkopf & Grünow-Lutter, see article p. 198).

4. The situation of patients with chronic pain in the health care system: professional and institutional aspects

The Nuprin Pain Report states that 88% of those suffering from pain more than occasionally, and all of those suffering from severe pain, make use of the facilities provided by the health care system. As the health insurance system in the Federal Republic of Germany facilitates access to medical resources and since the view is widespread that chronic pain has to be treated by doctors, one may assume that reliance on medical care is similarly extensive in this country.

4.1. Pain analysis

The first and usual resort for a pain patient is his general practitioner or possibly certain specialists like the neurologist in the case of headaches, the orthopedist for back and joint pain, or the internist for stomach pain. These in turn will refer the patient to other specialists. (The Nuprin Pain Report states that only 3% of chronic pain patients consult a pain specialist, 3% a nutrition specialist and 2% a spiritual healer.)

Owing to the perception of his own role as well as to a lack of knowledge and resources, the physician working by himself is seldom in a position to decipher the individually determined and complex pain experience of his patient. Chronic pain often transgresses the borders of any medical specialty and from the very beginning, it should be dealt with, at the somatic level, from the point of view of several medical disciplines (Zimmermann & Seemann, 1986).

4.1.1. Towards an interdisciplinary approach

Among pain specialists there is a growing consensus, due to increasing experience with severe chronic pain, that an interdisciplinary diagnosis established through group consultation is more likely to provide an effective solution than the assessment made by single physicians, even if several specialists are consulted successively (Flöter, see article p. 277). The composition of these interdisiciplinary pain consultations varies according to the problem involved: the group may include anesthesists, neurologists, psychologists, orthopedists, general practitioners, internists, throat-nose-ear specialists, etc. who try to reach together an understanding of the complex pain state, in cooperation with the pain patient.

All who are concerned with chronic pain regularly insist on the fact that pain is basically a perception transmitted by the central nervous system and consists of sensory as well as affective-reactive components, which are determined by somatic, psychological and social conditions. Yet, the organic view of pain usually prevails in the inter-disciplinary pain anamnesis and diagnosis, even in the presence of psychiatrists and psychologists. The patient is asked questions to that effect,and is also expected to gear his answers in that direction. In the case of a successful medical anamnesis, i.e. if the state of the patient, supported by medical evidence, matches with a known and defined pain syndrome, the case is closed and the usual procedure, including the choice of therapy, will be on its way. The patient, as a person, is interesting only as a carrier of information for the nosological classification.

Apart from a few exceptions, there is a consensus about the taboo of referring to mental or social circumstances within the context of a pain consultation. Mental aspects are discussed only when somatic evidence is missing or cannot be clearly defined, but this does not happen before the patient has left the conference room. Then it may be decided to ask the treating physician to arrange for a psychotherapeutic treatment of the patient.

This procedure has been justified by the assumption that many pain patients have a purely somatic view of illness with respect to their pain and that they might react in a rejecting or even aggressive way at any hint of a possible psychogenesis of their pain. This is obviously a misunderstanding on both sides. Doctors should realize that they have educated their patients in such a way as to exclusively present somatic symptoms. There are already enough patients who will never talk to a doctor about the subjective part of their illness or their suffering, but rather adapt with remarkable flexibility to the medical language, since this is what the doctors expect.

Doctors who often see pain patients know very well that the experience of pain and its individual intensity and stress are always deeply influenced by psychological and social factors, but quite frequently they are unable to talk with the patient in such a manner that the patient does not have the feeling that he is a simulator or a neurotic. The patient should be encouraged to express his pain in a holistic way – in the same way he experiences it – and he should be made aware that it is important, for the diagnosis, to indicate the degree to which his integrity as a person, his attitude towards life and his sense of fulfilment in social life are impaired. If a physician does not feel in a position to conduct a pain-centered social and psychological anamnesis because of his somatically orientated training, he should involve a psychologist from the start, as team work is preferable to separate and successive explorations. This enables the patient to learn about the interaction and mutual influence of somatic, mental and social factors, thus avoiding the dreaded labelling of "psychiatric patient". The physician himself, who had hitherto restricted the doctor-patient interaction to the discussion of somatic (and thus partial) factors must now not only allow the patient to discuss his pain in the context of his entire mental and social background but also teach him to do so. However, doctors may have to learn such a holistic perspective themselves in the first place.

4.1.2 Pain anamneses questionnaires facilitate a holistic view

In order to facilitate this task for doctors, standardized pain anamneses in the form of questionnaires have been introduced recently, and are now coming into widespread use by pain specialists. Apart from a few questions on general anamnesis and the preceding pain history, they concentrate on the present state of pain: intensity, frequency and duration of occurrence, day cycles, and topography of pain in a schematic representation of the body. They also ask the patient to describe the properties of the pain through adjectives like "burning", "cutting", "knocking", "drilling", etc. as well as adjectives showing the affective stress resulting from the pain ("torturing", "threatening", "fearful", "nerve racking", "cruel" etc.). This pain anamnesis also investigates the patient's mood (depression, fear), impairment of daily activities and stress as well as the patient's own opinion about the cause(s) of the pain, how it becomes worse or may be relieved, what kind of coping strategies he uses and which thoughts frighten him most in the context of the pain.

All the questions of the anamnesis are related to the subjective view of the patient about his pain.

Such questionnaires are now routinely used by institutions specializing in pain therapy. They are sent to the patients who have to return them by post before the first consultation. This has three advantages: the physician can draw information from the anamnesis before his first talk with the patient and decide in advance which points need further exploration; both the patient and the physician refer to a similar structure for the description of the pain state; and finally, the patient has been made aware that his own subjective views and the mental and social problems connected with the pain are important.

Our experience with pain anamneses strengthens the view that chronic pain patients do not see their state as exclusively somatogenous. The intepretation of 440 anamneses of outpatients attending two practices specialized in pain treatment indicates that more than a quarter of the patients consider mental factors to be the major cause of their pain, or to play a role in triggering or worsening their pain, and 30% use mental coping strategies, e.g. relaxation, focusing attention and avoidance of stress (Flöter, Jungck & Seemann, 1988).

A pain anamnesis centered on the subjective view of the patient is an important part of the analysis of the problem of "chronic pain" but it does not replace the traditional medical diagnosis and comes in addition. It is of importance to explore, in the private consultation as well as in the interdisciplinary group consultation, as many different aspects of the pain as possible and to have them discussed by physicians and psychologists with the participation of the patient. Everyone can then learn from the specific point of view of the others. One problem with this procedure which takes a lot of time – two to three hours altogether – is that it is not covered by health insurance.

4.1.3. A socio-psychosomatic view of chronic pain is needed

At present, we are far from a general system theory model of chronic pain which would throw light on interactions between the somatic, the mental and the spiritual levels and take into consideration the social and ecological conditions of the environment as well.

The various disciplines which have done increasing research on pain over the past ten years have come up with a wealth of results in neurophysiology, in psychology and in clinical medicine which give important clues to the various factors which may be involved in particular pain states, or which should be taken into consideration. It should not be forgotten, though, that traditional scientific research methodology is based on a reduction of complexity by selecting variables and interrelating them. This point of departure results in predictions of probability which may not be appropriate for an individual case. Therefore, it is of great importance that physicians, patients and everyone else concerned should realize that for a real understanding of the problem – i.e. why a certain person has a certain type of chronic pain at a certain moment of his or her life – it may be necessary to move away from a quantifying analysis towards a holistic approach, i.e. towards a hermeneutic, interpretative approach.

However, when it comes to symptoms of illness, including pain, few people have learned to ask themselves: "why?", with reference to their life context, and instead, they delegate the question to the physician, thus reducing it to the biomedical domain. On the other hand, if a patient turns to the psychologist to ask "why?", then the answer usually focuses on the mental side of the problem.

Only few doctors and psychologists concerned with pain therapy hold a psychosomatic view of chronic pain, which implies the possibility that mental influences may lead to dramatic functional and structural changes in the body, or that physical illness may contribute or lead to severe mental disorders. Unfortunately, this view often remains on a theoretical level.

Many patients are aware that chronic headaches are often due to stress and that severe or permanent muscle tension may cause pain. However, they are not able to recognize the situations causing stress or tension, to ask why these situations are stressful, and to find ways to cope with them before they can induce pain. Some people's perception is strongly oriented towards exterior events and they have little insight about aspects of their inner self such as feelings of anger, mourning, joy or fear, nor do they understand the vegetative reactions and the posture and muscle tensions associated with such feelings. I believe, for my part, that chronic pain is a loud cry of the body asking for help, when more subtle signals have failed.

What we need is a socio-psychosomatic view of chronic pain, not only for professional pain therapists, but also – and one should even say especially – for the patients to help them towards self-understanding. From the perspective of health promotion, the quality of the medical and psychological pain analysis, anamnesis and diagnosis has to be judged in relation to two questions: (a) does it include all relevant aspects, and (b) to what extent does it help the patient to reach an understanding of his pain problem on all levels?

In order to improve the judgment and awareness of the patient and his "expert status", it would be necessary to conduct studies on "subjective theories" about people suffering from chronic pain, similar to the study about cancer patients carried out by Verres (1986), who probed into the subjective hypotheses of those concerned and their relatives with regard to the causes, implications and consequences of their disease.

4.2. Pain therapy

This section will review two aspects of pain treatment: (a) the medical approach and (b the relatively new field of psychological pain therapy within the context of conditions that prevail in the Federal Republic of Germany.

4.2.1 Medical treatment

Roughly 90% of the estimated three million patients who suffer from chronic pain (cf. section 3) are cared for by general practitioners and internists with additional consultations from other specialists, mainly orthopedists and neurologists. On average, general practitioners are consulted once a week by each of their pain patients.

With respect to chronic pain, it is often difficult to decide which therapy is suitable for which syndrome at which stage. Oncologists for instance, but also general practitioners with tumor patients in the late stages, do not seem sufficiently informed about the fact that severe tumor pain may be alleviated by giving opioids orally according to a time schedule (WHO, 1986). Writing out prescriptions for analgesics (very often a combination of drugs) is quite common in the case of neuralgias and headaches; unfortunately, this is also the case with other types of pain. Practitioners do not have sufficient information on methods of pain treatment nor do they know how to locate pain specialists to whom they could turn for advice. Therefore, long lasting pain problems are often laid aside and ignored. Patients may react by becoming resigned or aggressive, and they change doctors frequently. There is a danger, which should not be underestimated, of pain patients running through a whole series of pain therapies successively, just to try them out. This may increase therapy resistance and lead to chronicity.

Most patients coming to a specialized institution for pain therapy suffer from pain which is in an advanced state of chronicity and for which several treatments have already failed. Basically, pain therapy approaches these problem (therapy resistant) cases with a wide range of methodological measures. Nevertheless, the therapist has to warn these patients that even in case of a successful reduction of pain, a complete and permanent remission can seldom be obtained.

Roughly, 300,000 to 400,000 patients in the Federal Republic of Germany are considered problem cases. General practitioners refer them to pain therapy units when such units are available nearby, which is far from being always the case. (Zimmermann & Seemann, 1986).

As doctors and especially patients greatly lack information on the existence of pain therapy units, we have collected data for a pain therapy guide in the Federal Republic of Germany (Seemann et al, 1987), listing 124 medical and 28 psychological units. Among the medical units, 93 are headed by an anesthesist and 16 by a neurologist; 74 units are organized as outpatient clinics; finally, there are 40 practices of pain therapy, of which 10 are pain clinics dedicated exclusively to the treatment of chronic pain patients and providing care for inpatients.

There is a consensus that 90 to 95% of the chronic pain patients needing multi-factorial treatment should be cared for as outpatients and close to their homes. Considering the fact that a pain therapy unit can take care of a maximum of about 400 patients a year, about 1000 such units are needed in the Federal Republic of Germany, particularly in rural areas.

The information contained in the pain therapy guide is provided by reproduction of the original questionnaires filled out by the pain therapy units. They show the address of the unit, the consulting physician, his specialty, opening hours and waiting times, and therapy methods used by the unit (see *Table 4*).

In 11 of the 74 outpatient clinics, psychologists work as external consultants or, more rarely, as permanent staff members. Psychotherapy is used by physicians in a further 10 clinics; in most cases they concentrate on relaxation methods, less frequently hypnosis is used. Among the 28 pain practices, eight work with psychologists, and 10 offer psychotherapy treatment based on their own programs of continued education. As medical students have very little opportunity to acquire knowledge about pain therapy methods, continued education is most important for developing knowledge in this area after completion of studies.

Table 4 shows that all units use extensively the "classical" somatic pain therapy methods, i.e. drugs, local and conduction anesthesia, lumbar opiate applications, physical therapy and neurolytic nerve blocks. It also shows a widespread availability of a range of "alternative" methods, mainly transcutaneous electrical nerve stimulation (TENS), which is well established by now (and covered by the health insurances), and acupuncture which

TABLE 4. THERAPY OFFERED BY OUTPATIENT PAIN CLINICS AND PAIN PRACTICES
PERCENTAGE OF UNITS OFFERING THE METHODS LISTED

	Pain clinics N = 74	Pain practices N = 40
Drugs	100%	100%
Local and conduction anesthesia	99%	100%
TENS (Transcutaneous Electrical Nerve Stimulation)	95%	70%
Lumbar peripheral opiate applications	88%	44%
Physical therapy	72%	72%
Neurolytic nerve blocks	72%	47%
Acupuncture	62%	75%
Implantations (pumps, stimulators etc.)	46%	8%
Minor psychotherapy	45%	68%
Withdrawal treatment	43%	70%
Relaxation methods	34%	52%
Surgical methods	31%	12%
Manipulative therapy	30%	42%
Biofeedback	22%	37%
Laser	19%	42%
Behavior therapy	14%	20%
Hypnosis	14%	25%
Body-oriented psychotherapy methods	10%	12%
Central stimulation	7%	2%

Source: Seeman et al (1987)

has been accepted as standard treatment for headaches (Fischer, 1985). Biofeedback is applied by the physicians themselves, while relaxation methods, behavioral therapy, hypnosis and body-oriented psychotherapy require the cooperation of psychologists.

The frequency of application of these alternative therapies is certainly not overwhelming, partly because they have to be paid for by the patients themselves. However, their frequent mention by the pain therapy units allows the conclusion that these forms of therapy are found useful and that pain therapists try to acquire additional knowledge about them. We do not know if other methods (not recognized by official medical circles) are applied in the Federal Republic of Germany, such as air ionisation (Inglis & West, 1984), osteopathy which seems to be widespread in the USA (Inglis, 1978) or spiritual healing by the imposition of hands, which is considered a standard method of therapy at the Bristol Cancer Help Centre in Great Britain (M. Wetzler, 1987, personal communication). A relatively new way to exert a positive influence on pain and depression by a suitable diet in combination with L-tryptophan is beginning to be accepted by pain therapists (Flöter, 1985; Seltzer, Marcus & Stoch, 1981; Kolata, 1982).

It seems to me that the distinction between "classical" and "alternative" methods is not justified in pain therapy. (This of course does not concern pain therapy in homeopathy and anthroposophical medicine as it is based on very different theoretical and existential philosophical assumptions, which may be regarded as alternative in their own way.) This is to say that pain therapy is very often purely empirical, because we lack an adequate understanding of the causes and mechanisms of many types of pain ... "First, we have no, or only vague notions regarding how and why many types of chronic pain originate. Second, frequently we do not have a clue why one kind of treatment works and another does not. And third, despite our ignorance we are still able to offer the patient an effective treatment in most cases of chronic pain." (Schmidt & Struppler, 1982, p. 39). (This presupposes, however, a comprehensive analysis of pain, otherwise the choice of therapy would remain probatory.) As the mechanisms of pain genesis, in particular those of chronic pain, cannot be identified in many cases, pain therapists generally take a whole series of measures directed towards different influences in order to improve the chances of success.

One approach to holistic treatment is the schematic classification used by Herget (1985) and Vogelsberger (1987, personal communication). This includes a basic therapy, e.g. symbiotic directives, fasting, nutrition, application of herbs, which is designed to teach patients to integrate these applications in their daily lives. (For example, if an infusion of St. John's wort is prescribed against depressive irritation, the patient will be required to search for St. John's wort in the fields and learn to identify it.) Regulative therapies, such as climatic therapies, balneotherapy and relaxation may also be applied by the patient himself and integrated in his daily activities. Acupuncture, homeopathy, manipulative and physical forms of therapy have a rather specific approach to the disease being treated, while drug therapy, local anesthesia and TENS may be regarded as symptomatic therapies. Herget calls this therapy design "poly-pragmatic" and complementary in order to stress the complementary nature of the various applications. My suggestion would be to judge therapy methods also in relation to their absence of side effects and their capacity to stimulate the regulative powers of the body.

From the point of view of health promotion, it is of some interest to determine how much cooperation from the patient is accepted or required by the different therapies, apart from the fact that the patient should have an understanding of the mode of action of the therapy and believe in it. This belief also depends on the attitude of the therapist and his interaction with the patient. Neuro-surgical interventions, nerve blocks, analgesics and psycho-drugs, as well as less common medical methods like skin permeating applications (cantharide plasters, Baunscheidt method), just require the acceptance of the patient for their application. Transcutaneous electrical nerve stimulation, however, requires an active understanding and cooperation because it has to be applied regularly and correctly. It may be assumed that a clear reduction of therapy effects over time can be attributed to incorrect or interrupted application. Flöter (1985) was able to show that appropriate and controlled applications maintained the positive effects of therapy.

Physiotherapy and gymnastics are training methods demanding understanding, self-activity and perseverance. This brings up the question, which applies also to relaxation techniques, whether the patient can be taught to think of such daily exercises as a desirable enrichment of his daily life rather than as a tedious duty and an additional burden.

The case of biofeedback shows very clearly to what extent the usefulness and effectiveness of a therapy depends on the way it is applied. Biofeedback is used in pain therapy as a relaxation method in the widest sense (EMG, EEG respiratory and skin resistance biofeedback). The patient learns, usually very quickly, to adapt defined physiological parameters like muscle tension, breathing frequency, electrical brain potentials to a desired value by "feeding back" to himself his present state, i.e. he learns to adjust his body's reactions in a self-regulatory manner. If the patient, however, has not been instructed properly, he may apply the method wrongly and use the apparatus in a purely technical way, i.e. directing his attention towards the auditive signals of the machine, rather than towards the changes taking place in his body. Thus, he misses the opportunity of improving his ability to perceive the signals and the state of his body in a discriminating way. Furthermore, by reducing symptoms like tension headaches in a simple manner, biofeedback possibly prevents the search for the underlying causes, e.g. stress or inadequate conflict coping. Last but not least, the dependency on a technical apparatus should not be underestimated, particularly since biofeedback has not been found superior to other methods of relaxation like the Jacobson training methods or cognitive strategies that do not rely on machines and are thus available at any time (Jessup et al, 1979; Turner & Chapman, 1982; Rehfish, see article p. 279).

I will end this overview by listing some of the obstacles to the development of a comprehensive approach to pain therapy in the medical field in the Federal Republic of Germany:

- there are severe deficits in medical training: diagnosis and therapy of chronic pain are not part of the syllabus of medical schools;

- methods of treatment used by "healers" and paraprofessionals, including homeopathy until recently, are taboo and do not figure in continued education schemes;

- restrictive regulations on specialization impede the development of multi-disciplinary diagnosis and therapy which are needed for chronic pain;

- serious problems result from the fact that the health insurance bodies do not cover costs for certain therapies (e.g. acupuncture, and also extensive counseling talks) which are vital for chronic pain patients; this mainly affects the practicing pain therapists;

- outpatient pain clinics complain about the lack of staff and consultation space as well as the frequent change of doctors.

4.2.2. Psychological pain therapy

In the relatively new field of pain therapy, psychologists have to rely mainly on their own initiative, as the university syllabi do not include this topic. Nevertheless they can fall back on physiology, psychodiagnosis, psychotherapy, psychopathology and clinical psychology and combine this knowledge with pain therapy methods originating from the USA.

Two methods in particular are used: the cognitive, behaviorally-oriented pain coping training (Meichenbaum & Turk, 1976) which teaches coping strategies like stress immunization, attention, diversion and self-instruction; and the operant learning concept of the Fordyce school mentioned earlier (Fordyce, 1974; see also p. 124 in this book) which is mainly intended to remove positive reinforcement of pain behavior, to increase bodily activity (gymnastics and note-taking of "up-time"), and to achieve a gradual withdrawal of drugs. A modified kind of pain coping training is applied mainly in the field of rheumatic pain (Köhler, 1982; Prümel et al, see article p. 221).

In the psychological treatment of migraine specific stress coping techniques have been developed which use relaxation methods like the progressive muscle relaxation technique of Jacobson (1939) or biofeedback training, e.g. the vasoconstrictional biofeedback (Falkenstein, see article p. 223). Both training methods demand a high degree of self-activities and cooperation from the patient, for instance when tracing up individual stress triggers, when migraine diaries have to be kept or when health related activities have to be noted (Miltner et al, 1986). They are thus strongly educational in nature.

Psychological intervention for *chronic pain* tends towards multi-dimensional treatment concepts intervening at different levels of the pain experience. Relaxation techniques, increasingly combined with pain specific imagery techniques or biofeedback, represent one component of such interventions. Other methods used include diversion of attention by hypnosis, focusing and defocusing methods, and alteration of pain behavior and of the emotional state by intervening in three directions, namely: encouraging positive emotions and a positive self-view, promoting self-awareness, and providing support to patients in dealing with disablements, bereavement, guilt, mourning and death.

The development of psychological pain therapy is still at an early stage and it would be desirable to have access to a broad spectrum of therapeutic concepts in this area and to bring together psychologists and psychotherapists working in this field in order to exchange views and experiences. This would be particularly useful as there are still only very few studies on well evaluated therapies. It is my feeling that body-oriented techniques like the Feldenkrais method, the Chinese Chi Gong (a variation of Tai Chi) and hypnotherapeutic techniques like Erickson's hypnotherapy and neurolinguistic programing (NLP) should carry more weight in treatment, but their efficacity needs to be evaluated.

From the point of view of health promotion, psychological pain therapy should be judged on its ability to motivate or rather awaken the patient's own motivations and desire for activity. Techniques to strengthen competence and skills are more suitable in this perspective than techniques concentrating on problem analysis (like psychoanalysis) and are more readily accepted by the patient.

The psychological techniques mostly used at present in pain therapy are shown in Table 5.

Eight units also offer group therapy for pain patients. On average, 4.5 different therapy methods are offered in each unit.

TABLE 5. PSYCHOLOGICAL TECHNIQUES USED IN PAIN THERAPY

Therapy techniques	number of units (n=28)
Behavior therapy (cognitive, multimodal)	21
Pain coping training	6
Operant methods	2
Social skills training	2
Relaxation techniques	21
Autogenous training	4
Communication therapy	13
Hypnotherapy	11
Visualization techniques	2
NLP (neurolinguistic programing)	2
Biofeedback	10
Family therapy	5
Psychodynamic techniques	4
Concentrative gymnastics	2
Gestalt therapy	2

Source: Seemann et al (1987).

To sum up, the following are obstacles which obstruct a positive development of pain therapy in the psychological area in the Federal Republic of Germany:

- current regulations regarding the psychological profession prevent continued education programs from being creative and introducing new therapy concepts;

- only a few psychologists are trained in psychological pain therapy;

- the fact that health insurance bodies only reimburse behavioral therapy means that all the other methods, like hypnosis or Erickson-oriented pain therapy, for instance, have to be covered by the patients themselves; as a result, cooperation between medical pain therapists and psychologists is often limited to that group of patients who can pay for psychotherapeutic treatment themselves;

- the basic element of interdisciplinary cooperation in pain therapy, i.e. the cooperation between doctor and psychologist, is largely impossible due to this situation and not because of a lack of insight or willingness to cooperate.

5. Integrative pain therapy

The following commentaries on the criteria that pain therapy must satisfy in order to be considered "integrative" have been inspired by Lerner's proposals (1985) for an integrative cancer therapy.

- Integrative pain therapy is directed towards the person suffering from pain and not just towards the pain syndrome. Choice of treatment should not be exclusively determined by the indications of diagnosis; it should involve the pain patient and include him in the decision.
Stressing the autonomy of the patient also implies a modified distribution of responsibility: the authority of the doctor may be questioned with regard to the therapy proposed. Even if the belief system of the patient leads to an irrational decision – from the doctor's point of view – the placebo effect should be taken into consideration as it plays an important and positive role in pain therapy, whereas feelings of rejection on the part of the patient may cause nocebo effects. The compliance of the patient, which is of great value for the doctor, should not be limited to mere obedience.

- A holistic pain therapy requires a concept centered on the individual. To paraphrase Sir William Osler (cited by Lerner, 1985): "It is more important to know what kind of patient suffers from pain, than what kind of pain the patient has." Therapy has to be suited to the personality of the patient, especially in the psychotherapy of pain. Therapist and patient should largely agree in their basic attitudes and the methods of therapy selected should be adjusted to the constructs of reality of the patient and start off from existing competencies. To my knowledge, in the Federal Republic of Germany, only Herget (1985) selects pain therapies with a view to the constitutional type of the patient. Some therapies widely used in the Federal Republic of Germany, such as gymnastics or physical therapy, may be regarded as disparaging by individuals from a different cultural background who have a rather passive understanding of healing. For Turkish men, for instance, gymnastic therapy arouses feelings close to derision, especially when instructions are given by female staff, whereas dancing is accepted (G. Blechner, 1986, personal communication).

- Integrative pain therapy can intervene at different levels: at the physical, mental, cognitive, emotional, religious or spiritual levels and must take into account the social and ecological environments. If pain therapy is to encompass a broad methodological spectrum, then it has to cover different levels. It has been found useful to start at the point where the patient stands, i.e. the therapist has to consider what the patient thinks about the pain, what kind of help he expects and what he is willing to accept. Therapeutic help for problem pain patients always implies advice on nutrition, work, recreational behavior, and last but not least on how to deal with pain on a cognitive and emotional level in order to find relief. A comprehensive pain therapy must include the social environment and the personal opinions of the patient on life. In view of the multiple circumstances that may influence chronic pain, medical efforts will be in vain if these points are disregarded.

- There should be fresh thinking about the role to be assigned to alternative methods in an integrative treatment. From a holistic point of view it seems preferable to call these methods complementary and treat them as necessarily complementary to classical therapy (Herget, 1985).

- Treating and healing are different matters (Groddeck, 1913; Bresler, 1979; see also Lerner, p. 84 in this book). The level at which healing takes place may differ from the level at which the therapy has initially been directed. Treatment may be directed palliatively at the symptom, for instance, and relieve pain by the analgesic effect of drugs; but it may also prompt self-regulatory healing powers on the somatic or mental level. There is no way of classifying the different kinds of pain therapy in this regard. We do not know, for instance, what may be the role of consciousness or of the inner attitude and expectations of the patient, nor do we know what influence the physician's attitude may have in this context. If the patient has feelings of fear and rejection vis-à-vis certain therapies or does not believe in their usefulness, the process of healing will be drastically impeded by stress. I think it is important to give a clear idea of the effect a given therapy may have in order to allow the patient to strengthen inner processes in that direction as much as possible. To this effect, imagery techniques and visualization are used explicitly in psychological pain therapy for symptomatic as well as for functional treatment. An example applying to the former case is the dissociation of pain, where pain is catapulted out of consciousness by means of various imagery techniques. For functional treatment, useful techniques include imagery aimed at relieving tension and vegetative disturbances, and trance therapeutic procedures facilitating access to the subconscious and access to deeply rooted conflicts. Whether the form of application of biofeedback, acupuncture or acupressure and of reflex massage techniques will be symptomatic or self-regulatory depends very much on the attitude of the therapist.

- The frequently encountered fatalism of the therapist in the face of severe states of pain, expressed in words like "There is nothing else I can do for you. You just have to live with your pain", evokes resignation and hopelessness in the patient and contributes to further deteriorate his state. The physician should feel obliged to show the patient how he can survive with severe pain. There are some powerful approaches in psychological pain therapy, like biofeedback and auto-suggestive methods,which enable patients to control pain.

- We have to treat the relationship between patient and physician as the most important aspect of integrative pain therapy. Lerner quotes Paracelsus: "The main reason for healing is love". Patients suffering from severe pain often create an atmosphere causing aggression and distancing among those treating them. Very often I have the impression that these patients, as little children do, hide their longing for attention and personal contact by rejection and aggressivity. This rigid mental armor evokes in their environment those very feelings which they fear most. One feature of this behavior — which is a nightmare for doctors — is an ostensible auto-aggressive attitude inviting invasive and destructive measures. In the case of patients suffering from pain for a long time, it is extremely important to meet them in a warmhearted, positive and encouraging manner, to identify those traits of their personality that have remained unscathed, positive and attractive and to strengthen these. "We should be attentive to the patients' qualities and strengths, however hidden they may be. And we should keep in mind that a person's greatest weaknesses may turn out to be his greatest strength." (Vrancken, see article p. 131).

6. The chronic pain patient in his psychosocial environment

There are no studies on how the psychosocial environment of pain patients perceives and copes with persisting or recurring severe pain. A decisive aspect distinguishing pain from other chronic disablements or states of illness is that it cannot be observed directly from outside; furthermore, the behavioral expression of those concerned varies greatly. Whether pain is communicated at all, and if so in which way it is communicated to the social environment (including the professional advisers), depends on many factors. A few examples will be listed below.
Ethnical background. Southerners express pain more often by wailing and moaning than North Americans and northern Europeans (Wolff & Langley, 1975).
In Eastern cultures, e.g. Taiwan, the expression of an emotional disablement is considered unacceptable: 70% of patients coming to a psychiatric university clinic first complained exclusively about physical symptoms (Kleinmann, 1980). This kind of "somatization" can also be observed in western cultures, particularly in lower social classes. Births and painful initiation rites are acute pain experiences tolerated in some social communities without the expression of pain (Schiefenhövel, 1976).

Learning experiences in the family context. In some families (e.g. doctors' families) complaints about physical disablements are not allowed. Parents, especially the mother, serve as models and children take over parental views with respect to the danger and necessary actions following painful experiences.

Specific social context. Pain is more easily accepted as an explanation for withdrawing from certain situations, e.g. social obligations or work, than mental problems.

Personality traits. Introverts are more likely to suppress expressions of pain than extroverts (Weisenberg, 1982).

The age factor. The inability of small children who suffer from a persistent and painful illness to express their pain in a significant way, distinct from general complaints, has led pain researchers and doctors to conclude that children are less sensitive to pain. Reasonable doubts have been expressed about this point of view, for instance by Owens (1984).

Expectations or experiences. Quite a few patients adopt expressions or attitudes of suffering because they expect sympathy from the doctor and persons close to them. Whether these expressions of pain do or do not produce the expected reactions or help influence pain behaviors.

Reimbursement procedures. The widespread notion that persons who have applied for pensions or have a case for insurance and compensation communicate their pain in an exaggerated fashion is obviously incorrect, as shown in a study by Mendelson (1984). (N.B. Pain is not an accepted criterion for pension and insurance compensation.)

Zborowski (1952) points out that the culturally specific acceptance and the interpretation of certain kinds of pain as part of ordinary life, determines whether pain will be regarded as personal "bad luck" or as a disease which has to be treated medically. How the patient deals with his pain will depend on culturally accepted views of life: if pain is experienced as a (god's) punishment then it has to be borne without complaint. Expiation may possibly be sought through prayers or, if the patient is convinced that pain is caused by an "evil eye" or witchcraft, an adequate answer would be an amulet or a ritual ceremony.

In the Federal Republic of Germany and other Western industrial societies we have to assume that pain patients and their social environment see chronic pain as a symptom of disease and, accordingly, will refer the problem to curative medicine. As an unpleasant, disturbing and in some cases disabling symptom it must disappear immediately and entirely, if possible.
This attitude, which has already been characterized as "algophobia" by Buytendijk (1948), causes many people suffering from chronic pain to move constantly from one doctor to the next and to put off any kind of "normal life" until the time they are well again. We can assume that the social environment shares such an attitude and implicitly or explicitly demands a visit to the doctor.
It is far from clear which other interpretations are taken into consideration by the social environment of the patient. We know from psychologists working with pain patients, however, that it may prove difficult to lead the patient away from a specific view of pain as a symptom of disease and prompt him to put pain in a broader context of life. One first step which is easily taken might be to induce the patient to recognize the specific changes of life resulting from a state of pain. It is more difficult for the patient to analyze the meaning of the pain in his personal life, its consequences, the mistakes to which it points and what it wants to express. This inability makes it harder for the patient as well as for his social environment to deal with pain constructively. Persons in close contact react helplessly and push the patient into his sick-role even further. Secondary gains such as relief from unpleasant chores, support in conflict situations, emotional attention from close persons and the uncontrolled administration of analgesics maintain pain or even reinforce it.
One can assume a profound lack of knowledge in the population about chronic pain, about the details of its occurrence and chronification, and about coping strategies. In particular, the fact that something can be done by those concerned (apart from visiting a doctor) is not known and cuts off the very thought of taking action. In my opinion this is the reason why hardly any self-help activities have been established in the field of chronic pain.
A few existing self-help groups, e.g. associations of patients suffering from chronic migraine and rheumatism, constitute a continuation of therapeutic groups with the aim to further develop the pain

coping competencies they learned in group therapy.

In adult education colleges (Volkshochschulen), courses on pain-specific topics are rarely listed in the program. Autogenous training, other relaxation methods and movement therapy methods, e.g. the Feldenkrais or concentrative movement therapy, are not used by pain patients, because they do not know how to apply these techniques for pain relief. The basic problem turns out to be *the information deficit.*

Two important works, *Free yourself from pain* (Bresler, 1979) and *How can I learn to live with pain when it hurts so much?* (R.A. Sternbach, 1977, unpublished manuscript) are directed to patients and offer very concrete information and practical advice. Another useful source of information relating to pain is the alternative health guide from Inglis and West (1984).

Apart from the small circle of pain therapists and psychologists who have studied intensively chronic pain and possible treatments, hardly anyone is able to assess the problem. Furthermore, each single chronic pain syndrome entails its own psychosocial problems, so that the small group of professionals concerned with pain are subdivided in turn in those specializing in rheumatic pain, headaches, backache or tumor pain. These experts on pain are by no means oriented towards an ecological and holistic approach when treating and advising their patients. On the other hand, this growing area of research is so young that it is not yet consolidated and there is hope, therefore, for the emergence of new and guiding concepts.

7. Health promotion and chronic pain: areas for action

Fundamental changes in the outlook of society and of the health care system are indispensable to achieve concrete changes in the attitudes and behavior of pain patients and their social environment, and to enable chronic sufferers to cope effectively.

As there are few concrete developments in the field of health promotion for chronic pain, the following are suggestions regarding concepts and approaches which deserve our attention.

The approach. A positively formulated lifestyle concept needs to be stressed – especially in primary prevention – rather than the risk avoidance approach which has dominated until now. This has implications for the educational role of professionals: instead of warning people against health damaging actions such as smoking, drug overconsumption, excessive watching of television or one-sided nutrition, they should teach people – and demonstrate – how positive concepts of life can be developed.

Rehabilitation. The rehabilitation of chronic pain patients should not be merely, or even predominantly, concerned with performance and fitness for work, although the return to work constitutes a very important step for the patient (Badura & Lehmann, 1987). Other aspects like the ability to build up human relations, and to enjoy recreational activities are of great importance for the quality of life and beneficial to health. As such, these aspects have to receive support from the public health system.

Changes in roles. If pain has become chronic, a change in roles is necessary for the patients and their social environment and for doctors. Patients must relinquish their role as patients and try to integrate illness in their normal life with the support of their social environment. For their part, doctors should no longer consider their role limited to fighting illness but consider themselves as companions and advisers to their patients for coping with difficult life circumstances.

Education of the educators. To enable doctors, psychologists and professional advisers to modify their roles, additional training in advisory functions is required. Nursing staff who work in the medical and health care sectors as well as workers in the social services who are confronted with the practical problems of pain patients should be involved in the continued education of their colleagues alongside physicians and psychologists.

Sources of information and advice. Advice and information on medical and psychological as well as on practical problems should be available close to the place of residence and easily accessible. This implies that advice should also be available in non-crisis situations, e.g. when somebody is just interested in general information on the subject. Furthermore, there is a need for centers of contact and advice to which patients and their relatives may turn with questions and problems. This may be done through telephone services, like the Cancer Information

Service for the Citizen at the Cancer Research Center in Heidelberg, and/or in social institutions which are able to provide social contacts in addition to information and advice.

Self-help. It is important to find adequate forms of self-help for the specific problems of chronic pain. In order to start off meaningful self-help in this area, the way in which pain patients can help themselves and each other must be discussed. Without professional guidance, these self-help groups run the risk of focusing on pain therapies and experiences with doctors and thus reduce their activity to the mere exchange of complaints. With professional guidance, on the other hand, self-help groups might be set up to train participants in methods of relaxation, pain coping techniques, massage, the preparation of healthy foodstuff and other kinds of self-help which would enable their members to become more and more independent from the professional support (Breitkopf & Grünow-Lutter, see article p. 198).

General health education. In the Federal Republic of Germany, some adult education institutions (Volkshochschulen) and a few health insurance bodies (e.g. the General Local Health Insurance have recently designed health programs to provide advice and information concerning nutrition, relaxation, gymnastics (especially for rheumatic and migraine patients), recreational and social activities of various kinds and, in a few cases, pain coping programs. Such initiatives help to prevent the social isolation which is so detrimental to chronic pain sufferers. Adult colleges are well-known for being open to suggestions for the introduction of new courses in their programs. Professionals should consider it a duty, therefore, to provide these institutions with information on chronic pain and pain coping strategies and make full use of their education facilities.

Participation. Adult education courses, group activities and various kinds of institutionalized help for chronic pain sufferers should be tailored to the specific needs of participants, in order to avoid a passively consuming attitude. This implies that patients should be involved at an early stage and in a comprehensive manner in the design of such courses.

Activation of patients. Opportunities for participation, as mentioned above, can be instrumental in motivating patients to become active and take over responsibility for improving their condition through their own efforts. It is one of the most important and, at the same time, most difficult tasks for psychologists in pain therapy to strengthen the motivation towards self-activity and responsibility, especially as many patients have sunk into resignation and hopelessness and tend to become dependent on the therapist due to their feelings of forlornness.

Access to health promoting measures. A healthy and balanced nutrition with natural foods is just too expensive for some patients. As the health insurance bodies do not pay for measures to maintain health, a large group of people with chronic pain cannot afford healthy foods nor supportive measures like baths, massages, or counseling sessions. They are thus deprived of important therapeutic means to improve their health.

Public relations. The media have taken up the topic of "chronic pain" increasingly over the past five years. However, they focus primarily on questions related to medical care, for instance the existence and equipment of pain therapy institutions, but they do not discuss aspects of health promotion. Pain therapists and psychologists should feel it is their responsibility, therefore, to engage in public relations - using understandable down-to-earth language - via the printed media, radio and television.

In order to implement these concepts, we need a new, holistic and ecological conceptualization of the phenomenon of chronic pain. Pain research requires an interdisciplinary approach and demands the cooperation of basic, clinical, psychological and social scientific research. With respect to contents, we should appeal to the social obligation of scientists to choose topics of research which have to be elucidated urgently in the interest of patients and to present their findings in such a manner that they can be easily integrated into practical work.

PAIN: A KALEIDOSCOPE OF IDEAS, CONCEPTS AND APPROACHES

In her background paper, Dr Hanne Seemann indicated that many theories have been advanced to explain chronic pain. Some researchers see in this phenomenon a symptom of disintegration, a disruption in the integrity of the system, or a sign of existential distress, while others consider it as a relational phenomenon, a negative processing of experience or of the social learning process. Others yet, as Bresler (cf. p. 139), see in chronic pain the incapacity of the individual to confront change and to grow.

The following pages supplement Dr Seemann's paper with summaries or short statements providing material for reflection and for debate, namely:

a) synopses of recent findings on:
- the physiology and biochemistry of pain;
- the contribution of psychoneuroimmunology;

b) some views on a sociology of pain;

c) analysis of various concepts and approaches which consider pain as:
- a symptom of disease
- a form of behavior
- a psychosomatic reaction and a social learning process
- a communication phenomenon
- a symptom of disintegrated life
- a disruption in the integrity of the system
- a signal of broken unity
- a breach in the wholeness of the individual ;

d) a holistic approach in pain therapy;

e) some unanswered questions.

LATEST FINDINGS ON THE PHYSIOLOGY AND BIOCHEMISTRY OF PAIN

by Manfred Zimmermann

Basic research in the physiology and biochemistry of pain has completely changed our scientific concepts in relation to pain. Five basic findings emerge from this research:

1. Both acute and chronic pain may be considered a warning system of great biological significance. Mechanisms involved have the following features: specialized *nociceptors* (pain receptors) are excited by noxious conditions; injury of the nervous system results in *neuropathic pain;* neurochemical and other pathology in the central nervous system may result in *centrally originating pain;* dysfunctions of the sympathetic, motor or endocrine output systems may act as "positive feedback" in initiating or maintaining pain states, which may be termed *reactive pain;* behavioral, affective and cognitive influences and manipulations may have access to the above-mentioned reactive pain mechanisms. The fact that the nociceptors are not involved in most chronic pain conditions means that other ways of treatment than those which influence nociceptors (i.e. acetylsalicylic acid) must be found.

2. In many cases, the straightforward interpretation of pain as a *protective system* is not valid, e.g. the pains without disease, or severe diseases without pain.

3. There are no distinct pain centers in the central nervous system. Neurobiological analysis has revealed that central processes related to pain are of *great complexity* and may involve major parts of the central nervous system. Sensory, motor, sympathetic, limbic and endocrine functions mutually interact.

4. Central nervous information related to pain is subject to modulation, e.g. by *inhibitory systems.* Endogenous opioids and other inhibitory transmitters are in-

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volved; they may partly explain the inter- and intraindividual variability of pain experience.

5. The understanding of central inhibitory modulation of pain information has resulted in new therapeutic approaches in the fields of medicine and psychology, and in new concepts of patient self-control.

PSYCHONEUROIMMUNOLOGY PROVIDES A NEW OUTLOOK

by Rieke Alten

Psychoneuroimmunology is a relatively young science. Until the publication of Robert Ader's book on *Psychoneuroimmunology* (1981), only a small circle of scientists were familiar with its findings, resulting primarily from simultaneous investigations carried out by immunologists, endocrinologists and neurologists. In the preface to Ader's volume, the well-known immunologist Robert A. Good writes: "Immunologists are often asked whether the state of mind can influence the body's defenses. Can positive attitude, a constructive frame of mind, grief, depression, or anxiety alter ability to resist infections, allergies, autoimmunities, or even cancer? Such questions leave me with a feeling of inadequacy because I know deep down that such influences exist, but I am unable to tell how they work, nor can I in any scientific way describe how to harness these influences, predict or control them."
Our knowledge of chronic illnesses has undergone considerable change as a consequence of the elaboration of the system theory. The doctor who refers to this theory is aware that illness is a developmental process and that the particular illness with which he is dealing is a "crisis" which began long before and will also continue afterwards. The system theory also takes into account the fact that the doctor, as well, is at a particular stage in his own developmental process. The interaction between doctor and patient is thus an encounter between two individuals, each with a reality formed by his own biography. A subject-subject relationship is only possible if a common reality can be elaborated.
An important finding – one that is self-evident to every social scientist but has had little effect to date on medical practice – is that the viewpoint and the theories held by the observer determines the outcome of the observations.
More recent results in the field of psychoneuroimmunology have shown that the brain and the immune system work very closely together. Nerve fibres were shown to be present in the thymus, lymph nodes, spleen and bone marrow. It was also shown that cells of the immune system respond to chemical signals from the central nervous system communicated via neuropeptides and neurotransmitters. In depth studies established both the immuno-suppressive and the immuno-stimulative role of stressors. It was not, however, possible to isolate the individual psychological factors which affect immuno-competence. In pioneerer work, Pert (1987) identified more precisely the part of the brain where emotions can have an effect on immunity – namely certain areas of the limbic system – due to the concentration of neuropeptide receptors, which she found to be forty times higher in that area. Such findings support the assumption that these substances communicate emotions by biochemical means.
Another important result of the research conducted on the substance P indicates that the release of this neuropeptide is associated with the sensation of pain. Further studies are being conducted on personality and coping mechanisms in relation to the course of the illness in the case of chronic illnesses. At present, it cannot be said definitively whether psychotherapy can directly influence the immunological function and hence alter the manifestation or the course of chronic illnesses. No conclusive assessment can be made of various methods such as autogenous training, biofeedback, meditation, hypnosis and visualization techniques in this context.
On the basis of his research, Antonovsky (1987) developed the "coherence concept". The individual experiences a need for coherence which means that he must be able to manage his life and give it value and meaning. Antonovsky calls for "salutology" to be included in medicine on an equal basis with pathology. In his own words: "Thinking salutogenically not only opens the way for the formulation and advance of a theory of coping but compels us to devote our energies to it. Having adopted this orientation, I myself was led in due course to formulating the concept of the sense of coherence as the core of the

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answer to the salutogenic question."

Today we know that the physiology of every individual is marked by experiences that have led to an individual pattern of potential immunoreactions. We also know that life-experiences connected with emotions at sensitive points of life are accompanied by specific immunological reactions so that, later in life, if similar events occur – or if a person imagines they are occurring or feels threatened – these events will trigger similar specific immunoreactions.

This leads to a breakdown of the auto-immune balance which in turn results in an abnormal reaction of the immune system and hence in the manifestation, for example, of auto-immune illnesses.

Every state of health and illness is the result of a complex interaction involving not only genetic, age-related and sex-related characteristics but also bacterial, viral and many other factors. Nevertheless, the primary concern in a biopsychosocial approach (Engel, 1977) should be to identify the meaning of the illness for the particular patient with respect to his inner experience and external world. Thus the reintroduction of biographical methods, already urged by the representatives of anthropological medicine, is highly relevant in view of present psychoneuroimmunology data. Only a continuous dialogue between clinicians and immunology researchers working primarily in the laboratory will meet the requirements of a form of medicine which confronts the biomechanical with the biosocial model (Uexküll & Wesiack, 1988).

TOWARDS A SOCIOLOGY OF PAIN

by David Field

Sociological approaches to pain are not well developed. Three main focuses can be distinguished. The early work of researchers such as Zborowski (1952) and Zola (1966) explored social and cultural variations in the ways in which pain was experienced and interpreted among different ethnic groups. The management of pain in institutions by health workers has been examined by Strauss and his colleagues (Fagerhaugh & Strauss, 1977; Strauss, 1970). More recently a problem-specific approach has been adopted by Kotarba (1983) and Locker (1983) who examined the experience, meaning, and management of chronic back pain and pain from rheumatoid arthritis respectively. With the exception of Locker, these various studies were conducted in the USA. Common to all these approaches is the emphasis upon the social shaping of the experience of pain by individuals. The core of the embryonic sociology of pain lies in this emphasis upon the social patterning of interpretation, meaning, and experience by sufferers, health professionals, and significant others.

Thus, a sociology of pain should contribute to the understanding of chronic pain by elucidating social parameters of the experience of pain.

Rheumatoid arthritis provides a good starting point for the development of a sociology of pain. While the problems of sufferers from rheumatoid arthritis are similar in many ways to those who are disabled by other disease conditions, their experience of chronic illness has two elements which set them apart from most other disabled people. Their condition is characterized by both high levels of uncertainty and by often severe chronic pain. The main symptom is pain in one or more joints of the body, and while this may fluctuate in both the long- and short-term, it is nearly always present and becomes a central feature of the sufferer's life. Social life for someone with rheumatoid arthritis may become organized around the minimization and handling of pain. However, the uncertainty of the course of the disease and the levels of pain which may be experienced create great difficulty in arriving at a satisfactory and stable solution with regard to coping with the disease. The only thing which is certain is that there will be pain, but how much pain, and affecting which joints, and with what consequences for mobility and activity is never certain.

Pain is not merely an unpleasant experience but is also a direct source of activity restriction. Activity may be restricted in order to reduce pain, and there is a constant tension between maintaining the expectations and demands of social life and keeping pain and exhaustion within tolerable limits. There is a constant juggling of conflicting demands and tactics: between accepting and living with the disease constraints and fighting them and keeping up "normal life". These conflicting demands have been carefully examined and discussed by Weiner (1975).

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Pain is also one source of psychological difficulty. It is well known that pain interacts with anxiety and depression, both of which may result from the pattern of experience of the rheumatoid sufferer. Uncertainty may lead to anxiety, which in turn may increase susceptibility to pain. Activity restriction may lead to withdrawal from or limitation of social interaction, which in turn may lead to depression (Strauss & Glaser, 1975). The depressed sufferer is also likely to be more susceptible to pain.

These specific features of pain and its management interact with and are affected by other common problems which confront the long-term chronically ill and physically disabled. One common problem is the impact of the disability upon others and – as with other disabling conditions – there may be severe restrictions placed upon the carers of those suffering from rheumatoid arthritis. One of the problems which confront the sufferer here is that pain is essentially private by virtue of its invisibility to others. Hence, it may be difficult to convey to others the meaning and severity of pain, or to persuade them to validate and cooperate in management strategies aimed at its reduction or minimization.

As has already been noted, pain may also cause problems for attempts to adopt a "normalizing" strategy in the management of rheumatoid arthritis. Instead, the sufferers may be forced, for example to give up work and familial roles, and such a withdrawal from social life may affect both self-concept and psychological well-being. Both the temporal and moral order may be severely disrupted by the sufferer's difficulties in performing everyday tasks, leading to problems in social and family life. These may also raise questions of identity and self-esteem for the sufferer. Finally, the failure of medical treatment to alleviate or control pain may lead to the search for alternative treatment.

The central problem is that of uncertainty and control. A range of evidence suggests that unpredictability amplifies the experience of pain. The development of routines and the search for alternative regimes may both perform the important psychological function of providing the sufferer with apparent control and predictability. Routines and regimes may not directly reduce the physiological bases of pain, but by the provision of predictability in the organization of the sufferer's social life they may enable the impact of pain to be diminished and possibly reduce the level of pain experienced. A fine balance seems to exist here, and other factors of a psychological nature are clearly relevant.

PAIN: A SYMPTOM OF DISEASE

Summary by *Mariët A.E. Vrancken*

The somato-therapeutic school does not differentiate between pain and chronic pain, at least not in principle.

Every pain (complaint) is seen as organic in nature, i.e. as a symptom of disease or as the disease itself. The doctor tries to make a diagnosis and to repair the underlying pathological substrate. Chronic pain is recognized in so far as some known syndrome is involved, for instance: trigeminusneuralgia, postherpetic neuralgia, sympathetic reflex dystrophy (Sudecks atrophy), mechanical back pain coming from the uncovertebral joints etc. Otherwise, patients are judged as not having "real pain", or as psychiatric patients.

PAIN: A FORM OF BEHAVIOR

Summary by *Mariët A.E. Vrancken*

The behavioral therapeutic school looks upon chronic pain as a form of behavior and as a multi-dimensional disease entity. The model used is the "egg of Loeser" (1980), which subdivides pain in four components: nociception, pain sensation, pain suffering, and pain behavior. The starting point is that the person in pain is forced to *react* to his pain. Chronic pain sufferers are regarded as having reacted in a wrong way. Chronic pain then becomes a typical form of somatic fixation, called "pain fixation".

Furthermore, pain patients derive some benefits from their complaints. Thus pain can be very quickly maintained by various conditions which help to alleviate it, for example: attention from others, the need to rest, or the possibility to avoid unpleasant situations such as going to work or facing difficulties. These conditions are not only present in the existing situ-

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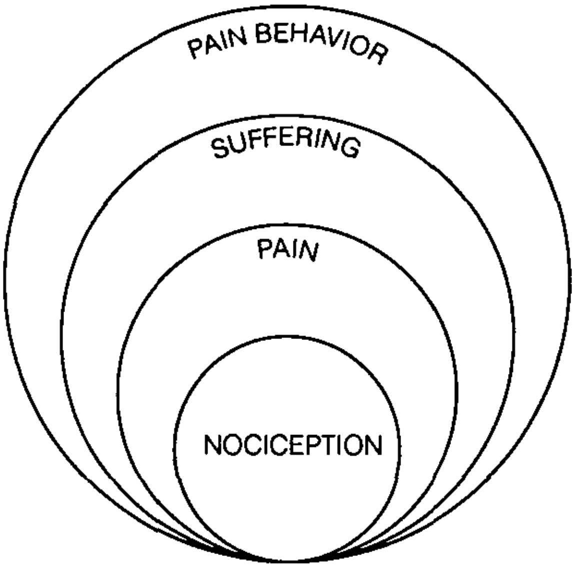

ation, but have also been made "operant" as a result of past experience. Psychologists assume that behavior in which pain and rewards are associated is memorized and reactivated in new situations.

After evaluating the pain behavior and the array of factors which may influence this behavior, a therapy is proposed. Its objectives are sometimes laid down in a contract, so that the patient feels bound to implement what is thought best for him (Fordyce, 1978). The therapy aims:

- to reduce the pain behavior which evokes protective actions by others;
- to increase the activity level and improve physical condition;
- to reduce medication;
- to establish effective well-behavior;
- to reduce pain-related health care utilization.

In short, the therapy tries to rehabilitate the patient by focusing his attention on other aspects of life. The patient learns "to live with pain and in spite of pain". Experience shows that after having followed the program, patients still suffer but the pain bothers them less. In other words, the patient has learned to cope. This approach is mostly used with benign cases of chronic pain.

PAIN: A PSYCHOSOMATIC REACTION OR THE RESULT OF A SOCIAL LEARNING PROCESS

by Dieter Kallinke

Psychology has made a major contribution to our understanding of the fact that pain is more than the perception of a physical-chemical-noxious irritation of the nociceptors. Pain is often the expression of a psychophysiological activation or of a depressive reaction which leads to behavior alterations; these are determined by the subject's perception of the pain and influenced by his social environment.

A quarter to a third of all patients who visit a special institution for the treatment of chronic pain present significant psychic pain-conducive conditions. Often the pain is part of a (hidden) depressive syndrome and represents *a psychosomatic reaction,* i.e. it is associated with an autonomic activation condition resulting from the failure to master human interaction conflicts and/or to cope with situations that are too demanding for the individual.

Pain can also be regarded as expressing (a) excessive strain of the complete behavior system and movement apparatus, or (b) psychophysical exhaustion (exhaustion depression) after continuous overstrain in highly competitive situations.

The chronification of pain syndromes, on the other hand, is often linked to the sympathetic reaction of the social environment.

The attention given by family, friends or colleagues to illness behavior encourages its reappearance. The behavior may then extend far beyond the period of the original pain sensation, especially in the case of persons who are unable to attract attention in a normal way. Thus, chronic pain can be the outcome of *a social learning process.*

For treatment, solutions should be sought at both a fundamental and a pragmatic level.

At the fundamental level, we have to overcome historically rooted hindrances. We must succeed in eliminating the occidental "algophobia", i.e. the fear of pain and its avoidance at all cost. Simultaneously, we must promote a *new attitude to pain* which recognizes (a) that the patient can do something about his pain, and (b) that pain indicates more than an organic lesion. Pain has a meaning. It is a constituent of life.

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At the pragmatic level, we need a behavior therapy approach focusing on self-help and whereby the patient can learn:

- to control autonomic-nervous agitation (fear, tension) and to influence pain through relaxation processes, including biofeedback;

- to develop positive attitudes through active participation in social life, avoiding social withdrawal and its sequel of depression which favors pain feelings;

- to reduce or relativize pain through physical activity and expel pain from the focal point of life;

- to enhance the pain therapy through appropriate diet since the threshold of pain is closely linked to eating habits.

Once the patient has understood that pain is influenced in many cases by psychic factors, he/she becomes aware of the possibility to reduce pain without medical means, by learning to analyze the pain condition and to interpret its meaning. Furthermore, when the patient realizes that pain has a function as a warner and internal advisor, pain is no longer seen as an enemy.
Chronically ill patients need more than symptomatic help. They require overlapping concepts which enable them to understand their affection and give them the courage to alter many areas of their life.

PAIN: A COMMUNICATION PHENOMENON

by Hanne Seemann

Chronic pain can be seen as a communication phenomenon which relates to three different communication systems.

First, the individual inner psychic system. Pain represents here a signal from the body which is consciously perceived and interpreted at different levels: the sensory-discriminative level, the cognitive-evaluative level and the affective-motivational level. False evaluations of pain signals may result from ethnic or religious factors, upbringing, learning experiences, deficient knowledge, etc. As cognition and emotions are reciprocally conditioned, fear, depression, helplessness, hopelessness, aggression, etc, are frequently associated with chronic pain and can be interpreted as the outcome of a negative cognitive processing of experience.
The second communication system concerns the doctor-patient interaction. Here a discrepancy often exists between what the patient knows and what the doctor requires to know; the doctor-patient communication is deficient when the subjective level of the pain experience cannot be incorporated into diagnosis and therapy. Another problem concerns responsibility for recovery which is often delegated by the patient to the doctor; this has very negative consequences in the case of chronic pain since changes must take place at the subjective level and require motivation on the part of the patient.

Finally, pain relates to the family and other social communication contexts. Here two contrary reactions contribute to the increase and maintenance of pain. On the one hand, there are social advantages and rewards of various kinds such as the release from unpleasant duties, financial compensations, etc. which are associated with pain conditions and encourage the maintenance of illness behavior. On the other hand, the exclusion of persons unable to participate fully can lead to isolation, whereby pain, depression and loneliness are reciprocally maintained in a vicious circle.
Psychotherapeutic strategies involve helping patients:

- to extend their perception of signals of the body and to improve their understanding of these signals;

- to achieve a realistic appraisal of personal perspectives with regard to chronic pain;

- to strengthen their ego and develop a positive emotional "counter world";

- to extend their competence and prevent depressive states through participation in self-help groups, etc.

With regard to the doctor-patient relationship, it is most important that the doctor should give preference to diagnostic and therapeutic measures that encourage individual activity and the self-responsibility of the patient. Asking the patient to make daily notes at home on the pain symptoms and his coping strategies is one way to create awareness. On the other hand, invasive treatment methods which diminish the self-healing capacity should be reduced whenever possible, although there are some important exceptions, e.g. the use of morphine for cancer pain patients.

PAIN: A SYMPTOM OF DISINTEGRATED LIFE

Summary by *Robert Lafaille*

Metz (1964, 1975) carried out research in a neurosurgical clinic for incurable pain patients. He used the phenomenological method, i.e. he recorded observations for more than three years without a preconceived theoretical framework. Furthermore, he took into consideration his own personal reactions which he reported in short biographical notes (thoughts, feelings, etc.). He came to the following conclusions:

1. Classical medical models (especially the physiology of pain) are influenced by Descartes' theory of sensory awareness which sees man as a robot and ignores the experiential reality of pain. Yet, it is evident that pain cannot (and should not) be disconnected from the experience (perception) of pain.

2. In the neurosurgical clinic, this *experience* of pain is practically left aside. "Diagnosis translates the pain into anatomical-physiological categories. It translates the language of the subject into the language of the body. It transforms subjectivity into objectivity. For the patient, diagnosis is a relief. The reality of his pain experience needs no confirmation by an objective diagnosis. But as a child of his time, he believes that his pain is caused by a biological deviation and the objective confirmation of this belief is very welcome. He feels understood. From another viewpoint he also welcomes this confirmation because the diagnosis forecasts a surgical intervention. And in the majority of cases, the pain disappears after the intervention. What more can he want? He is lucky, because the decision could have gone in another direction." (Metz, 1975: 32-33).

3. The neurophysiological model has no answer for cases where no objective, demonstrable deviation can be found. With the classical pain theory, the doctor would have to tell the patient: "The investigation did not reveal any deviation which could cause your pain. Without cause no effect. What you experience is not pain. Forget it: you feel nothing!" To which the patient could reply: "Doctor, I do not doubt your expertise. Perhaps the current state of science does not enable you as yet to make a diagnosis of my pathology? But so far as the *pain experience* is concerned: do you feel it, or do I?" (Metz, 1975: 32-33).

4. The causal way of thinking of neurophysiology makes it difficult as well to give an adequate answer (a) to the "changeable" character of the experience of pain unrelated to objective variations, and (b) to strong individual differences in the pain experience. The causal frame of reference of the pain theory implies a correspondence between the gravity of the pain and the gravity of the affection. This contradicts empiricism. There can be severe pain in cases of minor deviations or even without deviation; and no pain although there is very serious damage. The meaning a person gives to the damage is decisive (Beecher, 1959) and pain associated with an outcome that is strongly desired will be controlled much more easily.

5. Pain patients describe their pain by using metaphors; they are unable to put their experience into words. It is an "as-if" reality. Yet, this obvious incapacity to convey *what* pain is, obstructs in no way the ability to communicate *that* there is pain.

6. An important distinction has to be made between a case history and a life history. The neurophysiologist is only interested in the case history. Yet, pain must be apprehended first of all as part of the life history.

In conclusion:

From the study of the life histories of 250 patients, it appears to Metz that the pain experience is a *mode of existence,* the symptom of a disintegrated life.
A primary characteristic in the experience of pain is that the perception of the world disappears and gives place to an orientation towards the body. "The body becomes the center of one's life-world". A secondary characteristic is that this results in the breakdown of the harmonious

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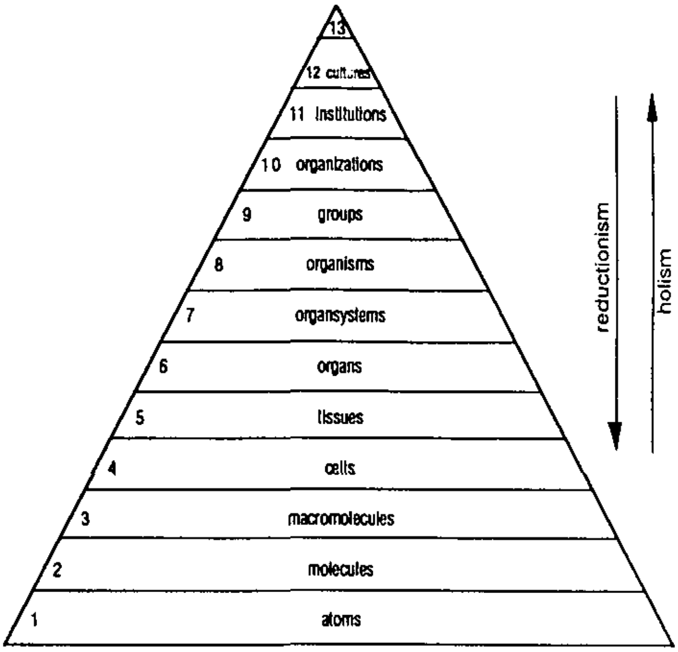
integration of the structures of reality; a single structure (the painful body) becomes dominant in human existence.
The existence of pain inhibits the structuring power of consciousness in relation to the surrounding world. Yet, this structuring power can regain its influence and the pain experience gives place to reality perception either in connexion with very ordinary events — like watching television, for instance — or when a challenge of essential importance brings the subject back to the world. "It is obvious that fluctuations in the pain experience can be ascribed to a succession of integration and disintegration processes." (Metz, 1975, p. 92).
From a therapeutic point of view, the patient must be helped to abolish the disintegration of his existence. This disintegration is only in minor part an attribute of the person; its origin is to be found essentially in the network of relationships (and their interdependence) of which the patient is part. Counseling and relation therapy are therefore the most indicated pathways to recovery. This leads to a fundamental change in the task of the physician since he becomes concerned, first of all, with healing the disintegration, not with the "deviation". Such a therapy cannot be implemented through a dictatorial approach nor the mere knowledge of the human body. In the context of daily life, what matters is not the mechanisms nor the processes, but the relationships; not exact objectivity but subjectivity, not death but life, not the formula but the word. In a certain sense, this deprofessionalizes the physician who elects to apply such a therapy. His knowledge plays a negative, and at best a preventive role, as deep-rooted medical drills may hinder the therapeutic process. Space must be made for the living world and the social network: the pain originated in that network, and in that network it has to be healed (Metz, 1975: p. 109).

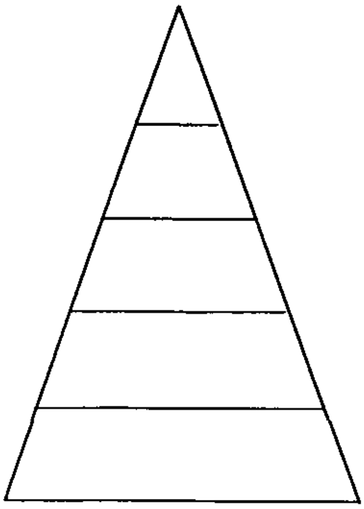
PAIN: A DISRUPTION IN THE INTEGRITY OF THE SYSTEM

Summary by *Robert Lafaille*

In his book *Behoud van Leven* ("Preservation of Life", 1985) Marco de Vries tries to integrate into a scientific model the holistic approach in medicine and the general system theory. According to de Vries we can observe in science a shift from a Cartesian to a post-Cartesian worldview. The differences between the old and the new model are represented in the following scheme, which has been adopted by many other researchers.



De Vries (1985, 1984, 1983a, 1983b, 1981) applies this new viewpoint also to the subject of pain. Pain may then be defined as a universal signal indicating disruption, or the impending disruption of the integrity of the system at any level. Pain is the starting point and as such also the first phase of the healing process. It plays a role at every moment of the day, although most of the time we are not aware of it. Pain draws attention to tissue damage and forges an adequate answer: to bring the (part of) the body in safety and to take measures to remove the cause of the pain. This function of pain tends to be neglected by our modern, technological society which tries as much as possible to avoid pain.
The pain experience can be defined as an unpleasant, and in its more intense form, an intolerable subjective experience. Often it may, at least temporarily, be so overwhelming that it blocks consciousness from any other experience, precludes all mental or physical activity and evokes anxiety and fear for one's life. This definition of pain applies not only to the physical level, but to all levels of human organization. We may distinguish physical, emotional, mental, existential and relational pain. All indicate a break of the integrity on that particular level, either in a person, between persons, or between a person and his or her environment.
At the level of *physical pain* one may distinguish between primary and secondary



levels of life organization	*modalities of pain*
relational pain	combination of pain modalities of the other levels
existential pain	despair, existential shame and guilt, bottomless fear
mental pain	confusion and disorientation
emotional pain	sorrow, anger, depression, guilt, shame and fear
physical pain	stinging, stabbing, burning, throbbing, gnawing, spasmodic or nauseating pain

pain. Primary pain appears immediately. It is a warning signal which gives immediate information about the occurrence, the localization and the extent of tissue damage. This kind of pain is a sharp, clear and precisely located sensation. Secondary pain appears immediately after the disappearance of the primary pain. It may be conceived as a reminding signal. Secondary pain is diffuse, gnawing, not as easy to locate, and may persist until an advanced phase of the healing process.

Physical pain may have many modalities. One may distinguish between stinging, stabbing, burning, throbbing, gnawing, spasmodic or nauseating pain. These qualitative distinctions are crucial to medical diagnosis.

Emotional pain may be conceived as a signal of the disruption of the emotional integrity or as an accompanying signal of the disruption of integrity on other levels. This pain has the modalities of sorrow, anger, depression, guilt, shame and fear.

Mental pain points to a disruption of the mental integrity. Some of its modalities are confusion and disorientation, which are often experienced as very painful.

Existential pain is the signal of the disruption of the integrity of the person as a whole, especially the disruption, or a threat of disruption, of the connexion between the ego – as a regulating center and a center of consciousness and will – and the other part of the personality (conceived here as a system integrating body, emotions and mind). Its modalities are despair, existential shame and guilt, and bottomless fear. Shame, guilt and fear are distinguished here from their corresponding emotional forms in that they are experienced as more profound, more painful, and as a greater threat to existence as a whole.

Relational pain occurs when the integrity of interpersonal relationships is threatened or disrupted. Its modalities can be the same as in the case of emotional, mental or existential pain or a combination of them.

As there are so many functional interconnexions between the different parts of the personality, it is clear that these different manifestations of pain may present themselves in various combinations. Pain on one level may evoke pain on another. Physical pain may evoke fear and, reversely, emotional or existential pain may be accompanied by physical pain, such as pain in the region of the heart, for example, after bereavement.
This model has been further elaborated by Vrancken (1983, 1985) and by Engelbart & Vrancken (1984).

PAIN: A SIGNAL OF BROKEN UNITY

Summary by *Robert Lafaille*

The theory of psychosynthesis (Assagioly, 1985) considers that the "natural" or "culturally normal" response to pain is to divide our inner world in two parts: the happy, healthy side on the one hand, and the painful, fortuitous side on the other hand. This inner division is a co-constituent of the experience of pain and can be an important factor in its chronicity. The Institute of Ecological Health Care in Rotterdam applies psychosynthesis to the medical field. Hence the view that therapy has to focus on the possibility of "including pain in one's life", to accept pain as a constituent of life, and not to be an enemy or a victim of pain. It is very important that a person accepts pain as *a meaningful signal of change*. Therapy (guidance) can help to uncover the deeper meaning of the relation between the pain and the (inner) development of life. Basic models and views are based on a careful study of consciousness, its evolution and development. On the most general level, one can say that consciousness develops as a permanent succession of unity and differentiation (= the breakdown of unity) as seen in *Figure 1.*

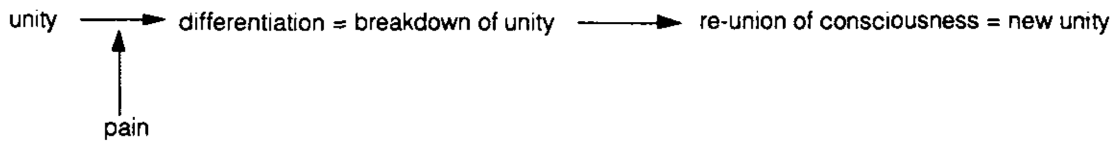
When the homeostasis at level B is broken this is felt as pain. There are two possibilities at each level:

1) to reach the higher level (C) and achieve a new homeostasis (= unity) on that higher level; or

2) to regress to a lower level, which practically always means the somatization of the failure to reach the higher level; this causes pain.

In a certain way the somatization is a second opportunity to reach level C: by becoming aware of the process of somatization and unconscious activity, etc. In many circumstances, although there was a failure at first, a new harmony is found in a second phase. In this case, pain generally functions as a motor and guide in bringing the process to completion. Ignoring this particular role of pain can cause chronicity and even be dangerous. These general principles become more concrete when they are applied to biographical processes which are seldom linear and usually involve an alternation between periods of relative tranquillity and periods of turbulence, which are periods of transition.

FIGURE 1. THE PROCESS OF CONSCIOUSNESS DEVELOPMENT



Each time the unity of consciousness is disrupted, we experience pain. In some cases we are not much aware of this experience and we might even not notice it. But in other cases we are very much aware of the pain and sometimes it remains for a long period. This can happen in particular when the development of consciousness goes to a higher level of inner organization, as represented in *Figure 2:*

FIGURE 2. ACHIEVING A NEW HOMEOSTASIS

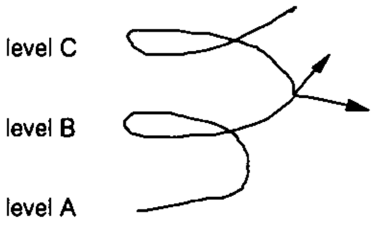
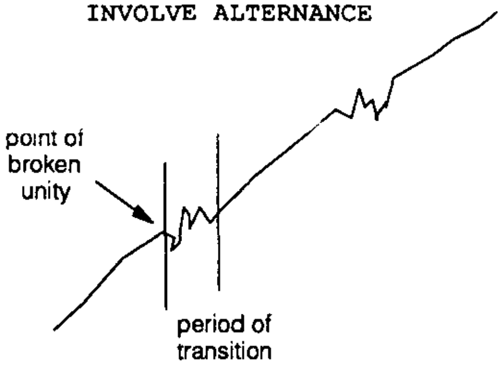


FIGURE 3. BIOGRAPHICAL PROCESSES INVOLVE ALTERNANCE



In these transition periods, the experience of broken unity is felt as pain, anxiety, fear, feelings of discomfort, meaninglessness. Although most of the time, the feelings related to this transition are defined as *negative*, the function of this period, with its related feelings and experiences, is *positive*. It reflects the personal situation at this moment of life and accompanies the creative process of penetrating into the unknown. From this point of view pain is a signal of search for new meaning in life, instead of a pathological state.

These concepts and principles are applicable on every level of the human system. Even on the biological level, we can interpret pain as a signal of broken unity and a positive factor in the healing process.

Application of this frame of reference to therapy implies a redefinition of the function of therapy and the role of the therapist. In this perspective, therapy aims to provide guidance in the process of penetrating into the unknown with, as a target, the search for new (or more) meaning in life. The subjective reality of the individual, of which pain experience is part, should be the therapist's main concern. In the case of an individual with chronic pain, this subjective reality is usually "lost" due to the painful condition. Treating this condition does not necessarily help the individual to rediscover himself as a subject. We need therefore to help the patient develop a dialogue with his inner reality.

A prerequisite for being a good guide is to have achieved integration of pain in one's own life because the ability to help people cope with their pain depends to a large extent on the guide's capacity to cope with his or her own pain.

PAIN: A BREACH IN THE WHOLENESS OF THE INDIVIDUAL

by Mariët A.E. Vrancken

The term *chronic pain* is highly ambiguous. From a common sense point of view, time would seem the decisive factor for speaking of "chronic" pain. But is time really of crucial importance for the genesis of chronic pain syndromes or for people suffering and complaining for weeks, months or years?

The answer also depends on what one seeks to find in a patient: even if pain is the chief complaint, an in-depth conversation will soon reveal other equally important facts. Why is it that in the patient's history exclusive attention is given to pain? It could be that pain is so impinging on everybody's existence – whether on the sufferers or on their fellow human beings – that this complaint is singled out. Maybe this is also why the complaint of pain is soon leading a life of its own. Of course, other things contribute to the genesis of "chronic" pain.

The concept of the pain patient is no less ambiguous. Most of the time it is used as a pars pro toto designating people who seem to have inexplicable or "intractable" pain. When people are in "acute" pain, why are they not considered as "pain patients"? After all, in the word "patient" the concept of suffering is etymologically suggested: *pati* means to suffer. Every pain patient suffers, but not every person who is in pain is (identified as) a "pain patient". In the case of pain patients, pain has become the central concern.

Pain: a breach and an appeal

I see pain as a concept which has the connotation of something lacking. I start off from the idea that "All is One", and in pain, a breach in that Oneness is imminent.

The notion of being hurt can only exist if somehow, on an unconscious level, we know that wholeness exists. Pain may have its source at various levels of existence (the biological level, the psychological level, the existential, moral or spiritual level), yet be expressed on any other level depending on the person's answer to the impending breach in his integrity. Thus, pain can be considered as a signal which, on the one hand, pinpoints to this lost integrity, and on the other hand, indicates that "there is more". A person in pain has a chance since this creates awareness of an opportunity to become part of a greater unity. Pain is the invitation to go beyond old patterns of thinking and of experiencing existence. It is a life crisis which calls for a highly personal answer.

Kahlil Gibran, the well-known philosopher and poet, says: "Your pain is the breaking of the shell that encloses your understanding." Pain is an appeal to switch over to another order, to implement a transformation.

When people complain about physical pain, as chronic pain patients do, we should focus on the most meaningful level of existence that their story entails. In chronic pain, the existential level may well prevail.

Suffering or the inability to integrate problems

Suffering relates to all aspects of life, not merely to the physical aspects. Except for the immediate satisfaction of biological needs, man lives in a world of symbols, not of objects, as von Bertalanffy, the founder of the general system theory, pointed out. Chronic pain patients seem to ask for an explanation in physical terms, but the therapist knows there is more to their questions and will explore whether the patients are unable to integrate the pain experience in their life due to a lack of understanding, and/or whether they simply ask for help, warmth and devotion, feeling hurt as they do by lost or broken relationships.

Illich (1976) also states that pain raises a question. Medicine tends to ignore that question and in so doing, it can contribute to suffering. According to Illich, the fundamental question is: "Why do I suffer? Why me?" In this question, the existential problem comes again to the fore.

If pain patients do not come to terms with their problems, they will never be able to accept their pain, a step which is, in my view, of vital importance. With acceptance comes understanding that the pain is their own, that they have to relate to it and to find an answer themselves. This, of course, might well involve taking analgesics when the pain is overwhelming.

Suffering means that people are not able to integrate their problems (i.e. pain) psychologically. This happens when the pain is a real threat to life, not only biologically but also with regard to the integrity of the person as a whole. (This is true for every situation in which the possibility to determine oneself and one's life is lost.)

Guidelines at the diagnostic level

Chronic pain may exist without any actual relationship to nociception although the history of most pain patients reveals an incident of pain suffering which has continued beyond healing time and has somehow been incorporated. The quality of the experience has thus been changed. The obvious question is: why? Two possible explanations, often forgotten, need to be stressed. Some pain patients once suffered so much that they dare not "enter" their body again, afraid of more pain; the circumstances in which the painful incident occurred may be of crucial importance. Another possibility is that patients have been taking tranquillizers like diazepam or seresta, or are otherwise drugged. One of the withdrawal symptoms of psychotropic drugs can be pain, even after a short time and even if the patient uses them only now and then.

The fundamental question for the therapist is: why does this patient come to me at this moment? The patient may have a "real" disease but there are many people with a chronic disease, commonly regarded as painful, yet *who do not suffer*. This proves that it is possible to subordinate the organic level to the personal, existential level (Engelbart & Vrancken, 1984, p. 1388). When, on the contrary, patients complain about pain, this means that their life has come to a standstill. They are no longer able to direct their life. The therapist must therefore apply a "bifocal" or a stereoscopic view: one eye will be on the physical aspect and the other eye on the needs of the whole individual.

Therapy: the patient has the answer

In chronic pain, the patient has lost contact with that part of his body which hurts, and that part is a part of him*self*. If he is to experience his body as subject again, integration must take place at the personal, existential level. Therefore it is not the pain that should be treated (as if it existed by itself), but the person. The restoration of this integrity may take years. It may even take a lifetime, but evidently the moment comes when professional help is no longer needed. A deep insight into the healing process, both on the physical level and on the psychological, mental and existential levels, is needed. Therapists as well as patients have their own ways of handling problems. For me, the guiding concept is the following: *the person who has the question also has the answer*. This goes very far, indeed. We should be attentive to the patients' qualities and strengths, however hidden they may be. And we should keep in mind that a person's greatest weaknesses may turn out to be his greatest strength. If we assume that the pain patient has lost his relationship not only with his body but with the outer world as well, the best therapy would be one which restores both. This requires a synthesis of the physical experience and problems that come up in the conversation: problems with spouse, partner, family members or friends, sleeping problems, vocational problems, etc. All these problems may be

an indication of a divided inner self.
To guide someone towards this synthesis is not an easy task. It requires a new kind of medicine, in which knowledge on the human organism is always linked to the subjective physical experience of the patient, both being brought together in a scenario that reveals the person's life. This means a voyage for two or more persons in which unknown paths are explored. However, in our view, this is the answer to pain. Pain lingers alongside life and death and demands that we step out of the traditional boundaries into the realm of life.

HOLISTIC MEDICINE IN REHABILITATIVE PAIN THERAPY

by H. Christof Müller-Busch

When looking at the phenomenon of pain from a historical and cultural point of view, we are confronted with some difficult questions: why is it that certain pain syndromes such as low back pain, migraine, rheumatic complaints and polyneuropathies have become such an immense social problem? Why is there such fear of these complaints – algophobia as Buytendijk (1962) calls it – and why do they seem on the increase rather than the decrease in spite of the many successes achieved by specialists in the field of diagnosis and therapy?
Since pain is inseparable from consciousness, we need to enquire, along with Groddeck (1912) and von Weizsäcker (1927), why this particular person, at this particular time and with his or her particular life circumstances, is suffering from this or that pain, or has this or that illness. This question points to the essential meaning and message of the pain, which is not only objectified as an indication of a mechanistic functional disturbance but is also perceived and experienced as an existentially determined phenomenon of consciousness. To obtain an answer, we need therefore to take into account not only the specificity of the illness but also the individual reality of the person (Uexküll, 1986), including his or her biographical and cultural development. Within this broad perspective, the message of the illness becomes the basis of an integral holistic approach in algesiology. Appropriate pain therapy, then, is no longer limited to a few special treatments, but takes into account the personality of the patient, for whom the individual experience of pain as an illness has taken on an existential significance. Here, the therapist must beware of the often unreflected objectification of the pain and become conscious of his own attitude to pain (Schipperges, 1984), without always using his own experience, however, as the guideline for therapeutic procedure.
Smuts (1935), Haldane (1935) and Meyer (1935a, 1935b) among others have – through the analysis of materialistic, mechanistic and vitalistic philosophical doctrines – come to develop the concept of holism which can be seen as the forerunner of modern system theories (Engel, 1980; Laszlo, 1972; Weiss, 1969; von Bertalanffy, 1968). Holism originates from the idea of a graduated organization of historically determined reality, the structure, integrity and dynamics of which are dependent on the relationships and regulatory processes existing at the various stages or between them.
Holism in medicine also starts with the assumption of a universal, a whole (*Holon*) – a concept that already in Aristotle's work is clearly distinguished from a mere collection of items (*Pantes*). Whereas in Descartes the healthy person is compared to a clock in perfect mechanical condition that is functioning well, holism considers that the clock is more than the sum of its parts, just as man is more than can be identified by the analysis of individual biochemical and biophysical processes. Hence, man must be understood as a unity of body, soul and mind, with an individual biography. The crucial point is that these three areas can be differentially perceived and form an intersecting, determining unity for human existence all the way from birth till death. Just as there can be no physical, biological or psychological holism, so there can also be no medical holism – an expression coined by Gross (1986) in an editorial of the medical journal Deutsches Ärzteblatt – but at most a type of medical understanding oriented towards holistic or system theory principles.
A holistic approach in medicine is of course nothing new. We find it both in Western and Eastern healing traditions.

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Even Hippocrates recognized the natural healing forces present in the living organism, with the main function of the doctor in the therapy process being to help activate these processes. The Chinese ideas of harmony and disharmony, as part of the polarity and elements theories, are based on the fact that the human organism is seen as a system in which all the parts are connected and mutually dependent.
In many naturopathic and homeopathic approaches in medicine, an important part is also played by the investigation and treatment of disorders on a dynamic-energetic plane according to a holistic principle. What is common to all these approaches is that from an anthropological point of view *the therapeutic relationship is oriented more to the development of individual healing powers than to the specific treatment of an illness*. This aspect, in my opinion, receives far too little attention in the evaluation of many treatment methods, particularly with respect to pain therapy.

The following sums up the multiple aspects that must be taken into consideration in the diagnosis and therapy of pain conditions.

A holistic pain assessment: concepts and objectives

The assessment is based on three premises:

1. Chronic pain is a long-lasting and/or intermittently occurring unpleasant condition which is related to the body or parts of it. The individual experience of pain has consequences for the lifestyle of the person and his environment.

2. Chronic pain is determined by the individuality of the person, by historical/cultural developments and by the particularity of a disease.

3. Chronic pain is always a historically and existentially determined phenomenon of consciousness. It is not always pain which determines the lifestyle but rather the lifestyle which determines pain.

The assessment has four objectives:

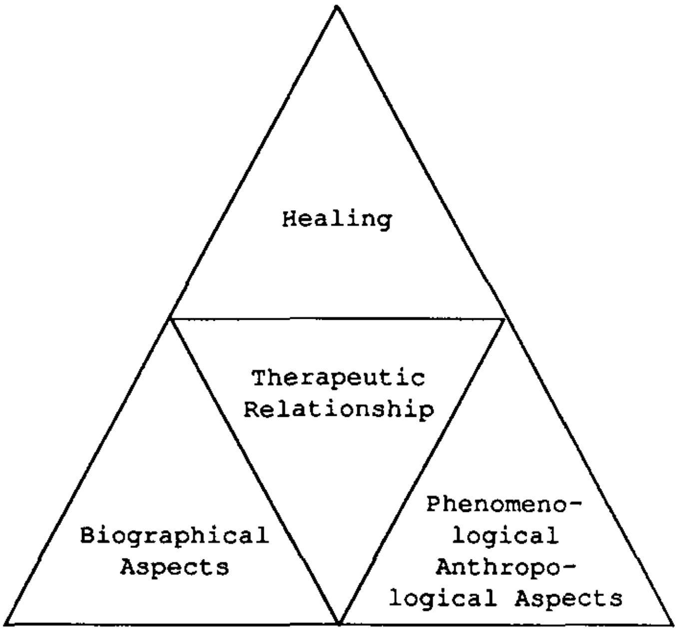
1. To search for the meaning of pain for the person: "Why does this individual suffer from this pain at this time?"

2. To interrupt a specific "pain career".

3. To develop together with the patient an individual, integrative treatment concept regarding the pain experience seen as a phenomenon of consciousness.

4. To support the patient's capacity for self-healing and self-determination.

To achieve these objectives – which aim towards healing – the assessment must rely on a careful analysis of phenomenological and biographical aspects leading to a constructive therapeutic relationship.



Phenomenological aspects

1. constitution, posture, orientation;
2. localization, modality of painful sensation;
3. verbalization – pain expression, the way to suffer;
4. pain behavior, mood, emotions;
5. biological rhythms, stage in life;
6. mind-body relationship – separation?;
7. vegetative status, warmth, coldness;
8. ethnic background;
9. ability to visualize and imagine;
10. fears, affective status.

Biographical aspects

1. cultural background – pain education;
2. family history of pain and pleasure in early childhood, youth;
3. attitudes towards health and illness;
4. social activities;
5. illnesses related to pain;
6. intellectual, emotional capacities, education and interests;

7. rhythm of pain experience, sleeping habits;
8. therapeutic experience and expectations;
9. coping abilities with difficulties in life;
10. pain in relation to love.

Therapeutic relationship

1. pain is often a problem of communication;
2. with respect to subjective perception, the pain therapist relies on the same functional laws as the pain sufferer;
3. pain always has a meaning;
4. therapeutic intervention can help, not heal;
5. the therapeutic intervention requires imagination and intuition;
6. love, confidence and participation are needed to break a pain career;
7. knowledge is the basis for healing;
8. pain influences lifestyle, but lifestyle also influences pain;
9. there are many ways to cope with pain, but it is often difficult to identify them;
10. healing is an activity of the whole person.

An insight into the complexity of chronic pain

The four case studies which follow indicate clearly why the treatment of the symptom "pain" cannot merely be based on a diagnosis limited to the analysis of specific pathological mechanisms and somatogenic/psychic factors.

Case 1: Stumpneuralgia

Mr K, a 42-year-old chemical laboratory technician, started developing Raynaud's disease at the age of 15. In 1962, at the age of 18, he underwent his first operation, followed in the next six years by many others leading to the amputation of the left foot and the right leg from the thigh. Since 1982 he suffered neuralgic stump pain in the scar area. This pain increased in intensity and duration in spite of treatment with various drugs, physiotherapy and acupuncture. At the first examination in January 1987, Mr K complained of constant penetrating pain and twitching in the remaining part of the right limb. Before his illness, he had been healthy and active, doing sports, and having no problem in handling things by himself. Although he had found the long hospitalizations a strain, he felt he had made the best of his fate. As a result of his illness he had to change his profession to economics, now holding an important position in a big industrial company. Due to the fact that over the last three years his pain had become intolerable, resulting in sleepless nights, and due to conflicts with the company, he saw no future in his work.

Therapeutic intervention consisted of administration of local anesthetics in the scar, TENS, ear acupuncture, and bryophyllum. This resulted in an easing of the pain for hours or days. By visualization and inner advising, an interpretation of the pain experience in connexion with the psychosocial conflicts at work was attempted.

After six weeks, Mr K reported that he was almost painfree at night. The remaining symptoms became rare and bearable and did not affect him anymore. He has now given up smoking and his working conditions improved following the appointment of a new manager. The modifications in his lifestyle have changed his approach to pain. For him pain has become an important companion, a kind of friend, and he is able to imagine that he may even fulfil the dreams of his youth sometime in the future.

Case 2: post-encephalitic cephalgia

Mrs T, a 60-year-old patient, became ill with tuberculous meningoencephalitis in 1960 and was treated with streptomycin over several months. Since then she suffered blunt pressing and stabbing headaches, especially in the evening and at night. The pain increased under emotional distress, in spring and autumn and by extreme heat and cold.

At her first appointment in January 1987 she also complained of impaired hearing, disturbed balance, ringing in the ears and tremor of the head. Previous therapies with various analgesics, anticonvulsants, autogenic training, breathing exercises and acupuncture had not been successful. Before the encephalitis she had always been healthy and even the deliveries of her three children had not been particularly painful.

Mrs T had been brought up in a religious family. Her life was determined by a great sense of duty. When she married she gave up her profession as a pediatric nurse. Her husband had suffered during the war and in captivity. She described him as harsh and authoritarian and abusing alcohol for many years. During her illness her husband had an affair with an "attractive housemaid". This hurt her a lot but she had the strength to fulfil her role as a housewife in spite of the painful situation. Although she had considered divorce, she felt that her husband and her son, who still lived at home, needed her. Mrs T described her pain as having a dark, black and jagged shape. "Can you imagine what it's like to be constantly wearing a gear around your head after having had meningitis?" She considered her headache to be the cause of her uneasiness, tension and despair. She refused treatment with antidepressants. Therapeutic intervention as attempted with anthroposophic medication, L-tryptophan accompanied by a careful interpretation of her pain experience in relation to her religious upbringing. After three months, Mrs T reported that she could now relax and find peace within herself through evening meditation exercises. By reconsidering religious questions, she was able to give to her destiny - especially to pain and suffering - a different quality and a new meaning.

Case 3: thalamic pain

Mrs D, a petite alert conscientious secretary, is the mother of two children. In 1985, at the age of 45, she suffered a left-sided CVA with intraventricular bleeding while attending the funeral of her mother-in-law. Up to this time she had been healthy and active; hypertension had been diagnosed but not treated. However, due to a house sale, to which the children did not agree, family relations had become quite strained. At the funeral, the patient saw her children for the first time after a long separation. It occurred to her later that "Maybe my head couldn't cope with the joy of seeing my children and the sadness of the occasion."

Over the following nine months the right-sided paresis and speech impairment improved. Yet, she developed a typical thalamic pain syndrome accentuated in the right forearm and aggravated in the morning. Treatment with carbamazepine, neuroleptics, analgesics, autogenic training physiotherapy and ergotherapy was not very successful. Pain was aggravated especially by telephoning, writing, reading, shopping, sitting in the car and watching TV. The fear of another stroke put a great strain on her.

During hospitalization from January to March 1987 she underwent BP-regulation and pain therapy with low doses of antidepressants, eurhythmia, anthroposophical medication, visualization and inner advising. During her hospital stay she experienced painfree episodes for the first time, which she related as a feeling of joy although she experienced the right side of her body very intensely and described it in warm colors.

Following discharge, Mrs D started driving and shopping on her own again but various other tasks requiring concentration were still not possible. Following an extended stay in Spain with her husband, the patient reported that for the first time she had been painfree for a longer period, in fact until the end of her stay. She identified the period with happiness and thought that even now, though her right side was not without pain, the stay abroad - with the warm climate, the harmony and the different lifestyle - could be the starting point of a new life.

Case 4: chronic stump pain

In 1982 Mr and Mrs S, a Latvian couple of Jewish origin, emigrated to West Berlin. At the first meeting in the pain clinic in 1983, Mrs S reported that her husband, with whom she had been married for nearly 50 years, suffered from intolerable stump pain ever since the amputation of his right thigh in 1944. He also had hypertension, angina pectoris, diabetes and impaired hepatic and renal functions. Consultation with over 40 doctors in the Soviet Union and the Federal Republic of Germany had no effect on the pain in spite of various operations, nerve block and pharmacological treatment.

Mrs S called the emergency unit several times a week to get analgesic injections which she noted meticulously for possible side effects. Her 73-year-old husband looked quite athletic despite his age and his handicap. He would endorse his wife's statements with lively, pathetic and sometimes even mischievous mimicry. On the other hand, he was not able to verbally describe his stump problem. "It is cruel and I would be lost without my wife", he repeated several times and remarked with some pride that he had been an actor in his early years.

This quite burdensome therapeutic relationship lasted for nearly three years and was completely dominated by Mrs S. She regularly came to, or called up the pain clinic in a shrill, demanding voice, to remind us of our humanitarian duties and

to ask that we visit her husband at home when she could no longer cope with his pain and suffering. Hospitalization of Mr S was arranged several times, in most cases with his wife, but all the usual treatments failed. Sometimes, particularly when they were separated, the patient was found to feel quite well. This, however, was not accepted by Mrs S.
In 1986 Mrs S died of intestinal cancer. Shortly after her death Mr S was brought to a home for senior citizens as the stump pain had gone ...
In July 1987 Mr S rang up the pain clinic for the first time and complained of his usual stump pain. The day he called was the anniversary of his wife's death.

In conclusion: pain is more

Chronic pain must be seen as a phenomenon of consciousness which corresponds to fundamental experiences in life and consists of four aspects:

1. *The physiological phenomenon* in which pain is related to the stimulation of pain receptors by noxious stimuli and to the modulation of sensation by inhibitory systems (pain mechanism).

2. *The cognitive phenomenon* in which pain manifests itself in the form of emotional qualities similar to those to be found in joy, desire, sadness (perception of pain).

3. *The communication phenomenon* in which the individual, because of his pain, interacts with himself and his environment (pain tolerance, pain behavior).

4. *The existential phenomenon* in which pain is individually and socially/historically determined, which in turn affects the social/cultural environment (pain experience).

The history of human pain cannot be separated from the history of the human mind. From a teleological viewpoint, particularly with regard to chronic pain, it should be possible to expand our understanding of pain and to support individual healing powers. This is the basis of the holistic pain assessment and of the integrative pain treatment approach.
The results of observations show that in special cases it is indeed possible to influence yet unknown healing sources in the process of therapeutic interaction.
The assessment of pain and the capacity to endure pain are not only determined by the particular disease with its psychic aspects, but also by social and environmental conditions which are beyond the control of the individual and by the historical development of man. Concepts which take these aspects into account will broaden our incomplete understanding of pain in medicine.

SOME UNANSWERED QUESTIONS

by Robert Lafaille

In his masterly work on the process of civilization, Elias (1969) put forward the hypothesis that there is a parallellism between sociogenesis and psychogenesis. This hypothesis has been very fruitful, even for practice. De Swaan (1983) for instance applied this theory to agoraphobia and to the intake conversations of psychotherapists (Brinkgreve et al, 1979; De Swaan et al, 1979). With regard to pain and chronic pain, it would be of value to examine how these two processes are interrelated. We know from the work of Elias that the "threshold of painfulness" is a historically shifting standard. Does this lead to fluctuations in individual pain feelings as well? What role does this shifting standard play in the chronicity of pain? Does the categorization – and even the stigmatization – of people as "chronic pain patients" act as a factor of chronicity?
Another area of study pertains to the relationship between power and pain. The experience and research of many therapeutical schools such as Gestalt or psychosynthesis, indicate that a person usually feels pain when he/she is oppressed by another person. Society can be seen as a continuous process of structuration and re-structuration of power, and changes in power structures and power positions are a constant feature of life. What are the consequences of these processes (a) at the individual level and (b) at the macro-sociological level?
The fact that changes in power structure can have severe consequences for the health of people is supported by experimental zoopsychological research: change induced experimentally in the social stratification of animals causes illnesses and even the breakdown of the immune system (Bailleux, personal communication, 1987).
A third question concerns attitudes towards pain. We cannot deny that in many societies pain feelings remain hidden to a large extent. What does it mean that cer-

tain cultures deny pain? What are the mechanisms behind this attitude? How is this related to the way society deals with power? Power – powerlessness – pain: are they related to each other in some kind of a causal chain? What is the influence, at the level of the individual, of this collectively accepted denial of (taboo on) pain? Why is it not socially acceptable to express pain feelings? What happens, for instance, with the pain feelings unquestionably caused by the current economic crisis: do couples dicuss these at moments of intimacy or is there total repression and are we playing the "life-is-happy" game although our inner world cries with pain?

Medical anthropology can be of great importance for the subject under study. Not only can it deliver insight in the cross-cultural variety of pain experiences, but also in the variety and consequences of treatment.

HEALTH PROMOTION AND CHRONIC PAIN: CHALLENGES AND CHOICES

by David E. Bresler

> *"It is more important to know what kind of a person has a disease than what kind of a disease a person has."*
>
> Sir William Osler

The pain epidemic

Chronic pain has become the Western world's most expensive, disabling, and common disorder. An estimated 8-10% of the population of most Western countries suffer from some form of chronic headache. Arthritis alone afflicts over 50 million Americans, of whom 20 million require medical care (Arthritis Foundation, 1976; Pauley & Haskell, 1975). Each year, arthritis claims 600,000 new victims, and its cost to the national economy is estimated to be nearly $13 billion.

Low back pain - another of the most common pain complaints - has disabled seven million Americans and, according to the National Center for Health Statistics, generates nearly 19 million visits to doctors annually. Add to these the many other pain-related disorders - facial and dental pain, neuralgia and neuritis, cancer, aching necks and shoulders, tennis elbow, muscle spasms and others - and it is understandable how chronic pain can cost the nation's economy an estimated $60 billion annually. Its cost in terms of human suffering is incalculable.

The statistics are shocking to me. If a mysterious new flu virus were expected to infect tens of millions of citizens and cost billions of dollars in medical expenses and lost wages, a public campaign would be launched immediately to mobilize our scientific resources for battle. Chronic pain runs rampant in the land, inflicting severe physical, emotional, intellectual, social, and economic damage upon its victims, their families, and society as a whole. But the health care system has only now begun to respond to the problem.

And, in my opinion, the manner in which it is responding is far too narrow and impersonal. In this paper, I will discuss why global efforts to promote health in chronic pain patients must be designed not only to reduce pain, but also to alleviate suffering. I shall also discuss how a simple technique such as guided imagery can be used in a self-management program to accomplish both objectives.

Traditional treatment of pain

We live in an age of medical miracles. With the development of immunizations, antibiotics and improved health conditions, we have witnessed the virtual elimination of infectious diseases that once decimated entire civilizations. Infant mortality has dropped significantly, and almost daily, we read of astounding medical advances that would have been unthinkable only a few years ago.

Yet there is still no single form of therapy that is completely safe and effective for the treatment of pain. Many of the most frequently used contemporary techniques were developed by ancient civilizations, not modern man, and they have remained fundamentally unchanged over thousands of years.

Morphine, modern medicine's most well-known pain reliever, is derived from opium, which was widely used as an analgesic forty centuries ago by the Egyptians. The ancient Romans relied on a combination of opium and wine. Primitive tribes of India and South Africa employed willow leaves, which are rich in salicylic acid (an ingredient of aspirin), to ease joint discomfort as well as the pain of childbirth.

The Incas chewed on the leaves of the coca plant centuries before cocaine was isolated by a German scientist in 1860.

Transcutaneous electrical nerve stimulation (TENS) - a technique for controlling pain by applying a small amount of electricity - was utilized by Pedanius Discordides, a surgeon with Nero's armies, who applied a torpedo fish as a source of electricity.

Even before that, Plato and Aristotle had

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written about the numbing effects of the electric fish to treat gout and headaches. However, the mortality rate associated with this procedure was often greater than 50%, so understandably, it did not achieve major public acceptance.

Acupuncture, herbs and various physical therapies (heat, cold, and massage) have been an integral part of Chinese medicine for at least 5,000 years. Acupuncture needles carved from stone have been found in China and have been dated back to the Stone Age.

Acute pain vs chronic pain

By refining and expanding the insights of ancient civilizations, modern technology has created an almost endless variety of pharmaceutic products, many of which are available over the counter. For management of acute or self-limiting pain, these agents are usually highly effective, for they provide temporary relief while the body heals itself. With the development of neural blockade and other modern anesthetic techniques, patients who undergo operative procedures are generally spared even the slightest degree of surgical discomfort. Yet the sophisticated pharmacologic approaches which have proven so successful in the management of acute pain are often ineffective or even counter-intentional for controlling *chronic* or long-term pain. While acute pain will usually get better by itself as the body heals, *chronic pain typically becomes worse with time.*

As a rough rule of thumb, chronic pain refers to any pain problem that lasts longer than six months. Its victims are referred endlessly from doctor to doctor, for even if temporary relief can be obtained, the pain inevitably returns.

For example, when analgesic and/or anesthetic agents are used over a prolonged period of time, pharmacologic tolerance begins to develop and effectiveness is progressively reduced. As tolerance develops, patients often increase their medication dosages with the idea that "if a little is good, a lot will be even better". Unfortunately, higher dosages only produce greater amounts of side-effects, for tolerance continues to develop. In addition, most of the more effective analgesic agents carry a profoundly high risk of dependency.

As a result, it is typical to find patients with chronic pain dependent upon large amounts of relatively ineffective medications that produce significant side-effects, many of which contribute to the pain experience. In addition, when patients attempt to reduce these medications, subsequent withdrawal symptoms make their discomfort even less tolerable and they return in desperation to their former regimes.

When medications fail, patients often are told, "Nothing more can be done. You'll have to learn to live with it." But in my opinion, there is always hope for someone in pain. Until every conceivable therapeutic approach has been attempted, no one should be told, "Nothing can be done." This statement has two iatrogenic implications: first and foremost, it destroys the most significant healing asset that the victims of chronic pain (or other chronic illnesses) possess – namely, hope. This will be discussed in more detail later. Secondly, it conveys the subtle message that if you "have to learn to live with it", the only time you *won't* have it is when you are no longer alive. This may contribute to the already significant suicidal ideation experienced by many people in chronic pain.

The pain experience

One of the greatest clinical and research challenges in studying chronic pain is to resolve the ambiguity in the terms and concepts used to describe it. For example, we find it helpful to distinguish between a painful *sensation* (mental awareness of an unpleasant stimulus) and the pain *experience* (the total subjective experience of pain). Furthermore, it is important to recognize that *there is not necessarily any direct relationship between the sensation and experience of pain.*

This is seen in a study reported by Beecher, who found that soldiers seriously wounded in battle reported only mild discomfort; for they were elated to learn that they were to be sent home for the duration of the war (Beecher, 1959). In contrast, phantom limb pain often produces agonizing discomfort even while the entire stump is anesthetized (Melzack, 1973).

Many individuals think of pain as a *thing*, much like a splinter is a thing – that is, an object or substance from the outside that infiltrates the body. Thus, if you accidentally strike your thumb with a hammer, you might say you have "pain in your thumb which is radiating to your hand".

Such a notion is inaccurate, for pain does not reside in your thumb. When you injure it, you stimulate neural receptors that send a barrage of electrical and chemical messages up through the nerves in your hand and arm to your spinal cord and brain. *Whether or not a given sensation is "painful" depends upon the way it is interpreted by the nervous system.* If the nervous system decides that the messages from the thumb are urgent and require immediate action, it may create an experience of pain that is identified with the thumb and hand. However, it is important to note that the main pain receptor is between the ears, for that is really where pain resides.

It is easy to see that pain is not a "thing" when we consider its complement, the phenomenon of pleasure. If you eat something that tastes delicious, you probably would not say, "Boy, do I have a lot of pleasure in my mouth! My mouth is just filled with pleasure that is now radiating around my tongue, down my throat, and into my stomach." Such a statement sounds ridiculous, but it is this terminology that is commonly used to describe pain. Clearly, both pleasure and pain reflect a sophisticated, higher-order interpretation of a complex series of events.

Pain is well-known to be influenced by learning and early developmental predispositions. For example, animals raised in a pain-free environment show insensitivity to noxious stimuli in later life (Melzack & Scott, 1957; Gonda, 1962). Social, cultural and ethnic differences in the experience of pain also are well documented (Gonda, 1962; Sternbach, 1968; Zborowski, 1969). A vivid example are the elective initiation rituals of many primitive tribes, which would be considered nothing short of torture if practiced by members of Western cultures.

Aristotle was the first to suggest that "pain is an emotion" as pervasive as anger, terror, or joy. For the early philosophers, the answer to the question "What is pain?" was "the opposite of pleasure". The emotional component of pain is inexorably bound to other aspects of the pain experience; for anxiety and agitation are the natural consequence of a painful sensation that tells higher cognitive centers that "something is wrong". If the "something" can be clearly identified and appropriate corrective action can be taken, the (acute) pain experience is terminated.

However, for most patients with chronic pain, the "something" is vague, and fear of continued pain in an unknown future produces even greater anxiety. On a physiologic level, sympathetic hyper-activity develops, as manifested by increased heart rate, blood pressure, respiration, palmar sweating, and muscle tension (Sternbach, 1976). In patients with musculoskeletal pain, this increased muscle tension often augments the sensation of pain, which further increases anxiety, which, in turn, produces even greater muscular tension and more pain. The relationship between pain and anxiety is well known to clinicians, for treatment of one frequently provides relief of the other as well (Gonda, 1962; Sternbach, 1968; Jamison, Brechner, Brechner & McCreary, 1976).

With time, exhaustion of sympathetic hyperactivity is inevitable, and more vegetative signs and symptoms soon emerge, such as feelings of helplessness, hopelessness, and despair, sleep and appetite disturbances, irritability, decreased interests and libido, erosion of personal relationships with family and friends, as well as increased somatization of complaints (Sternbach, 1976). Thus, acute pain and anxiety become chronic pain and depression.

It is well-known that the most notable emotional change in patients with chronic pain is the development of reactive depression (Sternbach, 1976; Merskey, 1976). This may be overt or masked to both patient and health practitioner alike. In a sense, depression can be considered a type of emotional pain, for when it is effectively treated, the chronic pain experience is also often relieved (Bresler & Trubo, 1979).

It is important to emphasize the psychophysiological basis of chronic pain, for it is a complex subjective experience that involves physical, perceptual, cognitive, emotional, and spiritual factors. When a patient with arthritis of the spine reports, "My back hurts", his/her pain experience may also involve anxiety or depression (producing insomnia, loss of appetite, and decreased sexual desire), drug dependence or addiction, numerous secondary gains, separation from work, family and friends, masochistic behavior, and a host of other problems. These may remain indelibly associated with the experience of back pain, even after the entire spine has been chemically anesthetized. Thus, it is easy to see why no simple pill or shot can cure chronic pain. The most common error made by clinicians is to evaluate and treat only the physical aspect of the problem; for they assume that the objective of therapy is to *treat pain* in people. To me, however, the objective of therapy is to *treat people* in pain. From this perspective, it is nonsensical to wonder if a patient has "real" versus "unreal" (imaginary) pain, "organic" versus "psychologic" pain, or "legitimate" versus "hysterical" pain. Pain is an intensely subjective and personal experience, and even if no physical explanation for it can be found, *all pain is real*.

Pain vs suffering

We also have found it helpful to distinguish between pain and suffering (i.e., how one endures or tolerates pain). As I shall argue below, pain is as much a part of health as is pleasure. It is a teacher, a guide, a motivator, an incentive for change.

Suffering, on the other hand, is completely unnecessary and counter-productive. When one cannot cope effectively with pain, he or she suffers, which is manifested as an inability to sleep, eat, work, or fully enjoy one's life. Life, in the most personal, meaningful sense, stops.

As discussed later in this paper, I believe that suffering is primarily an epiphenomenon of one's attitude, and on the basis of thousands of clinical cases, I am also convinced that *it is possible to have significant pain, and yet not suffer*.

In the more traditional psychological literature, a distinction is made between pain sensitivity and pain tolerance. To illustrate the clinical importance of pain tolerance when teaching medical students and residents at UCLA, I found it helpful to show them X-ray films taken of two patients with knee pain.

The first patient was mildly injured on-the-job and had filed an extensive worker's compensation claim. Although his knee X-rays were completely normal, he suffered greatly and was unable to climb stairs, drive a car, or sleep for more than two hours at a time. He was totally disabled, despondent and depressed, and dependent on his family and six or seven different medications.

The second patient was a professional football player who had undergone six prior knee surgeries with extensive scarification. While examining these knee X-rays (which looked more like road maps than roentgenograms), we wondered how this individual could even walk, much less continue to play football. He reported little discomfort, took no pain medications (since they made him "feel less ferocious"), and only desired treatment if it would increase stability and range of motion in his knee.

The first patient had not been helped by nerve blocks, acupuncture, TENS, physical therapy, and various medications. However, with self-management training and psychotherapeutic support and planning, he did learn to embrace a different point of view (belief system) about his injury, and was able to markedly enhance his pain tolerance (and reduce his suffering).

The second patient had already achieved a high level of pain tolerance. Fortunately, acupuncture and an appropriate exercise program proved to be beneficial.

In the clinical situation, we often confront limitations in our ability to reverse severe physical pathology (e.g. degeneration of cartilage in a joint). However, our ability to help patients enhance their tolerance to pain is usually an open-ended one; thus, the holistic practitioner is often successful in helping to reduce suffering even when "nothing more (medically) can be done".

For example, in an elderly patient with advanced degenerative joint disease, periodic cortisone shots may produce some acute symptomatic relief (reduced sensitivity), but the problem can continue to be "unbearable". On the other hand, by learning guided imagery and self-hypnosis techniques designed to raise pain tolerance, the patient may report that the joints "don't bother me anymore".

Although no definitive research yet exists on this subject to my knowledge, I expect we will find that endorphins have little to do with pain, and everything to do with suffering. When a patient is given an injection of morphine, he or she will often state that "it still hurts, but it doesn't bother me". This represents enhanced tolerance, not reduced sensitivity.

The extent to which a patient's suffering can be reduced depends upon many complex variables including the patient's belief systems and attitudes, early life experiences, the degree of physical pathology, and perhaps most importantly, the meaning of pain in the context of the patient's life.

The meaning of pain

Since the dawn of creation, pain has provided critically important information concerning man's relationship to his inner and outer environments. Pain strongly conveys the message that "something is wrong" and it encourages the body to take action to prevent further injury. From an evolutionary point of view, it is one of the most powerful ways to insure the survival of an organism in a dangerous world. While most authorities acknowledge the positive aspects of acute pain, many believe that chronic pain is a "biological mistake" serving "no useful purpose". In order to correct this "mistake" they recommend strong drugs or surgical procedures to obliterate the sensation of pain. The exact technique utilized is more likely to depend upon the type of specialist consulted than upon the unique needs of the patient.

For example, an internist may prescribe medication; a psychologist, psychotherapy; an acupuncturist, needles; a chiropractor, manipulation; and so forth. As one of my teachers, Abraham Maslow used to say, "When you hold a hammer, you tend to look for nails."

In my opinion, the best long-term interests of the patient often are not served when the major goal of therapy is to artificially mask or suppress pain without attempting to understand its ultimate message. To do so is like responding to a ringing fire alarm by cutting its wires to stop the annoying clamor, rather than by leaving the burning building.

The "mistake" or "accident" notion or chronic pain is like saying that "the Martians did it". Sometimes, I suggest to a patient, "Perhaps you were just walking down the street when you accidentally stumbled into a Martian pain ray. I hope that this is not the case, for we don't yet have an antidote to the Martian ray, and we don't know how to contact them to ask that it be shut off".

I then suggest to them that there may be another explanation - that their own nervous system is generating the experience of pain *for a reason*. In essence, I believe that chronic pain is usually not a disease or a mistake; rather, it is a symptom generated through the wisdom of the body. In my opinion, *symptoms are the way that the body tries to heal itself or prevent further injury*. Once their message is heard and appropriate action is taken, symptoms usually will disappear, for they are no longer needed.

For example, a low-grade fever (under 103) represents the body's attempt to arise its temperature in order to "burn out" an invading microbe. Practitioners of Oriental medicine consider fever to be a *healthy* response to danger, and they make no attempts to reduce it unless it rises to injurious levels (over 104). But in the Western world, most people quickly reach for an aspirin.

Much of contemporary medicine is based on an "adjustment model" of therapy designed to suppress symptoms. If a patient is unable to sleep, sleeping pills are given for sedation at night. If a patient has excessive anxiety, tranquillizers are often utilized. But *why* does a given patient have hypertension, sleep disorders, or anxiety neurosis? What is the message that the symptoms are trying to convey?

I always have liked the concept of "organ language", the way the body communicates through symptoms. Examples are "pain in the neck", "a broken heart", and we all know what hemorrhoids mean.

Pain is a message that alerts us to danger. Through the primitive, survival-oriented wisdom of the nervous system, it also motivates us to correct the situation by changing and adapting to the shifting demands of the world in which we live. Through pain we are warned about *all* of the dangers we face, and if we continue to ignore them, the intensity of pain will increase.

Perhaps this is why many chronic pain patients receive only temporary relief after symptomatic treatment. Although the nervous system can be fooled for a short time by drugs or surgical treatment, if some subtle danger still remains, the pain will break through and, over time, continue to return until the message is heard and properly responded to.

What is the message that pain tries to convey? What is "wrong?" What therapy is needed? The answers to these questions differ from person to person, but most commonly, the message has to do with the process of *change*.

The transformational process

Change is fundamental to all of life. If you step back and examine how your own life changes, you will see that it typically alternates between times of peace, contentment, and pleasure, and periods of pain and insecurity. Both are essential to life and health.

Life is filled with periods of dissolution in which old patterns are destroyed to let new ones develop. These transitional phases are painful, but without them, we would never grow, advance, and progress. As Abraham Maslow used to say, "There is no growth without pain. If you're not hurting, you're not growing."

When I interview people in pain, I attempt to gain a full understanding of their life cycles - that is, the patterns of change that characterize their lives. Amazingly, these patterns are quite typically spirals, for people seem destined to return to the same situational places through which they have struggled before, but hopefully, at a higher level. As Nietzsche stated, "If you have any character at all, you repeat the same crises throughout your life." A more contemporary version of this same notion is "the game's the same – only the players and the uniforms change".

People who suffer from chronic pain typically have difficulty dealing with the process of change. When confronted with a transformational crisis, they become immobilized, unwilling to let go of the old and make the hard but essential changes necessary for a meaningful new life.

Some think of the life cycle as a death/rebirth phenomenon. Whenever we reach a new plateau, something dies but simultaneously, something new is born to replace it. This death/rebirth process exists throughout the entire universe.

Take the human fetus, for example. In a sense, it is more like a plant than an animal. It lives in water and sends roots into the uterus from which it receives nourishment. But at the moment of birth, the water is released, the stalk is cut, and the roots are ripped up. At this precise instant, the "plant" has ceased to exist, and the infant is born. Something has died, but simultaneously, something else has begun to live. Is the death of the plant not synonymous with the birth of the fetus? Are they not just two aspects of the same process?

The same phenomenon is found throughout nature. The seed grows to become a tree, which, at the peak of its glory, gives forth its flowers. But can the tree cling forever to those blossoms? No. They soon wither and die. But is the death of the flowers not synonymous with the birth of the fruit – the real nourishment of the tree? And after the fruit reaches its full maturity, it withers and dies, too. But in the process, it distributes its seeds, which provide for the real immortality of the tree.

The life cycle occurs in our personal lives as well. For example, we confront the process of change time and time again in relationships. While we hope that our bonds to those closest to us will remain secure forever, all relationships must change sooner or later. The only permanent relationship we have is the relationship with ourselves. We value our interactions with others because they allow us to experience different parts of ourselves. As those relationships change, we, too, must change.

The experience of change is characterized by pain, anger, fear, and uncertainty. Psychologists often identify four phases in the transformational process. The first is denial: "This is not really happening. It's all a mistake." The second is anger: "Why me? I don't deserve this. It's not fair." The third is mourning: "What will I do now? How can I live without him/her/it?" The final stage is adjustment: "I wonder what lies ahead? Maybe things will be even better."

People who experience chronic pain typically get stuck in the first three stages of this process. In a literal sense, they allow their lives to grind to a halt, and all growth stops. *Pain does not make their lives unbearable. Rather, their lives make pain unbearable. Pain is not the cause of their lives stopping. It is the result.*

My personal experiences and my work with thousands of patients have convinced me beyond a shadow of a doubt that *it is possible to feel pain and yet not suffer.* The critical difference is the manner of perceiving the reality of the pain experience.

The nature of reality

To understand modern perspectives of reality, we must turn to physics, the science of defining and quantifying reality. The Newtonian view of the universe was shattered by the theory of relativity which expanded the limits of our understanding of the real world.

Albert Einstein postulated the equivalence of matter and energy in the classic law of relativity, and he explored the ways in which time influences our perception of events. I have always liked Einstein's definition which states, "When you sit on a hot stove for two seconds, it seems like two hours. But when you sit with a nice woman for two hours, it seems like two seconds. That's relativity."

The theory of quantum mechanics expands even further our concepts concerning the world in which we live. According to the principle of complementarity, the reality of an event is vague and ambiguous; for it depends entirely upon the frame of reference through which it is viewed. In other words, what you experience depends entirely upon how you look at it.

For example, imagine that two of your friends have just had a serious argument. After talking with the first friend, you feel outraged by the other friend's behavior. Yet, after talking with the second friend, you see his/her position as well. Who is *really* right? Both and neither. The reality of the situation is ambiguous, and the question of "Who is right?" depends upon your frame of reference. As Werner Heisenberg, one of modern physics' greatest theorists, has stated, "The universe is not completely knowable or predictable."

It is important to understand the practical implications of this concept, for it truly affects the ways in which we live. There is an old anecdote about two priests who approach their bishop with a question. "May I smoke while I pray?" asked the first priest, "Of course not", replied the bishop. "When you pray, all of your attention must be focused on the creator." The second priest then asked, "May I pray while I smoke?" and the bishop replied, "Of course. Prayer is appropriate during any activity."

When we understand that reality is vague and ambiguous, we are forced to view our lives in radically different ways. What may appear to be a tragedy from one frame of reference, may indeed be a blessing from another point of view. Remember, from the perspective of an egg, a chicken is just the way one egg makes another egg. Even more significantly, the theory of quantum mechanics stipulates that the act of observing influences what is seen. A classic illustration of this notion involves a small tank of water at an unknown temperature. How can you determine the real temperature of the water? You might use a thermometer. But the instant the thermometer touches the water, the temperature of the water changes, even if the thermometer's temperature differs from that of the water by only a millionth of a degree.

In the same way, when you see yourself as a helpless, hopeless victim in an impossible situation, that is the way you experience your reality. If you change your way of looking at yourself and the world in which you live, you change the reality of your situation as well. This is why it is possible to hurt and yet not to suffer. All of us must experience pain from time to time, but if we view the experience as opportunity for growth and change rather than as a catastrophe, our reality can be a highly positive one.

There is an old saying in medicine, "The conviction of illness leads to illness, and the conviction of cure leads to cure." As John C. Lilly, a physician, once said, "In the realm of the mind, what you believe to be true is true, or becomes true, within certain experiential and experimental limits that remain to be transcended." To use the vernacular, what you see is what you get.

How, then, do we change our frame of reference? We do so by changing our beliefs, attitudes, and expectations about the world. This requires us to communicate with the deepest levels of the body, psyche, and soul, and to speak the language of the unconscious mind through images and symbolism. As we shall see, guided imagery is an effective technique for facilitating this type of communication and for promoting the healing experience (Bresler & Trubo, 1979; Oyle, 1973a, 1975b, 1976c; Shorr, 1977; McKim, 1972; Samuels & Bennett, 1973; Samuels & Samuels, 1975; Singer, 1974; Kroger & Fezler, 1976; Assagioli, 1971; Jung, 1964; Sommer, 1978).

The importance of imagery and symbolism

Despite guided imagery's recent emergence as a therapeutic tool, the roots of this new technique may date back to the ancient Hebrew mystics, who recognized the relationship of images to events that went beyond normal experience. In more recent times, psychotherapists have utilized a variety of imagery techniques to tap the contents of the subconscious mind. For example, Hermann Rorschach, the Swiss psychiatrist, used standardized ink-blot designs to assess the psychological relevance of various images and emotions to his patients' mental states. Freud developed a technique he called "free association" as a way of reading the unconscious. He believed that the unconscious was the storehouse of instinctual and forbidden desires and fears that were outside of conscious awareness, and that through the images produced in free association, much of this rich information could be evaluated.

Carl Jung contended that the unconscious held more than just our forbidden desires and fears, but also was the repository of our deepest, most positive hopes for fulfillment and self-actualization. He developed several innovative imagery techniques designed to explore these aspects of the unconscious.

More recently, O. Carl Simonton and Stephanie Matthews-Simonton have used guided imagery as an adjunct to conventional methods of treating cancer (Simonton, Matthews-Simonton & Creighton, 1978; see also article by Bartkoviak, p. 225). The Simontons compare patients' images of the power of their body to the power of their cancer. They report that often, the stronger image prevails in the real battle. For example, if the cancer is pictured as a dangerous animal and the white cells as puffs of snow or cotton, the prognosis is poor. As one aspect of their program, they frequently teach patients to imagine their white blood cells as warriors attacking and destroying the malignancies.

A family physician, Dr Irving Oyle, has described a variety of guided-imagery techniques used to treat many different kinds of medical problems (Oyle, 1973a, 1975b, 1976c). He believes that we are normally in contact with only 10% of our brain, and that guided imagery is a way to find out what the other 90% thinks about.

As a growing number of therapists acknowledge the potential benefits of guided imagery, new techniques constantly are being developed (Bresler & Trubo, 1979; Jaffe, 1979). One basic approach involves having the patient draw a symbolic picture of his/her ailment. Such a picture can provide a more comprehensive perspective of the illness or symptom than any verbal description can.

One of my patients visualized her facial pain as her "mouth on fire". With this image in mind, I asked her to devise ways to put out the flames. The innovative ways available for extinguishing a fire are limited only by the patient's imagination, and she visualized herself absorbing those flames into cool, floating clouds of imaginary water. As she continued to practice this guided-imagery exercise, her pain gradually subsided. Remember, *how you view the world determines how you experience it.*

Languages of the nervous system

The human body is an enormously complex organism. Its nervous system contains at least seven to ten billion nerve cells, and an average cell has approximately 5,000 interconnexions. Thus, according to neurophysiologist Charles Herrick, there are at least 10 to the 2,783,000 power possible connexions for receiving, storing, correlating, and transmitting data (Herrick, 1956). How is this incredibly complex system regulated?

In a previous work, I have suggested that the answer may lie in the two fundamentally different ways the nervous system communicates with itself (Bresler & Trubo, 1979). One higher-order communication system uses words and verbal thoughts. This is the "conscious mind", the little voice in your head that talks to you constantly. It has instant access to the motoric nervous system, the division that controls muscles and mediates voluntary movement.

For a quick demonstration of how this particular part of the nervous system works, try the following:

First, raise your arm high into the air. Raise it as high as you can.

Now, *how* did you do that? Did you have to tell your body how to go about raising your arm? Did you have to say, "Deltoids – contract! Latissimus dorsi – relax?"

No, your body knows exactly what to do. When your mind gives certain verbal commands – "I'm going to raise my arm" – you just do it. Verbal commands or thoughts have immediate access to functions which are controlled by your motoric nervous system.

Now, tell your body to raise your blood pressure. Go ahead. Try it ......

You're not having much success? My explanation for this is that the autonomic nervous system (the division that regulates blood pressure as well as heartbeat, blood chemistry, digestion, tissue regeneration, and immune/inflammatory responses among others) does not respond to the same language used to raise your arm. To increase blood pressure, a second type of communication system is involved – one that uses the language of symbolism and imagery.

If you would like to see how easily imagery can be used to raise your blood pressure, try the following exercise. (Note: if you already have high blood pressure, your nervous system apparently knows too well how to raise your blood pressure. Do not give it further encouragement.)

Sitting quietly and comfortably in a chair, imagine being in the deepest, darkest woods of Africa, alone on a cold, wet night, naked and shivering. You do not know what you are doing there, but you are lost and terribly frightened.

Then, suddenly, you realize that you are not alone! In the distance, you hear a crashing, pounding noise that is quickly becoming louder and louder, closer and closer. Your heart begins to beat faster, and as the sound becomes even louder, you panic and begin to run. You run slowly at first but then desperately faster as this "thing" in the woods comes even closer.

It is now clear that this beast is chasing *you*! As you race through the forest, faster and faster, with the brush tearing at your flesh, the beast is coming closer and closer, until you can feel its hot breath burning the back of your neck. As it reaches out to take you, you scream louder than you ever have in your life...

What happened? If you were able to involve yourself in the scene described above, your mind almost certainly caused your blood pressure to rise. How did it do so? The results were produced in the same way you were able to raise your arm – by having an appropriate thought. But in this case, the language you used was not one of words, but images.

Try another illustration of the difference between verbal commands and imagery: first, using verbal language, order yourself to "manufacture and secrete saliva". By thinking about this command, see how much you can generate. If you are like most people, you probably produced a little but not much. It is not easy to do, because the parts of the nervous system that regulate salivation do not respond readily to verbal commands. Now try a different approach:

Imagine that you have a big, yellow, juicy lemon in your hand. Experience it in your mind's eye until you sense its fresh tartness. Now imagine taking a knife and slicing into the lemon. Carefully cut out a thick juicy section. Now take a deep bite of the lemon slice and sense the sour lemon juice splashing in your mouth, saturating every taste bud of your tongue so fully that your lips and cheeks curl.

How much saliva did you create this time? If you were able to paint the picture vividly in your mind's eye, the image probably produced substantial salivation, for the autonomic nervous system easily understands and responds to the language of imagery. You do not have to tell it *how* to respond any more than you need to instruct your muscles how to raise your arm.

Here is the crux of this discussion: *if thinking of a lemon makes you salivate, what happens when you think of yourself as a helpless victim of a hopeless problem?* Does it not tell your nervous system to give up?

In my opinion, negative expectations often become self-fulfilling prophecies; for, images have the power to create their own reality in the body. For example, if a patient experiences pain as "a sizzling hot poker" that is constantly being stabbed into his/her neck, or as "a lion gnawing on his/her back, tearing deeper into the nerves with every bite", these images will contribute significantly to the experience of suffering and will interfere with the healing process.

The brain's two hemispheres

Recent research studies suggest an anatomical explanation for the two languages used by the nervous system. This explanation may lie within the brain itself, which has two separate hemispheres. When viewed by the naked eye, these hemispheres appear identical, but functionally, they are quite unique.

In most individuals, the left hemisphere is the seat of the conscious mind, for it is involved in the process of rational, logical, analytic, and evaluative thinking. Most importantly, the nerve centers that control speech are localized primarily in the left hemisphere, so its major communication system is a verbal one. It is the seat of the little voice in your head that constantly talks to you.

The right hemisphere, on the other hand, processes the information it receives in an abstract, symbolic manner, and appears to be involved in more creative, impulsive, intuitive, and instinctual thought processes. Its linguistic abilities are quite limited, so it communicates primarily through the language of imagery – most notably in dreams, daydreams, and intuitions. It is the seat of the unconscious mind, and although it does not communicate in words, do not assume that it is unintelligent or uninformed. Remember, "A picture is worth a thousand words".

Consciousness and the brain

Although no one really knows what "consciousness" is, I believe that it is critically related to the process of "attention", for what we attend to is what we experience.

Your attention is one of your most valued attributes. There is nothing you can give that is more intimate.

Children show us the truth of this notion. They will perform the most outrageous acts to attract our attention. And even if they are punished as a result, it is worth it, for nothing is more valuable to them.

Over the years, most of us have learned to give our major attention to the conscious mind, the left hemisphere. We listen endlessly to the chatter of the little voice that maintains a logical, rational, analytic monologue concerning its perspective of the world. We quickly become lost in it, forgetting that any other part of us exists.

Nothing could be more counterproductive. You are not solely your conscious mind; it is no more (or less) important than any other aspect of your being. Your left hemisphere is just one part of your brain, and like other vital organs, it has a specialized function that aids survival – that is, it makes logical associations from Thought A to Thought B to Thought C, and so on.

Have you ever asked, "Now what made me think of that?" The conscious mind can race through a series of associations in a flash, and when you allow your attention to reside solely there, your total experience becomes identified with that chain of thought.

However, you are much more than your conscious mind. You are also your intuition, emotions, and feelings, your drives and motivations, your goals and aspirations, your values and beliefs, your personality, and, of course, your physical body. To me, it makes no more sense to believe that you are primarily your conscious mind than to believe that you are primarily your liver or kidneys (or your anger, your appetite, and so forth).

How do you get in touch with the other parts of yourself? You do so simply by giving them your attention. Unfortunately, most of us do this only as a result of accidents or under strong coercion. When a part of us desperately needs to be heard, it briefly will capture our attention. For example, when we injure ourselves, the alarms go off and our attention is temporarily shifted to the body. But shortly thereafter, we wander back to the conscious mind, and the inner voice begins again.

Why do we allow the conscious mind to dominate our attention so thoroughly? We permit this because most of us have been rewarded for doing so. In the Western world, the accomplishments of the left hemisphere – our rational, logical, articulate side – usually are respected over all others. Our educational, social, and vocational systems offer great recognition and advancement to people who are logical, analytic, and articulate.

True, athletes are rewarded for the accomplishments of their physical bodies (and as a result, their bodies receive much of their attention). In a similar manner, actors, writers, or artists may rely primarily on their intuitions and emotions. But most of us receive little, if any, recognition for the achievements of the right hemisphere – our creative, intuitive, instinctive side. In fact, we usually are discouraged from "wasteful" activities such as daydreaming. We suppress the most creative part of our nervous system and literally forget how to gain access to it. Thus, we identify almost exclusively with the conscious mind and allow it to keep our attention its prisoner.

If you think that you have control of your conscious mind, try these simple experiments.

First, stop your conscious mind from thinking for one full minute. Can you do it?

Next, tell your conscious mind to give you any wrong answer to the equation $2+2=?$. Do not let it return to the number "4".

These experiments illustrate the notion that the conscious mind is nothing more than a complex biocomputer, totally programed by the rewards and punishments from past life experiences.

Is it not important, therefore, to let your attention explore the right hemisphere as well?

Only in this way will you discover critical misconceptions about the nature of your personal reality that need to be corrected. For example, you may find that your right hemisphere is filled with negative beliefs and expectations that, in turn, are responsible for many or most of your negative experiences. These inappropriate expectations must be identified before they can be changed.

Through symbolism and imagery, you can readily access the autonomic nervous system and produce dramatic changes in your body. By learning to speak the language of the unconscious mind, you also may uncover new insights and information that will help you to optimize the quality of life that you experience.

Guided imagery training techniques

Some people feel that they have little ability to create images in their minds, but everyone can cultivate this talent to an amazingly high degree. In fact, the most common way that people do guided imagery is by *worrying*. What we worry about is real only in our imaginations; it is a fantasy, albeit a highly negative one.

Many patients insist that when they close their eyes, they see "nothing except blackness and some floating red, blue, or green dots". This is why I do not like the terms "visualization" or "visual fantasy". Although we are primarily visual creatures, imagery is a vicarious experience that does not necessarily involve seeing. For example, think of the tune "Jingle Bells" for a moment. Can you remember how it goes?.....

Now, where did you hear it? Was anyone playing it in the room? Or was it just an auditory image that you recalled? In the same way, we can vicariously experience olfactory images of burning leaves on an autumn day or the salty taste of a stale potato chip.

To utilize guided imagery, it is not necessary to literally see, hear, taste, feel, or smell inside our heads. All that is required is to experience what the image might be like by becoming involved in a vicarious adventure.

Many people have not tapped their power of imagination since childhood. Getting in touch with images in the mind has become a difficult and awkward process, for their creative and intuitive abilities have long been ignored. Elsewhere, I have described several training exercises that can be used to strengthen imagery skills (Bresler & Trubo, 1979). A prerequisite for maximum effectiveness of imagery techniques is the achievement of a state of deep relaxation. With diligent and conscientious practice, however, most people are easily able to utilize guided imagery.

Imagery and pain control

As a result of our work with thousands of people in pain over the past fifteen years, my colleagues and I have developed a wide variety of imagery techniques designed to alleviate pain and suffering (Bresler & Trubo, 1979). One approach is called "mind-controlled analgesia" (MCA); it uses the language of the unconscious mind to transform the pain experience in a positive way.

Before beginning MCA, patients are asked to prepare two drawings that symbolize the experience of their discomfort at its worst and at its best. Then they are instructed to imagine how they would feel if they were experiencing the most intense pleasure possible and to draw a third picture that symbolizes this experience. Next they are given a prerecorded cassette tape containing the MCA exercise and asked to practice it several times per day (1).

In essence, the exercise begins with a rapid induction-relaxation procedure, followed by a vivid experience of the first picture (pain at its worst). By means of systematic sensory enhancement, this experience is then transformed into the one symbolized by the second picture (pain at its best).

Finally, patients are encouraged to unlock their maximum creative potential and to dissolve this experience into the image of pleasure, health, and healing. Over time, many people find that as the images change, so does their experience of the world in which they live.

Another pain control technique is called "glove anesthesia". It involves a two-step imagery exercise in which patients first are taught to develop feelings of numbness in the hand, as if it were in an imaginary anesthetic glove. Next, they learn to transfer these feelings of numbness to any part of the body that hurts, simply by placing the "anesthetized" hand on it.

Glove anesthesia is a symptomatic technique – that is, it reduces the physical symptoms of pain without concern for its cause. It is a useful alternative to analgesic medications, and it is particularly helpful when discomfort is so intense that the patient cannot concentrate enough to use other guided-imagery approaches. Glove anesthesia often helps to "take the edge off" the pain sensation, thus permitting patients to explore other aspects of the pain experience more fully.

In addition, glove anesthesia provides a dramatic illustration of the power of self-control. When patients realize that they can produce feelings of numbness in their hands at will, they recognize that they may be able to control their discomfort, too. This is profoundly therapeutic for pain sufferers who feel totally helpless and unable to affect their discomfort.

Symptom substitution is another symptomatic technique that permits the nervous system to move the discomfort to a new area of the body where it will be less disruptive. For example, patients can learn to experience their headaches in, say, the little finger instead of the head. This technique does not ask the nervous system to stop the experience of pain (or to cover up the message it is trying to communicate). Rather, it moves it to a less traumatized area so that patients can work more effectively to identify what is wrong.

These and other approaches encourage patients to utilize the intuitive side of the brain and all of their inner resources. In essence, guided imagery is the formation of personalized mental images that facilitate the healing process. Thus, its use is not restricted to pain problems. Because it can mobilize the autonomic nervous system and the immune/inflammatory response system, it is an important tool for any type of self-healing.

Remember, reality is vague and ambiguous. If you see your life as living torture, that is how you will experience it. But if you can see yourself in your mind's eye as being healthy, functional, and happy to be alive, that is the way your personal world

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1) Professionally recorded cassette tapes of these guided imagery exercises are available from the Bresler Center Training Institute, Post Office Box 967, Pacific Palisades, California 90272.

will be.

The inner advisor

One of the most powerful guided imagery techniques involves the creation of an "advisor", a "counselor", an "inner doctor", or a "spirit guide". During a session of guided imagery, the patient is taught to relax and then is instructed on how to locate an imaginary living creature in his/her unconscious mind, who thereafter will serve as his/her advisor. These advisors have taken the form of everything from dogs and frogs to religious figures – but of course, they are just a reflection of the person who is creating the image.

By definition, the advisor has access to the entire realm of the unconscious, the part of the brain which normally is outside the individual's awareness. Our unconscious is a valuable storehouse of insights, suggestions, and desires, and through regular communication with the advisor, critically important information about the inner world often emerges.

Advisors frequently provide insights into past experiences that may have contributed to pain. They can also offer advice on specific ways to relieve discomfort.

One of my patients, a fifty-two-year-old cardiologist named John, was suffering from excruciating low back pain following treatment for rectal cancer. Although surgery and radiation therapy apparently had eradicated the cancer, the pain that remained was "unbearable". Because the area had been so heavily irradiated, neither repeated nerve blocks nor further surgery could be used to help relieve his terrible discomfort, and he had long ago developed tolerance to his pain medications.

When John first came to see me, he already had narrowed down his personal alternatives to three: (1) successful treatment, (2), voluntary commitment to a mental institution, or (3) suicide. John was convinced that under no circumstances could he continue to live with pain and, at the same time, maintain his sanity.

In reviewing his medical records, I noticed that during a psychiatric workup, John had described his pain as "a dog chewing on my spine". This image was so vivid that I suggested we make contact with the dog, using guided imagery. With his training in conventional medicine, he thought the idea was silly, but he was willing to give it a try.

In John's case, our initial goal was to have the dog stop chewing on his spine. Over the next few sessions, the dog began to reveal critically important information. According to the dog (named Skippy), John never had wanted to be a physician – his own career choice was architecture – but he had been pressured into medical school by his mother. Consequently, he felt resentment not only towards his mother, but also towards his patients and colleagues. Skippy suggested that this hostility had in turn contributed to the development of his cancer and to the subsequent pain problem as well.

During one session, Skippy told John, "You're a damn good doctor. It may not be the career you wanted, but it's time you recognized how good you are at what you do. When you stop being so resentful and start accepting yourself, I'll stop chewing on your spine." These insights were accompanied by an immediate alleviation of the pain, and in only a few weeks' time, John became a new person, and his pain progressively subsided.

The friend inside

When I first was introduced to the advisor technique by Dr Irving Oyle, I was as quick to challenge it as anyone. How could it do all the things he claimed? Also, it was so unorthodox that I doubted if the typical patient would accept it. After all, what would be your initial reaction to a doctor who encouraged you to start talking to little animals in your head? However, I have been surprised, not only by the immense value of guided imagery, but also by the receptivity of most patients to the technique. In retrospect, this open-mindedness on their part is not as amazing as I had originally thought. Guided imagery is basically just a way of talking to ourselves, which is hardly a new concept.

I am sure that sometimes we react to a particular event by saying, "Damn! I knew that was going to happen!" Well, *how* did you know? Who told you? The Martians? Of course, it was the intuitive part of your nervous system – in essence, an inner advisor. And you should have listened to it.

Interestingly, children are not as negligent of their unconscious mind as adults. They naturally communicate with that part of themselves and are constantly creating their own imaginary playmates.

But unfortunately, parents often discourage such behavior ("It's not real, don't daydream, stop talking to imaginary things"). As a result, they unknowingly disconnect their offspring from this vital part of themselves. I think this situation is tragic. For when children communicate with their intuitive side, it is a very normal, healthy activity. How sad it is when children are told not to be impulsive, spontaneous, or creative.

Through guided imagery, however, people once again can make contact with inner "playmates" who are able to provide important insights about their lives. They can give advice on how to reduce stress and improve health. They can supply encouragement for decisions made, with an enthusiasm that friends or family members are unable or unwilling to offer. Because advisors are a reflection of their creators, they are always loyal and faithful.

Occasionally, however, communication problems arise, but this is not really surprising. A dialogue with your advisor is just a reflection of what is going on inside of you. If your advisor acts timid or frightened, perhaps it is because you are feeling insecure. If your advisor will not talk to you, maybe it is because you are unwilling to open up about what really is going on inside.

Keep in mind that advisors always work on behalf of your best long-term survival-oriented interests. If an advisor will not cooperate with you, it may be a test of your sincerity.

For example, Irving Oyle reports the case history of a psychiatrist who suffered from severe migraine headaches. Though highly skeptical of guided imagery, he found an advisor – a mermaid named Ethel – who insisted that in order for them to talk, he would have to swim out to her in the imaginary ocean where she lived. He refused at first, but at Dr Oyle's urging, finally agreed. Once he had swum several hundred yards offshore, Ethel asked him to dive with her into the depths of the water so that their dialogue could begin.

The psychiatrist began feeling even more silly. "How corny!" he exclaimed. "Sinking down into the sea of the subconscious. This whole thing is ridiculous!" Ethel responded curtly, "So sue me! Not only do I know about your headaches, but you deserve worse! You're even more ridiculous than I am."

Later, after they had become friends, the psychiatrist asked Ethel why she had been so hostile initially. Ethel replied, "You were hostile, too, and it was the only way I could get your attention."

Ultimately, guided imagery boils down to making friends with your nervous system. When the technique is properly employed, it is safer than more invasive psychotherapeutic techniques, such as hypnosis. For example, if there is danger in breaking down a particular psychological safeguard or defense, the advisor usually will refuse to pursue the matter until the patient is able to deal with it more effectively.

In my experience, advisors never tell patients something they are not psychologically equipped to handle. Even more important, advisors often can tell exactly what must first be accomplished in order to make this information safely available.

From my point of view, another great benefit of the technique is that it decreases dependency on the therapist. After all, it is clearly the advisor, not the therapist, who is providing the insights that facilitate healing.

Although there are no proven complications resulting from guided imagery therapy, I do not recommend it for people who are emotionally hysterical, mentally unstable, schizophrenic, or prepsychotic. For these patients, guided imagery may some day prove to be as effective, or even more so, than conventional psychotherapy. But until more research has been conducted, it should be used with great discretion with such people.

The art of medicine

Guided imagery represents a different approach to health care, for it reflects more the art of medicine than the science of medicine. Rather than putting patients into prolonged psychotherapy designed to analyze and re-evaluate past life events, guided imagery allows them to participate in a great new adventure in self-knowledge. Rather than focusing on how a patient developed pain and other pathology in the past, it quickly allows us to determine where the patient wants to go with his or her life, and how to get there.

In practicing the art of medicine, one realizes that pain tolerance is maximally enhanced (and suffering reduced) when painful experiences are balanced by pleasurable experiences. That is why one of the most common prescriptions I write is "four hugs per day – one before each meal and one at bedtime". While physicians are quick to review serum cholesterol and serum triglyceride levels, most people in pain desperately need to increase their "serum fun levels".

To the extent that people in pain can laugh, have fun, and see the positive side of the world, they can choose to be free from suffering. From this point of view, our challenge in promoting health in pain patients is not a medical one, but a psychosocial one.

SOME CLEAR OBJECTIVES AND NEEDS

In preparation for the International Symposium on Health Promotion and Chronic Disease, the Federal Center for Health Education, Cologne, called an Expert Meeting which was held in West Berlin, 3-5 December 1986, under the chairmanship of Professor Bernhard Badura. The main purpose of the meeting was "to collect existing knowledge on the phenomenon of chronic pain conditions and to identify the social and health policy initiatives which have to be promoted more strongly so that persons suffering from chronic pain can be given help commensurate with their situation and modern-day practice".
The presentations made on this occasion have been integrated in various chapters of this book. Following are the recommendations made by the Expert Preparatory Meeting with regard to the action needed on several levels, namely:

- public information;
- professional education;
- the elaboration of adequate models; and
- research.

Enlighten the public

First, it is essential to make people understand that physical pain can be the expression of mental or emotional processes and that lifestyles are often at the root of the problem. People must be enlightened on possibilities of change through their own efforts.
Second, we must break the magic that has built up around the words "chronic disease". The patient feels there is no way to escape and the doctor follows traditional pathways of treatment. It is necessary therefore to make the public aware of the transitional aspects of chronic pain and realize that a choice exists: the patient can escape from imprisonment into the concept of being chronically ill, and from the sickness role.
In other words, we must open up public perception, awareness and consciousness. We must promote a different view of chronic pain and illness.

Modify the outlook of the medical, health and social work professions

The treatment of chronic pain is still essentially based on the model of acute pain. Pain is equated with its sensory aspect and seen as the expression of an organic lesion. Significant psychological factors for the diagnosis and management of pain are neglected.
It is urgent to inform medical and other health and social workers, as well as students, of recent findings regarding the physiology and biochemistry of pain, the role of the immunologic system, and the influence of both psychological factors and the social environment.
The main objective of training programs should be to reorient professional thinking on chronic disease and pain and change attitudes. A series of papers on needs and possibilities and innovative approaches are published on the subject in chapter 9.

Elaborate adequate models based on the health promotion concept

To improve the quality of life of patients with chronic pain, we need models which give full attention to:

- the subjective perception of the patient;

- the importance of the social network in the etiology of illness;

- the changing roles of the doctor and the patient;

- the value of the team approach; and

- the need to mobilize all personal and social resources.

Such models should first and foremost:

- allow for a choice of action by the patient;

- remove barriers to lifestyles conducive to health for individuals with limited capacities;

- include advocacy for the quality of life of patients with a chronic condition; and

- involve all sectors concerned in achieving this objective as certain factors which influence chronic pain conditions are beyond the control of the health sector.

Develop studies to meet the need for data on various levels

From the perspective of epidemiology the problem of chronic pain calls, first, for a representative survey of its prevalence and correlatives. Progress in our approach to chronic pain requires data on the most important demographic, economic, social and psychic variables involved. Only then will it be possible to discuss special risk groups and formulate proposals for the reduction of pain. Second, we need to broaden our knowledge on the mechanisms which cause chronic pain and those which enable its control. A longitudinal cross-section study is necessary to evaluate the importance of causal variables and determine which factors activate a selective process whereby certain individuals are afflicted with chronic pain and others are relatively free of pain. The same applies to the causal analysis of the more or less successful removal of pain.

Research at the clinical level is also very necessary. To improve our knowledge on prevention and treatment we need to identify more clearly the somatic and psychic factors involved in pain conditions. Studies carried out with patients in the clinical setting would be very helpful.

The need for *qualitative data* is just as pressing. Patients are different. Epidemiological data does not explain how people cope individually with health problems. Case studies should therefore be given high priority; they would facilitate a better grasp of the complexity of variables involved and help in identifying the patterns of chronic pain condition. Research on "good copers", for example, should yield valuable information. What is it that enables some chronic pain patients to control their pain? What makes a "healthy" pain patient?

In the classical medical tradition there is little scientific appraisal (if not condemnation) for collecting life histories about coping with pain. Since pain is essentially a *subjective experience*, the value of experiential knowledge has to be restored. Research is needed in the field of subjective experiences, in which subjectivity is not destroyed by concepts but, on the contrary, given proper visibility.

This kind of research would have immediate value for the pain patients themselves as they could read life histories, identify themselves with these examples and find their own pathways towards effective coping.

In conclusion

The views presented in this chapter make it clear that:

- Chronic pain conditions often cannot be changed by biomedical means alone: a combined involvement of social, psychological and technological knowledge is necessary; the complexity of the phenomenon of chronic pain calls for broad interdisciplinary cooperation.

- Social support, sympathetic care and acceptance, the readiness to help oneself and encouragement towards active participation, etc., all have a decisive influence on chronic pain conditions.

- Above all, it is important to encourage the persons concerned to make full use of the potential for information and active participation, and also to make them familiar with existing possibilities for action leading to effective change. People suffering from chronic pain often possess a considerable self-potential for a better quality of life which they themselves can actively promote.

- Some factors, however, lie beyond the ability of the individual to promote change; such is the case for the quality of foods, their composition and processing, and their availability and affordability which can have considerable influence on chronic pain conditions. Furthermore, the self-potential for a higher quality of life can only be activated if adequate environmental and professional support is provided, which is far from being always the case at present.

Such observations fully highlight the need to develop effective strategies based on the concept of health promotion.

PART II

INNOVATIVE APPROACHES IN THE IMPLEMENTATION OF HEALTH PROMOTION CONCEPTS

5.

BUILD HEALTHY PUBLIC POLICIES

Health promotion action means:
to build healthy public policy

Health promotion goes beyond health care. It puts health on the agenda of policy makers in all sectors and at all levels, directing them to be aware of the health consequences of their decisions and to accept their responsibilities for health.

Health promotion policy combines diverse but complementary approaches including legislation, fiscal measures, taxation and organizational change. It is coordinated action that leads to health, income and social policies that foster greater equity. Joint action contributes to ensuring safer and healthier goods and services, healthier public services, and cleaner, more enjoyable environments.

Health promotion policy requires the identification of obstacles to the adoption of healthy public policies in non-health sectors, and ways of removing them. The aim must be to make the healthier choice the easier choice for policy makers as well.

Ottawa Charter

CANADA'S FRAMEWORK FOR HEALTH PROMOTION AND CHRONIC ILLNESS

by Barbara Naegele

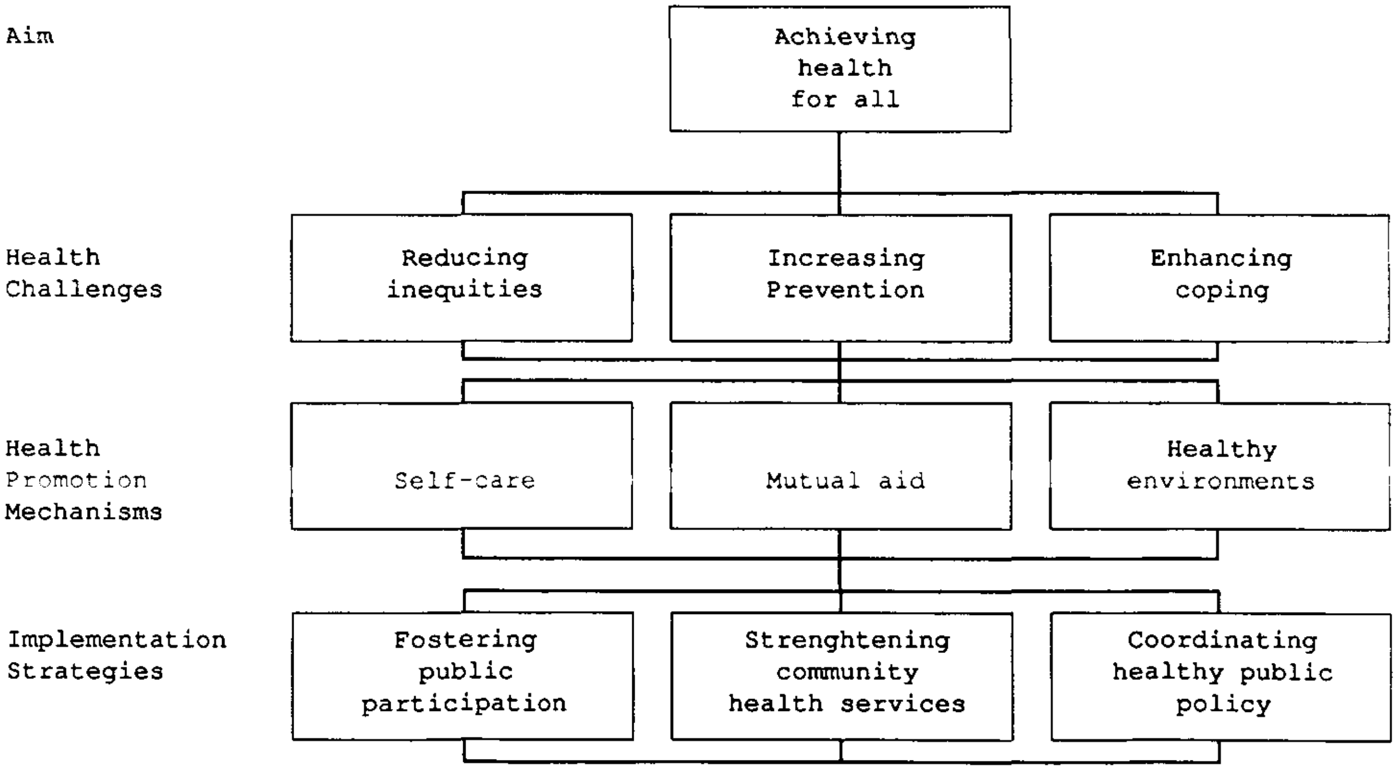
At the first International Conference for Health Promotion, Canada presented "Achieving Health for All: A Framework for Health Promotion". This document reflects current thinking and proposes a conceptual base for the analysis of contemporary and emerging health issues. The approach is founded on the principles of health promotion developed by the World Health Organization and assimilates the themes which subsequently emerged in the Ottawa Charter. As such, Canada's framework presents a context for discussing chronic illnesses and for identifying opportunities that will lead to an intersectoral course of action. The salient features of this framework (*Figure 1*) will be discussed briefly.

Chronic illness as a health promotion issue

Enhancing people's capacity to cope effectively with chronic conditions is perceived to be a major challenge, both for those with disabilities, and for caregivers. Although the Canadian framework identifies other health promotion challenges, including reducing inequities and increasing effective efforts in prevention, these issues lie alongside enhancing coping.

In Canada, chronic illnesses and their resulting disabilities are more prevalent among those with lower income, those who are older, and women in all age groups. Low income men, for example, experience 14

FIGURE 1. A FRAMEWORK FOR HEALTH PROMOTION



Source: Epp (1986)

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more years of disability than high income men (Epp, 1986). This broadening experience with chronic illness and disabilities, including chronic pain, is predicted to increase. Longevity, lifestyle changes, and an aging population, to name a few factors, are contributing to what has been referred to as longer life but worsening health (Verbrugge, 1984). Presently close to 13% of the population has one or more long-term functional disabilities while for those 65+ the figure is about 39% (Statistics Canada, 1986). Into this reality enters the notion of quality of life and the restricting of "activities of daily living".

Simply assessing the prevalence of chronic illness does not adequately convey the severity of the illnesses nor the consequences to well-being. Instead, measures of activity limitation are gaining acceptance as indicators for the impact of chronic illness. Although not yet refined, such measures show that, in Canada, the leading problems are limb and joint disorders, heart diseases, arthritis and rheumatism, trauma, mental disorders, asthma and hypertension (Wilkins et al, 1983). Based on this qualitative technique cancer is tenth. Rather than specific diseases, the restrictions on daily functioning and the interference with quality of life become the main concern of individuals and their support networks.

Processes and strategies involved in the health promotion approach

Recognizing the challenge of coping with disabilities the Canadian framework next focuses on three *processes* or mechanisms for dealing with this challenge. Namely:

- self-care or the decisions and actions individuals take in the interest of their own health;

- mutual aid whereby people take action to help each other;

- healthy environments or the creation and maintenance of conditions and surroundings conducive to health.

These mechanisms become even more meaningful when viewed as mutually reinforcing. Mutual aid, sometimes referred to as self-help, is particularly valuable in that it includes and reaches beyond the dissemination and acquisition of information and skills to provide support of a practical and emotional nature. Healthy environments, as a global concept, imply the recognition of health policies and practices within world sectors – from private homes, to cities, to natural environments. Healthy environments move the platform for health issues to spheres far outside the health care domain.

Lastly, the framework highlights several *strategies*:

- encouraging a social climate that favors public participation;

- strengthening community health services to become more supportive of personal and community needs;

- coordinating public policy and incorporating health as a consideration into the policy agendas of all sectors.

Certain systems and efforts are already in place. Most notably Canada maintains government funded health care services with universal coverage. Public participation is evident through several channels including volunteer organizations and a growing number of self-help groups. Government funded programs, e.g. the Health Promotion Contribution Program and New Horizons (for seniors) sponsor local initiatives. However, in comparison with medical and institutional services, resource allocation in support of public participation and community outreach remains modest.

Much of the mutual aid provided within communities is of an informal nature and goes unrecognized. For example, it is estimated that 80% of the care provided to the elderly comes from family, friends, or neighbors (Chappell, 1985). For those with chronic conditions and their caregivers there are many support options which could ease the daily strain and enhance living opportunities. These options include assessment, home making, home care nursing, respite care, meals-on-wheels, and telephone assurance. Unfortunately such services are not consistently available nor are they coordinated (Health Services and Promotion, 1986).

A potential for expanding horizons

The ultimate strategy, healthy public policy, is at times most visible by its absence. There are certainly exceptions. An important series of examples are the outcomes relating to the Year of the Handicapped whereby policies led to increased availability of para-transport buses, wheelchair washrooms, and ramps. Recently, one of the major undertakings has been what we call knowledge development. Meetings have been held involving every university in Canada in an attempt to bring the academic researchers together with community practitioners with a view to encouraging research based on concepts and principles within health promotion. At the same time we have carefully ensured that the federal government provides opportunities for funds to be made available for research with a stronger community and less biomedical focus. Within the next year we should start to see research submissions that reflect this "consensus building" exercise.

This in brief is Canada's conceptual contribution to a health promotion approach for chronic illness. This view expands our horizons and allows for a richer interplay of different sectors in achieving "Health for All".

GRADUAL REINTEGRATION INTO THE WORK PROCESS

by Wilfried Berg and Sabine Rinck

In their acute phase, numerous severe illnesses entail weeks or months of absence from working life and the work environment for the employee concerned. When the treatment has been successfully completed, a return to this work environment is frequently possible as well as desirable for therapeutic reasons, even in the case of chronic illnesses.

Returning to a full-time job after months of "abstinence" is nevertheless often highly problematic in terms of hours and duties. The abrupt transition to everyday working life is frequently beyond the capacity of the person concerned; he/she is unable to cope with the many demands suddenly being made and rapidly falls ill once more. In addition to the obvious damage to health, renewed illness occurring within a short time often gives rise to severe psychological problems. As a result, the sick person capitulates in the face of his illness and all concerned start thinking very quickly about early retirement.

A smooth and practical plan

Resuming work gradually, on the other hand, helps to avoid this kind of sudden overtaxing. It enables the employee to return to work at a very early stage, to resume contact with his colleagues, and to regain self-confidence by taking part in the work process and being reintegrated into the firm. This facilitates coping with the illness.

Over the last ten years, this experience has led to the development of "gradual reintegration" in individual firms, in particular large firms with their own health insurance schemes. At first, this involved individual cases where everyone concerned agreed that working hours should be increased gradually. This opened the way for rehabilitation within the firm, the advantages of which are now acknowledged by all health insurance companies.

Gradual reintegration is applied to protracted cases and to a certain number of cases of chronic illnesses. It is usually initiated by the patient's doctor, the medical examiner or the rehabilitation officer of the company health insurance scheme. In exceptional cases, the insured person himself takes action. The types of illness that are particularly suitable for occupational rehabilitation are heart and circulatory diseases (cardiac infarction), chronic diseases of the locomotor system, cancers and psychiatric illnesses. The person initiating the process asks the insured employee considered suitable for such a measure for permission to contact the employer to discuss the possibility of gradual reintegration into the job and the procedure to be followed. If the insured person is in agreement and if the employer is also prepared to carry out this measure, a reintegration plan is drawn up with the involvement of all concerned, including the company doctor, who sets out the details of how work is to be resumed and working time gradually increased, and indicates the overall duration of the measure. A plan of this nature is usually drawn up for periods varying from 6 weeks to 6 months. Once established, it can be adjusted to the actual state of health of the employee at any time. Once the plan is put into practice, the health insurance scheme normally acts as coordinator, with the participation of all involved.

There are various ways of financing such cases, depending on the firm, but they mainly fall into two different categories. In one, the employer pays the hours of work and the health insurance scheme makes up the rest in sickness benefit. On account of diverse legal regulations this often results in complicated calculation procedures, e.g. involving pension rights etc., which are not always very clear to the insured person. For this reason some firms – of which Siemens, a pioneer in the field of gradual reintegration into the work process, was probably the first – have developed a method of payment that is very easy for the insured person to understand and is also financially relatively advantageous. This provides for the in-

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sured person to receive full sickness benefit from his company health insurance scheme, provided his working week is less than 20 hours. For his part, the employer makes an independent contribution amounting to the difference between sickness benefit and the last net earnings before incapacitation, with subsequent increases in the wages or salary scale also being taken into account. If he works 20 hours a week or more the insured person receives the same amount as he would have for a full working week. As before, this is also based on the income in the last month before incapacitation, with subsequent increases in the wages or salary scale taken into account. This method is now practiced by numerous firms and company health insurance schemes as it is very convenient.

Many positive outcomes plus an 80% success rate

According to a survey conducted by the Federal Association of Company Health Insurance Schemes, there have been already several thousand cases of gradual reintegration in the working process in firms in the Federal Republic, since the introduction of these measures. The success rate, according to data from the company health insurance schemes, is 80-90%. At the end of 1987, around half of all company health insurance schemes in the Federal Republic were operating this system of rehabilitation within the company.

Finally, the following positive results have been noted – though not empirically proved – by the company health insurance schemes which are practicing the method of gradual reintegration.

The insured person returns to work at an earlier stage and thereby maintains contact with colleagues and the workplace. Full ability to work is usually regained sooner. The number of early retirements goes down and rehabilitative measures such as retraining, frequently connected with loss of the original job, are often unnecessary.

The employer can also draw again on the knowledge and ability of the employee at an earlier stage. The probability of retaining a qualified employee is higher.

For the health insurance schemes the particular advantage of gradual reintegration is that the periods of incapacity for work are usually shorter with the result that sickness benefit payments are lower and replaced in part by earnings. In the case of successful reintegration hardly any claims have to be made on other social insurance institutions such as pension funds or the employment exchange scheme.

The best proof of this positive experience is the institutionalization of gradual reintegration through law. Until the end of 1988, no legal endorsement of this procedure existed. Now, the health reform law recently adopted by the German Federal Parliament (No 74 SGB) fully acknowledges gradual reintegration in the work process.

MEETING CARERS' NEEDS: A TEN-POINT PLAN FOR CARERS

by Ann Richardson

The needs of people requiring extra care - people who are elderly, chronically ill or disabled - are now gaining long overdue recognition. Yet the somewhat different needs of those who look after them at home - known as "carers" - remain largely ignored. Two years ago, representatives of a group of organizations in Britain joined together to commission a project to redress this balance. They were concerned both to set out the range of carers' needs and to issue guidance on the kinds of services necessary to meet them. These documents, prepared following extensive consultation with people working in the field, have now been published (Richardson et al, 1989). This short article provides a brief overview of the issues.

Who are the carers ?

Carers can be defined as people who are looking after a relative or friend who cannot manage at home without help, because of disability, illness or old age. They may be parents of a mentally handicapped child, a husband whose wife has a disability, a daughter looking after her elderly mother or someone who is caring for a chronically ill friend. Most carers are women, but there are also many male carers. Their circumstances vary enormously. This is partly due to differences in the nature and severity of the condition of the person being cared for. But it is also due to differences in individual histories and expectations. Caring takes place within a relationship; the nature of that relationship over time tends to affect carers' feelings about the work.

Caring entails both physical and emotional involvement. The tasks can be tiring, unpleasant and even potentially dangerous; lifting, for example, is a frequent cause of injury. The carer's life may have to revolve around the person cared for; many carers cannot go out to work and some cannot go out at all. But it is often the emotional side which creates the greatest strain. Feelings of resentment, anguish and guilt can create many tensions. Of course, it must be said that many carers gain enormous satisfaction from their work, undertaking it with the love, generosity and loyalty associated with their family role.

People often find themselves deeply in the role of carer, with little chance to consider whether it is what they want to do. This is the case both when the job of caring has built up slowly, for instance a spouse with a chronic disease, and when it is acquired suddenly, as when a handicapped child is born. Once acquired, the role is exceedingly difficult to shed. All the pressures - both external and, perhaps more important, internal - are on the carer to care. In addition, it is often difficult to share the tasks. Many carers get little help from other relatives, are reluctant to ask for help and become very isolated.

A ten-point plan to help carers

So, what can be done to help? The ten-point plan for carers sets out ten distinct needs. To help meet each, there are many kinds of action which can be taken - ranging from major changes in policy direction for all carers in an area to small practical ideas for helping individual carers on a day-to-day basis. All are concerned to make the tasks of caring easier and to reduce the extent to which carers feel trapped by the caring role. They are spelled out at length in the longer document. A few brief examples are provided here, to give the flavor of the argument.

1. RECOGNITION OF CARERS' CONTRIBUTION and of their own needs as individuals in their own right.

Policies for community care, for instance discharging people from hospital, need to take into account carers' ability to cope - and the services available to support

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them. This is both at the area-wide and at the individual level. Those providing services, in clinics or in people's homes, should address carers' needs as well as those of the person cared for. In practical terms, this means taking time to talk to individual carers, listening to their concerns and respecting their contribution. Carers should not automatically be told they are "doing a great job"; it may be more appropriate to acknowledge that they seem tired and to suggest potential sources of help.

2. SERVICES TAILORED TO CARERS' INDIVIDUAL CIRCUMSTANCES, needs and views, through discussions at the time help is being planned.
Services need to be planned to be flexible and responsive to carers' needs, as well as to those of the person cared for. This is both in the overall design of services and in the planning for any one family. Some kind of case management system, where one person is responsible for pulling together and monitoring a range of services, should be established. Access to services should be simplified. Carers should be kept well informed about decisions made on their behalf. In some situations, there may be a need for some kind of mediation between a carer and the person cared for.

3. SERVICES WHICH REFLECT AN AWARENESS OF DIFFERING RACIAL, CULTURAL AND RELIGIOUS BACKGROUNDS and values, equally accessible to carers of every race and ethnic origin.
Services should be designed to meet the needs of all groups within society. There should be no discrimination on grounds of race, color or ethnic origin. In some circumstances, carers from minority groups have particular needs and efforts should be made to provide for them. Much of the help needed with caring is very personal and requires someone who understands the cultural norms of carers and their families. Those providing services also need to ensure that all groups are fully informed about their availability and that information is translated as appropriate.

4. OPPORTUNITIES FOR A BREAK, both for short spells (an afternoon) and for longer periods (a week or more), to relax and have time to themselves.
Respite care can be set up in many ways. It can be provided in the home, to allow the carer to go out, or elsewhere, to give the carer time at home alone. It can be for a very brief period or much longer. It can be a formal arrangement in a small institution or an informal arrangement between families. Many kinds of respite care should be available, to enable carers to choose the kind of help they most need. Such care should demonstrate an understanding of the individual needs of the person cared for, or it will not be used. Information about respite care arrangements should be widely available.

5. PRACTICAL HELP to lighten the tasks of caring, including domestic help, home adaptations, incontinence services and help with transport.
Carers need a wide range of practical help. Some need an extra pair of hands, to help with caring and other domestic tasks. Home aides should be provided for such families, including outside normal working hours. Some carers need various practical aids to help with feeding, bathing, lifting and so forth. These should be widely available and well publicized. Transport arrangements are also vital, to enable some carers to go out.

6. SOMEONE TO TALK TO about their own emotional needs, at the outset of caring, while they are caring and when the caring task is over.
Carers often suffer considerable isolation; they need opportunities to talk about their problems and experiences. This may be provided by a professional counselor of some kind. But many carers also welcome the chance to join carers' support groups because of the common understanding which arises from being in the same situation. Professionals should seek to encourage the development of support groups and to tell carers about them. It may also be helpful to put a carer in touch with one other carer in a similar situation.

7. INFORMATION about available benefits and services as well as how to cope with the particular condition of the person cared for.
Services for carers should be widely publicized. Especially where they are unable to go out of the house, carers have limited opportunity to find out about local services. All professionals who work with carers should aim to remind them about what is available, including benefits, local services and organizations which might help. Information centers for people

with disabilities should cater for carers as well. Carers' centers, providing information and advice, could prove particularly helpful. Carers should also be given full information on the nature and prognosis of the condition of the person cared for.

8. AN INCOME WHICH COVERS THE COSTS OF CARING and which does not preclude carers taking employment or sharing care with other people.
Carers' income is severely restricted by the caring situation. Many cannot work outside the home or have to take limited employment which enables them to maintain their responsibilities at home. At the same time, there are often additional costs incurred as a result of caring – extra washing, heating, transport, even adaptations to the home. Adequate state benefits should be available for carers and the person cared for. Employers should be encouraged to provide flexible working arrangements for carers.

9. OPPORTUNITIES TO EXPLORE ALTERNATIVES TO FAMILY CARE, both for the immediate and the long-term future.
Many carers feel they have no real option to caring, but would like to be able to discuss alternative arrangements. Those designing services should ensure that there is sufficient provision for people who do not live in the family home. Such provision needs to be widely publicized and made accessible to those who want to explore this option. Those working with carers need to handle discussions of this matter extremely sensitively, as they may be deeply reluctant to raise the issue.

10. SERVICES DESIGNED THROUGH CONSULTATION with carers, at all levels of policy planning.
In order for services to reflect carers' needs, they should be designed in discussion with carers. Those responsible for area-wide policy should set up formal systems for consulting carers about service provision. Those running individual institutions or services should also discuss day-to-day arrangements with carers. There may be central issues about what is provided, how much and in what ways. Carers may also be able to advise on many detailed issues, such as the hours when respite care is available. Carers' individual views should also be respected in discussions with professionals.

Two pressing needs: support and recognition

These proposals may seem highly radical in some areas. But they were developed in a spirit of reason and common sense. Carers are not a clamoring crowd – demanding their rights – nor would they wish to be seen as such. Their case is very clear. They currently save taxpayers substantial sums by keeping those they care for out of institutional care. More importantly, if they are not given adequate support, many may not be able to continue to do so. And finally, anyone concerned with equity cannot fail to be moved by the load carried by many carers. Finding some means of giving them help and support seems only right.

It can also be seen that the need for some change will become increasingly pressing. The number of people needing care is growing fast, most evident in the case of very elderly people. At the same time, the supply of "ready" carers is diminishing. With the increasing participation of women in the labor force, real questions arise about their continued willingness and ability to fulfil their traditional caring role. It can no longer be assumed that there is a sizeable supply of potential carers, sitting at home looking for something to do with their time.

In some countries, as in Britain, it may be difficult to argue for any new provision at a time of retrenchment. Those responsible for policy will feel hard-pressed to find any new resources. But not all of the recommendations involve resources. Some are more concerned with a need for changed attitudes and assumptions. Some professionals may need to review their own assumptions about family care, for instance, the obligation on women to provide care, giving up work if necessary. Overall, those providing services need to bring the carer into their thinking. This means talking with carers, keeping all options open for discussion and respecting their views. It means recognizing carers as people – not simply someone who helps out with the person they care for.

FOCUS ON THE FUTURE

Healthy public policies should be built to:

- ensure a more equitable distribution of financial, technological and other social resources between professionals and people suffering from chronic conditions, and their families;

- underpin health laws and regulations that are conducive to programs and measures that integrate rehabilitation and health promotion into the workplace;

- promote legislation on the patient's right to information, consent and access to records and to psychosocial support; and

- provide financial support for complementary therapies (including insurance coverage for health promotion measures) and for the development of self-care and self-help.

6.

CREATE SUPPORTIVE ENVIRONMENTS

Health promotion action means:
to create supportive environments

Our societies are complex and interrelated. Health cannot be separated from other goals. The inextricable links between people and their environment constitute the basis for a socio-ecological approach to health. The overall guiding principle for the world nations, regions and communities alike, is the need to encourage reciprocal maintenance – to take care of each other, our communities and our natural environment. The conservation of natural resources throughout the world should be emphasized as a global responsibility.

Changing patterns of life, work and leisure have a significant impact on health. Work and leisure should be a source of health for people. The way society organizes work should help create a healthy society. Health promotion generates living and working conditions that are safe, stimulating, satisfying and enjoyable.

Systematic assessment of the health impact of a rapidly changing environment – particularly in areas of technology, work, energy production and urbanization – is essential and must be followed by action to ensure positive benefit to the health of the public. The protection of the natural and built environments and the conservation of natural resources must be addressed in any health promotion strategy.

Ottawa Charter

THE WORKPLACE AND THE COMMUNITY

by Horst Noak

Difficult problems face the chronically ill person who goes back to work or tries to get employed again after a period of medical treatment. Steps need therefore to be taken by the chronically ill persons themselves, their families, their employers, communities and political decision-makers in order to promote conditions for a decent and productive life.

Employment – In general, the situation of chronically ill persons who were working before undergoing medical treatment differs considerably from the situation of those who were unemployed. In a society that places a high value on work, being employed is not only an essential economic resource; it also defines the social status and shapes the self-concept of a person. It is therefore essential to promote the return to work of formerly employed persons and to offer jobs to those who were unemployed. Only thus can the vicious circle of unemployment and continuing disablement be broken.

Appropriate jobs – There tends to be a shortage of suitable jobs for chronically ill persons, especially in countries with high unemployment rates and in the more traditional sectors of the economy. Appropriate jobs need to be created for specific categories of disabled people, including opportunities for part-time employment. Without a will for enforcement, equal opportunity laws or regulations are not sufficient.

Who should decide? – Given appropriate job opportunities, chronically ill persons should have a say in whether they can go back to work and under what conditions. In this respect, the roles of doctors, the social security system and other parties concerned need to be clarified. *Ad hoc* decisions on the employment status of the chronically ill should not be a substitute for an employment policy.

Unskilled workers – In countries with high unemployment, the unskilled or poorly trained workers require particular attention. Due to the demographic situation, this group is expected to grow faster than other social groups, thus widening the health gaps between the low and the high income groups. Although the problem is very difficult to solve, it needs to be brought to the attention of politicians and society as a whole.

Stigmatization – Stigmatization of the chronically ill person is another serious problem, especially in the workplace. Cancer, for example, may be considered contagious by workmates or colleagues. In order to integrate the chronically ill in the workplace, it is necessary to change the social image of diseases and of the chronically ill persons themselves. This is a very difficult process which requires multi-facetted efforts focusing mainly on providing adequate information, promoting self-help groups, and networking within companies and communities.

Support of the chronically ill person – In addition to medical care, the chronically ill person and his/her family need support to cope with the social consequences of the disease, in particular with the loss of social status and stigmatization. Personal advice, counseling, training courses and participation in self-help groups should be offered to help chronically ill persons to regain confidence.

The role of occupational health services – In larger companies or institutions, the occupational health service can facilitate the integration of the chronically ill and help them achieve a productive and satisfactory working life. These services normally include physicians, nurses and social workers. Other professionals and, very importantly, lay people should be included. Self-help groups and other groups led by professionals can play a useful role (e.g. the Volkswagen experience). Several companies may wish to join efforts to establish such a service; community health structures could also be used for the purpose.

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Health promotion in the company – In addition to occupational health services, companies should set up special health promotion groups to facilitate promotion at the workplace. Experience shows that a committee including management, trade unions and persons of reference can successfully deal with health problems (e.g. alcoholism). To set up such an infrastructure, companies need advice from experts and support from the community and the government.

The role of the community – Health promotion efforts in the community are a much needed prerequisite for the success of health promotion activities at the workplace. The community might, for instance, support companies in setting up integrated health promotion programs for both chronically ill and healthy employees. Consideration should be given to the contribution the community can make with regard to self-help resources, professional help, financial support, etc.

A HEART GROUP IN THE WORK SETTING

by Hauke Engelhardt

Texaco's heart group shows how joint efforts of the management of a firm on the one hand, and a company doctor on the other, can have very beneficial results for staff suffering from heart and circulatory diseases.

An idea becomes reality

At the suggestion of the company doctor, a sports group was established in October 1980 at the headquarters of the German Texaco company in Hamburg, with the aim to provide opportunities for therapeutic exercise for staff with coronary heart disease.

An adequate sports hall belonging to the firm was available and all we needed was a suitable sports teacher. That was not so easy to find. Even the local sports associations were unable to help, but finally the problem was solved. At this initial stage there were also informal discussions with the Association for cardiac prevention and rehabilitation in Hamburg, since this organization already had a wealth of experience with coronary or, as they are called today, "heart groups".

The establishment of such a group represented an additional practical measure to facilitate reintegration into the work process – an area where Texaco already had a positive record. After only a short time, the staff were making good use of this offer and all the participants soon confirmed that it was well worthwhile.

How the group functions and who participates

The hour of sport for the heart group takes place once a week *during* working hours. For insurance reasons only, the heart group comes under the company sport program. This enables the firm to cover all the costs more or less automatically – including payment of the teacher. During the exercises the company doctor is present, and another member of the company health service is also actively involved. For obvious reasons, only staff and retired staff of the company can participate in the heart group. A further requirement is the company doctor's prescription. A discussion with the doctor resulted in the decision that participants of the heart group would not include exclusively infarct patients but also patients who are particularly at risk and for whom the therapy is also a means of secondary prevention. In all cases participation is entirely voluntary.

A sportive, relaxed ambiance

Texaco's heart group is very similar to other groups organized by sports associations. Of the 20 participants registered, around 15 usually attend the exercise session. The balanced distribution of active staff and retired staff has changed slightly on account of premature retirement and the early retirement regulation, so that today around half of the group membership is comprised of retired patients.

The leader of the group is an experienced, qualified sports teacher who has been in charge of the group from the beginning. There seems to be several advantages in having a person from outside the firm, in particular the fact that he is not familiar with the company's hierarchy. For him, all the participants are members of the exercise group, and he takes only account of each individual's capacity. Among the participants themselves, there seems to be no problem with respect to existing (or former) hierarchies. At the beginning, however, it was a little difficult for the participants to hit on the appropriate form of address, with the familiar "Du" (you) form being usual in the sport setting while the formal "Sie" (thou) form is used in the company. Whatever each individual decided – "Du" or "Sie" – the difficulties were never serious.

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It is perhaps of interest to note that more recently, and particularly after a joint excursion to the rehabilitation clinic at Bad Segeberg, the "Du" form appears to be more generally used.

The kind of activities offered to participants resembles those of a training group (see Döhner and Görres, p. 34). Thus, emphasis is placed on games, keep-fit exercises and endurance training – naturally in a different form each time – with the aim of strengthening the heart and circulatory system. Exaggerated effort and competition are obviously out of place here.

The very real pleasure that participants experience in doing group exercise is very apparent throughout the session. Afterwards, some of the patients go back to work, others go home and a few go to the canteen to chat for a while over coffee.

In conclusion

Texaco Headquarters in Hamburg has had very good experience with its company heart group, according to all concerned. Company doctors should support and where necessary initiate similar programs in other firms.

Group problems to be feared with respect to the internal hierarchy of the firm did not occur and there have been no difficulties in this particular case.

There are definite advantages in employing a person from outside the firm to act as leader of heart groups.

On account of the overall positive outcome – and in particular the positive reaction of the participants – this is certainly a model that could be copied with profit by many firms.

FOYER-HANDICAP: A NICE, SUPPORTIVE, ENVIRONMENT

by Annette Kaplun

Hardly have you set foot in the Caroubiers' ateliers that you find yourself discussing software, hardware, and the evaluation of service systems ...
Most of the men and women with whom you talk are in wheelchairs. But you hardly notice it. "The physically handicapped persons who work here cannot be integrated in normal economic channels, often because of architectural barriers. Our aim is to give them an occupation 'à la carte', adapted to their individual capacities and which really gives them the feeling of their worth" says René Bonard, the director of the three workshops established by Foyer-Handicap – a Swiss private association, founded some 25 years ago and which has been developing residential and occupational centers in the Geneva area for adult persons, physically handicapped.
"Atelier" is used in French to designate a commercial workshop as well as an artist's workroom. In the case of Foyer-Handicap, it is something in-between: the workrooms are never very large – despite the need for extra space for the wheelchairs – but the atmosphere is very much that of the artist's atelier... Here, a group of five people are modelling clay; two of them are working in the garden, in the sun. There, another group – much larger and more "organized" – is stuffing envelopes with a series of documents announcing a fair for the renovation of Geneva's cathedral – a big local event. "Hello! How are things?" Bright smiles greet the visitor. "A lot of work?" – "Oh, yes!" Someone replies in English! Not surprising in Geneva, an international city par excellence. Actually, the group working that day includes some ten Swiss people aged 25 to 40, and three younger people, an Ethiopian, a Tunisian and a Moroccan, brought to Switzerland by Terre des Hommes (Man's Land).
In another room, as you enter, you can *feel* the concentration: people are working on PCs. Computers have completely transformed the life of the physically handicapped. In the past, people who found themselves in a wheelchair, no longer able to use their hands following an accident but whose intellect was intact, often experienced much difficulty in coping with their new situation. Michel is a case in point: when he came to stay at Foyer-Handicap, there was only one workshop with two kinds of activities: handicraft and processing. He was not the artistic type and packaging various materials was not the most exciting thing for him. So, he read all day long and "refused" to work. Usually, he was in a very bad mood. Then, he discovered the computer world. Today, Michel can still be in a bad mood, but only because his computer is misbehaving!

Who works in Foyer-Handicap ateliers?

There are about 110 persons employed in the three ateliers which are all located on the ground floor of residential centers of Foyer-Handicap – themselves integrated in residential districts, nearby shops and restaurants. This working population includes residents and outside employees. About 50% are in wheelchairs. The others, less handicapped, are all non-residents. They suffer from very diverse kinds of handicaps, many of them related to an illness of a degenerative nature, such as multiple-sclerosis. Others have been the victims of accidents and may be heavily or lightly dependent.
The range of activities offered to these people is quite extensive and "innovation" is the password. If I mention that a small group of handicapped was absorbed last year, during two months, in the construction of a solar car for which a firm had contracted their services, you will understand what I mean!
Making pastries is another popular activity: three young ladies, only slightly handicapped, are the assistants of a chef who has taught them all the secrets (well, almost...) of pastry making. Then, there is "the" shop where the pastries are sold, and the handicrafts. People come there, not just to be nice and buy things, but because Huguette, the always-smiling-lady-in-the-wheelchair, is the shop manager.

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Who does not like to have a chat with Huguette and her friend and assistant, Yvonne?

They share a pleasant, four-room flat with a balcony on the fourth floor of the building where the shop is located – one of the three residential and occupational centers of Foyer-Handicap. The nice thing about living there is that if they have a problem they can benefit – although they are only tenants – from the services available to residents: the restaurant, the cleaning services and in case of emergency, they can call on the caring staff or the night nurse.

But to come back to the ateliers. For the 110 employees spread out in the three workshops, there are no less then 23 instructors, most of them professionals who have graduated from a school which provides a three-year inservice course leading to a masters for people who want to work with the handicapped.

Relationships in Foyer-Handicap workshops are very much on the "horizontal" level: it is often hard to tell who are the employees and who are the instructors. This creates a nice, relaxed atmosphere. Visits from clients add to the animation and everyone enjoys it. Often, the visits end with a cup of coffee at the cafeteria which is manned by two 20 year-old girls, both slightly handicapped.

The economic aspect

A word on salaries first: these are established according to a scale set by the Swiss Federal Government, which takes into account the level of the pension allocated. This pension is determined by the degree of handicap and aims to compensate for partial or total incapacity to earn a living. The workshops do not try in any way to make a profit. Yet, Foyer-Handicap was very proud last year to announce that the ateliers had been able to total an income of Sw.frs 543,000. The activities which are most rewarding financially are those associated with computer work – including the bookkeeping service recently developed to keep the accounts of small business firms, sports clubs, associations, etc.

The income earned by the ateliers does not affect the salaries paid to the employees. It only influences the subsidies from the federal and cantonal autorities, which are adjusted according to the deficit. These subsidies are part of the total grants that Foyer-Handicap receives for its residential and occupational centers. They cover about 60% of its Sw.frs 7 million budget. Other income is derived in equal parts from (a) the fees paid by residents to cover nursing care, lodging, food, transport, etc. and (b) private sources. Community involvement and support are very high and represent important aspects of a sound economic balance and of the process of integration.

A supportive environment

The span of activities from which to choose as well as the pleasant surroundings are two factors which certainly contribute to the popularity of Foyer-Handicap ateliers. But there is a third factor – which is at least as important: a real concern for the *total* well-being of the employees. For the staff, if an employee has a problem at home, or a personal problem, this deserves as much attention as difficulties at work. People occupy posts and have responsibilities but first of all they are human beings who need care and support with a "plus" due to their handicap.

The fact that there is a waiting list of some 20 persons (soon another workshop will be opened) is the best proof of the supportive quality of the environment provided by Foyer-Handicap ateliers – a place where people like to come and work. From the point of view of health promotion, this very relaxed and human work environment enables handicapped people to better integrate their health problems – some might say their pain – and to develop fully their potential, often with surprising results.

HEALTHY FOODS: MANY ISSUES INVOLVED

by Sigrid Arndt

The part played by certain nutritional habits (too much food, too much fat, too much salt) in the development of cardiovascular diseases has been thoroughly researched. These habits stand out – together with smoking, lack of exercise and stress – as leading risk factors with regard to cardiac infarction. As it is possible to modify such habits (Shaefer & Blomke, 1978), three large community-oriented intervention studies aimed at influencing risk behavior of this type have been initiated in the Federal Republic of Germany (GCP Study Group, 1988; Nüssel & Lamm, 1983; Mettmann District Sickness Fund, 1987).

With regard to cancers, a causal relationship between nutritional behavior and the type and incidence of the cancer has not so far been clearly established. Nevertheless, cancers (in particular those affecting stomach, colon, uterus, breast and prostate) are being connected with nutritional habits, as indicated in a report of the German Society for Nutrition (1983).

Some of the more general nutritional recommendations aimed at preventing cancer were published in the US by the National Research Council (1982) and were later incorporated in the *European Code against Cancer* (Federal Center for Health Education, 1988).

Our current state of knowledge has resulted in cardiac infarction patients being strongly advised by their physician to change their lifestyle, while cancer patients are usually told to simply carry on living as before. As recently as 1983, the German Cancer Society guide was extremely critical of so-called "cancer diets" (Scheel & Aumiller, 1983).

Since then, three major vegetarian studies in the Federal Republic of Germany have shown that vegetarians are less likely to die of heart and circulatory diseases or cancer and show, overall, better results with respect to medical risk factors (German Association of Vegetarians, 1987; German Society for Nutrition, 1988).

Whole-food nutrition rich in vital substances, with a drastic reduction of meat and sausage consumption, is today no longer only recommended by a few "outsiders" in the medical profession.

The Bavarian Cancer Society, for instance, sponsored a study by Anemuller (1987) to introduce the public to metabolically active whole-food. In fact, there is now such interest in the subject of nutrition that a wealth of publications on whole-food nutrition, in particular recipe books, has appeared on the market.

Despite this interest, three problems stand out: first, providing adequate information on health foods; second, making these foods easily accessible; and third, their cost.

Ten years ago: the alternative scene

My personal experience in attempting to follow a healthy diet after being faced with cancer is very revealing. This was ten years ago. Nobody talked about whole-food diet at that time and the shops where you could buy such foods were quite few. They were also bizarre places. The people who worked there had long hair, they wore bright colored self-knitted sweaters and seemed to belong to the "alternative scene". I found it very difficult to go shopping there because I felt like an outsider. I was also very ignorant. I did not even know what buckwheat was, or any kind of whole grain, and I did not dare ask... So the first thing I did was to buy books and to read. I had a doctor who practiced naturopathic medicine. He had told me: "You must change your diet!" but he did not give me the slightest clue as to what to do. I had to discover everything by myself. Now, it is quite different. You find whole-food even in large department stores and most magazines carry recipes on "healthy foods".

What is whole-food nutrition?

Whole-food nutrition is not a diet, and there is no strict ideology behind it that tells the consumer exactly what he must do or not do. It means using foods as much as

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possible in their natural state (Moody-Thrash & Thrash, 1982).

Here the old principle of Hippocrates can be applied: "Your food should be your medicine and your medicine your food".

Whole-food nutrition consists primarily of vegetable foods. While only a few years ago one gram of animal protein per kilogram of body weight and per day was recommended for adults (hence on average 70g for a man), the German Nutrition Society today considers 55g to be sufficient, of which half should be of animal origin (i,e, the equivalent of about 200g of curd cheese). Cereals, peas, beans, pulses and potatoes are good sources of protein: this is something that few consumers know.

It is further recommended that at least one-third of the daily food intake be consumed in a raw state, i.e. as salad, fresh cereal muesli and fruit.

Cooking on a whole-food basis does not just mean leaving out meat altogether and otherwise eating as before: it implies eating foods that are different (cereals, peas, beans and pulses, nuts, salads, honey, concentrated fruit juice), cutting down on others (sausage, meat) and simply avoiding some (super-fine flour, sugar, ready-prepared products).

Whole-food is an enrichment of the daily menu and is no "ascetism" or "denial of pleasure". One important aspect is to make this food look good. If you cook whole grain, for example, it looks grey. But if you put in it some fresh vegetables like carrots and fresh herbs, then it becomes colorful. The problem is similar with whole grain noodles. They taste just as good as white noodles, but they look grey. So, they should be combined with a colorful sauce. After all, people eat also with their eyes, not just with their mouths.

Access to "health foods": a complex problem

An increasing number of consumers are not only interested in whole-food diets but want foods that have been grown without chemically synthesized nitrate, phosphate or potash fertilizers, and without insecticides, fungicides and herbicides. This is both for health reasons and to protect the environment.

The term "biologisch" (organic) is not legally regulated in the Federal Republic of Germany – by contrast with other countries like Austria and France. Since, however, adding the prefix "bio" on foods promises increased sales to scared consumers sensitized by chemical and hormone scandals, a growing number of supermarkets have "bio corners". The information "organically grown" does not say whether and by whom the cultivation is controlled. In addition, the producers often choose product names which closely resemble those introduced on the market by well-known associations for ecological agriculture, e.g. "Biolan" instead of "Bioland", "Naturkind" instead of "Naturland", "Detmer" instead of "Demeter". Original products are primarily found in so-called health food shops (Naturkostläden). One should be cautious about most of the products marked "naturally grown" or "organic" on some supermarket shelves, as a study by the Ecology and Health Working Group in Göttingen has shown (unpublished manuscript, 1988).

Health food shops known as "Reformhäuser", which have just celebrated their 100th anniversary, have a special position. These are strictly controlled by an organization called the "Neuform" (New formula), whereas the "Naturkostläden" are not.

The person interested in whole-foods or organically grown products should still look very carefully at the label: the "New Formula" symbol alone is not yet a guarantee and fewer than 40% of the products are grown in accordance with the above-mentioned guidelines. In addition, the health food shops have their own "new formula organic cultivation", but the exact guidelines for this have not yet been published in spite of repeated written requests. It is known that the "New Formula" organization also allows "partial changeover", in other words the farmer has a "new formula contract" for individual fields, but uses conventional fertilizers and sprays on neighboring fields (Ammar, 1989).

Most products in the health food shops in the Federal Republic of Germany fulfil the criteria for whole-foods. Nevertheless, even here not all the articles or their individual elements are products of organic cultivation. This is stated on the labels. Food additives, however, are only permitted in limited quantities.

It is fiercely disputed to what degree organically grown foods are healthier than conventional products. Equally disputed are the methods used for conducting research and publishing findings on the subject. A number of studies indicate, however, that differences exist between a conventional and alternative diet as far as agricultural chemical residues are concerned.

Organically grown foods were only rarely shown to contain residues of pesticides (Kapfelsperger & Pollmer, 1986) but up to 75% of the other foods had residues, though these were still less than the highest permitted quantity. Whether regulations concerning these quantities sufficiently protect the consumer remains a matter for debate (Philippeit & Schwertau, 1986).

Another problem relates to "convenience foods". These ready-prepared products contain additives which must be declared, at least with packaged products. But most consumers do not understand the chemical descriptions or numbering system, nor are they able to judge whether these substances could be related to their particular health problems.

Clinical ecologists have observed a constant increase in chronic illnesses which may be connected with over-sensitive reactions to chemical residues, nutritional additives and foods (Randolph & Moss, 1986; Calatin, 1988). For this reason, they advise chronically ill people to eat according to whole-food criteria, since the findings of various studies indicate that whole-food may improve their health more than a normal diet and help them to cope better with their illness (Anemueller, 1987; Mar, Kleine & Windstosser, 1985; Douwes, 1986). It seems reasonable to suggest that ill people can meet most of their needs more appropriately with food as free as possible from residues.

The economic aspects

The consumer center in Hamburg looked into the subject of whether "alternative" foods are more expensive than normal foods, as is generally assumed. They came to the conclusion that a whole-food diet comprised of organically grown products, when applied consistently, costs on average 12.50 marks extra per person per week (Kapfelsperger & Pollmer, 1986).

This difference can be reduced if the food is bought via producer-consumer societies, sometimes also called "food coops", rather than in health food shops. There are now such societies in most larger towns in the Federal Republic of Germany. Members of such producer-consumer societies obtain organically grown products directly from the producer. The products offered depend on the requirements of the members. Some societies have only fresh products, while others also buy processed ecological products. Costs such as rent, the purchase of food and food shrinkage processes are borne equally by the members. There are no trade margins.

A few weeks ago, I started an experiment with unemployed people. When I suggested they should change their diet, they replied that biological foods were much too expensive. We discussed whether they needed to buy only biological foods or could just improve their diet and buy fresh vegetables rather than a can of peas, for instance. So they started with fresh foods which they bought in their usual store and they were quite surprized to find that in the end this did not cost more. Of course, it is much better to buy organically grown foods but what is more important, is to encourage people to start. The first thing is to make them curious. Let them try and have a good experience – with tofu, for example, which people usually like – or with different combinations of whole grains.

In conclusion

Changing eating habits cannot cure a chronic illness. It can serve, however, to improve the general condition of the person concerned. It can also help to promote the metabolic activities of the organism with a wealth of vital substances, minerals and trace elements, and to strengthen the immune system. The fewer residues and nutritional additives a food contains, the better it can fulfil these functions.

There is still a long way to go, however, before our individual and social environments are fully supportive of health promoting nutrition behaviors.

CHRONIC ILLNESS: A MEDIA PERSPECTIVE

by C. Michael Shaw

The media can play a major role in creating supportive environments. They influence the man in the street as well as the decision-maker. They help set norms, they contribute to foster community action. The information they transmit carries prestige. Health workers know this. They realize the power of communication. But seldom do they know how to approach media professionals and to provide them with what they need most: adequate, to-the-point and lively information. This paper provides them with useful guidelines on how to develop effective cooperation with the media and "help the media to help them" transmit the health message and create supportive environments.

"The problem is simple: your idea is worthy and boring. Now, go away and come back with something that is genuinely lively and interesting, and preferably sexy." With these words one particular editor dismissed the suggestion from a colleague, a journalist on a national newspaper, for a feature article about a remarkable lady who had battled against a painful and debilitating spinal illness to raise money for charity.

That was ten years ago. The same editor was a heavy smoker and drinker, with predictable views on health and health promotion to match. These values and attitudes derived from a strong journalistic culture which has perhaps changed to some extent in recent times. Journalists, after all, are also part of the wider community. They are increasingly writing, broadcasting, and thinking about lifestyle issues. But the genuinely sympathetic proactive media health correspondents remain very much in the minority, and most professionals concerned with health education can recount negative experiences of attempts to get publicity for their ideas and campaigns. The exception is of course AIDS, which has one supreme advantage. It represents bad news: there are millions of potential victims, it has an important, though far from exclusive sexual base, and yet so far – at least as the media perceive it in many countries – its visible ravages are relatively concealed.

Most other issues, however, notably smoking and alcohol, are regular and timeless concerns, and therefore often lacking in media "novelty" and attraction. *Chronic illness* can have even less appeal. It is often, and unfairly, perceived to lack a social base. Family and wider social, economic and ecological factors tend to be overlooked by many journalists. It is evaluated mainly in terms of the experience of illness, and as such largely ignored. It remains, in other words, a suitable case for media treatment and action. How to reconcile this need with the inbuilt limitations of journalistic interest already outlined? In the first instance it is vital to come to terms with the fact that the issue may not necessarily appeal to the media, that it may be viewed as "worthy and boring". This is not a prescription for inertia and depression, rather a crucial appeal for self-knowledge and the use of *imagination*.

Three questions

In formulating any strategy for media action the key questions the health professional should ask herself or himself should always be WHY, WHAT and HOW?

WHY it is important to get the issue across to the public and/or social and political decision-makers by using the media?

WHAT precisely are these issues?

HOW can the publicity be achieved to ensure the greatest impact?

From practical experience in this field it would seem to me that health promotion professionals can usually agree on the general nature of the issues they would like to have discussed, and the reasons for this. Chronic illness, for example, can be very costly in social and individual terms, relevant contributory factors need to be identified, public awareness of these factors heightened through greater information flow, and appropriate actions initiated.

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But HOW to achieve this is another matter, and represents the greatest single difficulty experienced by those involved. I would also have to say that it is often the inadequate dissimination of information and argument, however well intentioned, that undermines attempts at media access. There is really not much point in simply hoping that your report or campaign press release or documentation will generate media interest. It is much more complex than that.

Pain: the final threshold – a successful media collaboration

"Pain does destroy people's lives. Most doctors still think that if a pain-killer does not take the discomfort away, then there is nothing wrong with you. It must be a mental illness." (Patient).

My multiple award-winning program on the nature, experience and treatment of pain came about in an interesting way. It was based on a relationship of trust between one section of the media and a range of health and health promotion professionals. Professor Michael Bond is Vice-Principal of Glasgow University in Scotland. He runs a specialized pain clinic in the city's Gartnavel Hospital. The author of many articles on the subject, he forwarded this material to a journalist he had identified as interested in and sympathetic to the analysis of this type of subject. In the preliminary program discussions he assessed carefully and courteously the aims of the program team, and then gave his permission for access to the clinic and related facilities.

The clinic deals with people who have some form of physical problem which has given rise to emotional symptoms, a condition for which they may require psychological treatment. There are also patients who are not coping well with chronic physical disability, and this has produced a depressive illness which has in turn made them liable to feel more pain. The treatment here involves dealing with the depression to lessen the pain, and make what pain is left more amenable to treatment with a range of physical and drug therapies. The third group of patients do not have any obvious physical explanation for their pain, and yet they complain of intense pain. Here psychological mechanisms are identified for treatment on an inpatient basis. The final group of patients consists of individuals who suffer from severe psychiatric illness, and in particular from severe depression. Such cases are also dealt with by Professor Bond and his staff on an inpatient basis, where the range of treatments include self-help and family support groups.

The media team was given permission to trace the experiences of one of the patients at the clinic, with the full support of the patient and her family. In this respect Professor Bond was taking two risks. One was that the treatment regime would be interrupted and fail. (In the event a partial cure was achieved). The second risk was that the media team would seek out the "sensational" in their program. But in the end such was the *positive relationship* between everyone concerned that a successful program was made, the issues fully explored, and much awareness and discussion generated. Moreover, in addition to *normalizing* the experience of chronic pain and making the experience *intelligible and accessible*, he was also able to call for action on *social, environmental* and *health* grounds, and indicate the *positive potential* for change. In the words of one newspaper headline: "A health program that actually made you feel well." Incidentally, the publicity generated for the program was not quite spontaneous, but pursued assiduously by all involved. For example, during the cutting of the program an engineer was put in a trance and fell asleep while a section on the uses of hypnotism was being played. The story was released to the rest or the press, including *The Times* diary. Modesty should really have little place when you are trying to generate publicity for your message in the media!

The message of the successful collaboration described above is that it is possible to generate valuable media interest in your project or campaign, whatever its nature, but to do this you must be prepared to take a number of carefully considered risks. For example, when you become involved with the media you inevitably lose a certain amount of professional control of your territory. In the case of the chronic pain program, the patient might have walked out of the hospital making the story one of "health failure"! In the event this did not occur, but such was the *trust* established between the health professionals and the media team that it was a very simple matter to discuss all aspects of the program's development.

But this trust was, of course, built up over time and pre-dated the period when the actual recordings were made. It is a key element to consider, with a number of important strategic implications.

Some practical guidelines to help the media help you

There is no simple prescription for success in achieving media support, particularly in the case of chronic illness, but there are certain strategies for action which, if followed, can give you a much improved chance of eliciting media attention and support. All health promotion requires *imagination*. To make an issue, report, paper or campaign memorable demands much more than a late gathering of a hastily convened publicity committee. You must allow time to think out your own angles. One approach might be to consider the use of celebrities, or to create your own special occasions or sponsored events. This has many attractions, for journalists often look for a strong *"human angle"* around which to write or broadcast their story.

Groups may have a genuine or understandable fear of exposing individuals in this way, particularly if they are already experiencing physical discomfort. All I can say is that there must always be a certain risk in any kind of publicity-seeking activity, but that groups are well advised to try and minimize these by their own rigorous selection of the facts and spokespersons they wish to put forward. It must always be worth considering, however, the possible consequences of an appearance by an individual or group (e.g. a family) on television or in a press picture. Do consider the effect of anything you say before agreeing to be interviewed. If you have any doubts, don't do it!

In general you should always try wherever possible to make contact with *named people*. Do your homework and check titles to obtain the names of editors, reporters, producers or researchers, and particularly those people whom you can identify as *sympathetic* to health promotion issues. Journalists *like* to receive information direct. It boosts their self-esteem and replenishes their list of "possible" stories and contacts. If you can make the effort, you increase your chances of success. Any "personal relationship" can also be vital in helping to ensure not only that the full facts are given, but that proper sensitivity is shown to any individual involved.

You must also remember that it is not uncommon for a news editor to receive up to 200 pieces of information each day from organizations, companies and individuals seeking to promote and publicize their activities. And since the news-desk of a newspaper or magazine is a very busy place, your information may have a very short life-span – about eight seconds from opening the envelope to being thrown into the waste-bin. So you need to follow certain rules when drafting the information.

- Is the message clear and simple?

- Have you avoided professional jargon?

- Is it short, to the point and typewritten?
A hand-written scrawl is a journalist/ news editor/ producer's nightmare. And a long, expensively produced report simply makes a louder noise as it hits the bin!

- Is it typed in double-spacing, and on one side of a piece of paper only?
This is so that the sub-editor/producer can annotate the piece of copy and pass it on without the need for retyping.

- Have you provided both day and evening contact telephone numbers?
And have you ensured that someone will be available on those numbers to answer follow-up enquiries?

Some other points need to be considered

1. The general *timing*, particularly of the press release, is extremely important. In general avoid the last-minute release. Much news is often determined by a "planning diary" because editors have to commit resources in advance. It would have to be a major news story to make any late impact.

Try to use the following system by giving advance information of your event: a 7-10 day advance notice can sometimes stimulate interest in your idea as a "possible future story" – but do remember to follow this with a second note and/or phone call 48 hours before the event. As a general rule, Friday and Saturday are poor days for an event or press release. Preferably target "Sunday for Monday", or "Monday for Tuesday" for events and news releases.

2. The *mailing list* should be large and include, for example, news editor, features editor, and woman's editor, with several copies to each contact. This "scattergun" approach is useful. What may not fit with one person's output may have great appeal for another. The plaintive cry of "I sent it to the news editor" is no excuse! And remember that you are competing with many other people for space and airtime – and journalists are busy people: they cannot be expected to pass on to a colleague information which they are not going to use.

3. Having made the initial contact, continue the *dialogue*. Find out from journalists themselves their requirements in terms of presentation and deadlines, etc.

Who to contact

There is a wide range of media contacts for you to consider.

1. *Radio and television*

- all types – national, local, community;

- all departments – news, current affairs, features, light entertainment including soap operas, education, religion, etc.

2. *Newspapers and journals*

- all types – national, local, community, specialist;

- all departments – news, features, women's page, letters page, etc.

3. You might also consider *collaboration* on a campaign or project with one section of the media. On occasion they might look for direct *financial assistance* with its organization, or indirect help through *back-up* regarding leaflets and/or telephone advice services. On other occasions they may be delighted to provide help "free" to promote their own community image. Be prepared to consider all options, particularly the latter!

HELP THE MEDIA TO HELP YOU.

FOCUS ON THE FUTURE

Supportive environments should be created to:

- change social attitudes towards and promote more positive views of people with chronic illness;

- remove barriers to patients' return to employment as work is highly important to people living with chronic illness and efforts are needed to create appropriate jobs, including special programs for less skilled workers;

- encourage and support businesses in developing health promotion programs in the workplace for people with a chronic illness; and

- promote support for caregivers, both professional and lay, through programs focusing on further education as well as on emotional needs, as health promotion in relation to chronic illness involves both patients and the people who care for them.

7.

STRENGHTEN COMMUNITY ACTION

Health promotion action means:
to strenghten community action

Health promotion works through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities, their ownership and control of their own endeavors and destinies.

Community development draws on existing human and material resources in the community to enhance self-help and social support, and to develop flexible systems for strengthening public participation and direction of health matters. This requires full and continuous access to information, learning opportunities for health, as well as funding support.

Ottawa Charter

FAMILIES AND SELF-HELP GROUPS AS KEY ACTORS

by Robert Anderson

The family, self-help groups, i.e. groups of people who think they have a common problem and come together to do something about it, are the main building blocks for supporting people with chronic illness, and this caring involvement extends throughout the experience of living with chronic illness.
To what extent are families and self-help groups conducive to health promotion of the chronically ill in different countries and in different cultures? Clearly, there are no simple yes/no answers, but rather several specific questions. First, is the role of self-help groups and families in the care of the chronically ill as marginal as some people think, including many professionals? If so, what are the main issues one should address in this respect? Secondly, when critically evaluating self-help, what is the main frame of reference one should use: the internal criteria of benefits for the group members? The impact of self-help ideology and action on a more global social level, especially on public policies, or both?

From the point of clinical practice, there is a wide range of interactions going on between health professionals and their patients' primary social support networks, including their families, self-help groups and the like. However, in most contacts there is no systematically organized or coordinated effort to support people with chronic illness or their families.

From a social epidemiological point of view, experiences in some countries show that accessibility to self-care and self-help resources is not equally distributed across different social strata. According to a sociological observation (from the UK) the social meaning and practice of self-help seem to be biased by the notion of "social elitism", with the result that self-help is regarded as a popular health promotion strategy for middle-class white women. It seems that too little attention has been paid to differences in the appropriateness of self-help initiatives among different age groups and between men and women. Other views indicate that the differential distribution of self-help and self-care resources is not so much a matter of social stratification as it is due to the specific character of the disease around which self-care practices and self-help groups are focused, i.e. self-help groups bring people together on the basis of common problems.
A general observation is that self-help resources at the moment are accessible to a rather small portion of the population as compared to expressed needs (examples from Great Britain and the Federal Republic of Germany show 30% of expressed needs in the total population as opposed to 2-3% of actual involvement with self-help groups). These proportions vary greatly between people with different conditions, and depend in part upon the stigma associated with the disease or the mobility of the person affected. While the problems and disadvantages experienced by people with different conditions are often similar, strategies for widening self-care and self-help appear to demand a variety of different approaches, for example working with marital partners together or separately. Participation is also influenced by the way self-help groups are organized and whether they allow for involvement and an active exchange of experience that meets the expectations of group members.

From a social cultural point of view, it is necessary to determine the extent to which the role of families is compatible with the role of alternative forms of lay care and lay support such as self-help groups provide. The family is a positive resource for health promotion but it can also have a negative impact on the health of people with chronic illness.

Are the family and self-help forms of lay support *complementary* and do they rein-

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force each other or not? If not, what can be done about it? In fact, the families and self-help groups play different roles in health promotion for chronically ill people and they are not interchangeable. The two serve different needs of the people afflicted by chronic diseases. Self-help groups are a source of information; they can be the starting point for the organization of services, of group activities, etc. In some instances, such as in the case of cardiac patients, an active involvement of the whole family in self-help at a group level may be conducive to overall health promotion, while in other instances (such as in the case of cancer patients where victim-blaming often represents part of family dynamics), family resources ought perhaps to be considered separately from the resources of self-help groups and/or other forms of community support.

THE MUNICH HEALTH PARK: A GLOBAL APPROACH TO OUTPATIENT HEART REHABILITATION

by Mark Schmid-Neuhaus

Some 500 men and women, healthy and less healthy or chronically ill, come daily to the Munich Health Park to enjoy activities that range from jazz gymnastic, Indian dances, meditation, massage therapy and autogenous training, to tango courses, psycho-drama, dream seminars, T'ai Chi, pottery and another 100 or so activities. These programs translate into reality a triple objective of the Health Park:

- to suppress the barriers between health care and other social structures and institutions;

- to take the concept of illness out of its isolation in a traditionally sickness-oriented medical system and to consider it in a broader reference; and

- to replace the dichotomy of health *vs* illness by a holistic approach.

For the individual who comes to the Park, this means: *achieving greater pleasure out of life, enlarging social contacts, increasing inner happiness and developing a more healthy body.*

When the Health Park opened its doors some 13 years ago, this strategy was understood by only a few. In the meantime, the concept of the Health Park has gained increased understanding among specialists, not least due to the background of strategic options consistently advocated by WHO. By accepting this institution, the people in Munich have shown clearly, from the beginning, that they appreciate the new approaches being used; in fact, by their commitment, they have made a key contribution to the development of the Health Park.

Our approach to outpatient rehabilitation of heart patients is both a consequence and an expression of our concepts. It should be noted that the many practical achievements which characterize the important reality of the Health Park are the result of our daily work with patients and primarily with chronic heart patients. In other words, conceptual thinking and practice intermingle and our program serves to demonstrate that therapeutic approaches reflecting our basic concept can be implemented in a social system -- a health institution in our case -- even if the environment does not yet fully share these concepts.

The concept of the Munich Health Park

The existence of unused premises built for the 1972 Olympic Games and the readiness of the City of Munich to make these premises available for a new type of health education institution led in 1973 to the creation of the "Health Park" or "Center for Preventive Psychophysical Health Care".

This institution is supported by the Munich Adult Education Center which has played a leading role in its conceptual development. As the Center cannot contribute financial assistance -- apart from organization and personnel -- joint financing was provided by the City of Munich, the Bavarian Labor and Social Ministries, the Munich AOK Health Insurance, the Land Social Security Office for Upper Bavaria and the Federal Social Security Office.Contractual agreements were concluded with the health insurance companies according to which they accepted to cover the cost of specific programs, provided participants would attend on the basis of a medical prescription.

Conditions for participation in Health Park activities without medical prescription were also determined and entry fees specified for each course. The proportion of self-financing increased from 23% in 1973/74 to approximately 68% at present, a remarkable result in the case of an adult education institution.

The Health Park is primarily meant to be a preventive institution, trying to close a gap in the overall health care system between purely verbal health information and active curative treatment. Its tasks are related to both primary and secondary prevention and, apart from translating

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these tasks into attractive recreational activities, it plays a leading role in the outpatient rehabilitation of heart patients and also, in a wider sense, in the treatment of psychosomatic diseases.

A determining factor for the conceptual design of the Health Park was the awareness that behavioral changes may be more lasting if the learner is not only provided with information but also has to use actively his emotional and creative potential in a learning process focusing on concrete experiences. Information alone is not sufficient for people to alter their lifestyles; personal experience is needed. The motto of the Health Park is therefore, *"Learning by Doing"*.

Moreover, medical science recognizes that the typical health impairments of our civilization are largely due to behavioral factors. Behavioral change accordingly represents a major goal both in preventive care and in therapeutic treatment, envisaged as a single educational task.

The success of the newly created institution was no doubt due to the fact that vague overall aims, such as "improvement of health" or "prevention of illness", were replaced from the outset by a list of concrete programs. This also enabled a permanent control of effectiveness, including whether the programs offered met expectations and needs.

The following *five learning goals* were established:

1) to restore and preserve physical abilities;

2) to be able to systematically relax and recover;

3) to revive the hidden emotional and sensory potential and to develop creativity, spontaneity and sensitivity;

4) to establish satisfactory social relationships through improved self-confidence and increased initiative, social contacts, and ability to face conflict; and

5) to understand health interrelationships through information and consultation.

At the *action level*, these goals were translated into the following *five tasks:*

1) to develop active prevention -- and hence cost-effective -- through the promotion of greater self-awareness;

2) to facilitate passing from a state of mere willingness to take preventive measures to a state of concrete implementation;

3) to supplement and extend medical follow-up measures through secondary prevention;

4) to follow-up on and strengthen health cure measures (usually expensive and frequently unsuccessful);

5) to increase the readiness to assume and share responsibility by changing health and illness behavior on the basis of practical experience.

Why do people come?

The 500 Munich citizens who attend the program daily are under the supervision and care of a team of about 30 full-time professional staff and approximately 140 associated free-lance colleagues including some 20 physicians, 70 psychologists, 50 sports instructors, arts teachers, therapists, physiotherapists, motion therapists, etc.

Some 40% of the participants are patients who have been referred to the Health Park via the medical system or following the recommendation of their physician; the remaining 60% attend the Health Park of their own initiative.

An investigation on the motivation of participants indicated that the majority had come following an event which changed their life and created awareness of existing problems as well as willingness to change and search for solutions.

At present, program participants include 14% of people with cardiovascular problems (post-myocardial infarction condition, cardiac deficiency, etc.).

The staff of the Health Park works closely with the family doctor in all aspects of the outpatient rehabilitation process.

The concept of cardiac rehabilitation

In light of the learning goals and tasks mentioned earlier, it is not difficult to conclude that, from the outset, the Health Park had to face the rehabilitation of heart patients as a particular challenge. One of the first outpatient heart groups started to function as early as 1973 when many German physicians still seriously doubted the value of exercise and psychosocial care. Until 1985 the number of groups increased to a total of nine, including four "practice" groups and four "training" groups -- which are much more demanding -- as well as one mixed group. During recent years, emphasis has been placed on the development of practice groups since it became clear that most heart groups associated with sporting clubs were going to function as training groups (cf. background paper by Döhner and Görres, p. 34).

All heart groups are placed under the direction of physicians with special training in cardiovascular diseases, assisted by instructors who are also specially trained. They are further assisted by a social worker and a psychologist who complete the team of each practice group and who are particularly concerned with psychosocial problems. Contrary to many health groups which regard themselves primarily as sporting groups, the heart groups of the Health Park pursue wider aims.

In our world of technology and civilization, the coronary heart condition is considered to be a typical behavioral disease. Consequently, long-term outpatient rehabilitation aims at providing systematic encouragements and support to patients towards changing their lifestyle. From this point of view the involvement of a psychologist in the work of the medical team has proved to be particularly successful although it has caused a problem of costs with which institutions other than the Health Park are presently unable to cope. It should also be mentioned that this multidisciplinary approach had been preceded by an unsuccessful attempt to integrate a special type of social workers, called social pedagogues, in the health team. The essential problem was the reluctance of heart patients to accept the assistance of this type of professionals and to show interest and readiness to come to grips with the psychosocial aspects of their illness. In the long run, it became clear that physicians were more apt to deal with the psychological components of group leadership than these social workers were able to become medically competent and thus be accepted by participants.

The design of the groups can best be understood from the program announcement of the Health Park in which heart groups are described as follows: "*Coronary outpatient group*. The course is appropriate for patients suffering from a coronary heart condition (e.g. after a myocardial infarction). It aims at the recovery and strengthening of physical capabilities, at the prevention of relapses and secondary illnesses, and at the strengthening of the ability of patients to assess their capacities. Participants will practice relaxation techniques and in some cases reduce drug treatment. Depending on their physical resistance and health condition, the participants may enroll in a "training" group or a "practice" group. The medical practitioner of the Health Park is available for consultations regarding the choice to be made. The course is permanently open and new admissions are possible at any time."

Movement, relaxation and discussion

The group activity aims to consolidate three elements: movement, relaxation and discussion. Groups are characterized by an atmosphere of quietness, relaxation, lack of stress and sociability, both in the group and in conversations between individual participants and with the doctor. The multiplicity of possibilities which the Health Park offers, makes it easier for heart patients to move into health groups. In addition, family members can take advantage of other programs while the patient is occupied in his heart group. The average annual capacity of the nine groups amounts to some 300 patients, who meet once a week in a two-hour group session. Were it not for the fact that getting to the Park is too strenuous for certain patients, there would be an even greater participation in the heart groups. As it stands, we are frequently surprised to see that some of our patients accept to travel long distances, sometimes for more than one hour, to attend the group meetings.

Due to our inadequate administrative means we are still lacking a detailed documentation on the therapeutic process in the groups. It seems important, however, to note that the practice groups, which include high-risk patients, have never so far recorded any adverse effects. We believe that this may be due to the emphasis placed on a careful and conscious exploration of one's corporeality. At the beginning, of course, most heart patients are rather unaware of their body image as they are essentially concerned with problems related to physical performance. Accordingly, the practice groups place greater emphasis on psychological factors related to the patients' lifestyles than on questions concerning physical capabilities.

People enjoy the Park

At a recent meeting of heart group practitioners, physicians with a long experience in cardiology expressed their astonishment at the long periods of participation of patients, particularly those with rather problematic health conditions. We suspect that an important factor may be the special group climate in which only relative value is attached to physical performance. Mentioning this special climate does not mean that the groups are conducted as psychotherapy groups. In the past we made several attempts to work with heart groups according to methods of psychotherapy group treatment, i.e. using psychoanalytical techniques. All these attempts proved more or less unsuccessful. The relatively most successful were periods of anti-stress treatment based on behavioral therapy, provided these sessions could be smoothly integrated in the activities of the group.

However, for patients who do not belong to the high-risk groups, reconstituting physical capabilities plays of course the most important role. The problem of coping psychologically with a state of illness is frequently repressed by such patients and needs to be carefully reformulated by the group leader. We believe that the decision to participate in an outpatient heart group is prompted by very different motivations and we try to take this into account in some way in selecting group participants; but with respect to the much more demanding training groups, we adhere to the principle that such groups have to go far beyond the aspect of "coronary sports".

This brings us back to our introductory remarks concerning the interdependence between environment and illness and between institution and therapeutic approach. The application of the Health Park concept to the chronically ill (or, as we prefer to say, to the "conditionally healthy") highlights a problem, namely the fact that the actual situations with which we are simultaneously dealing and which we try to conceptualize are always so complex that they are very difficult to document. We have to rely therefore on descriptions of a qualitative nature rather than on secure quantitative data. This short description of our work with heart patients confirms this view.

"TAKE HEART": FORMER HEART PATIENTS FORM SUPPORT GROUPS

by George Morland

For some time, doctors, nurses and social workers have recognized the need for heart people to receive support and encouragement to supplement the good medical care they are given. However, these professions are already overstretched and often cannot devote time and attention to rehabilitation. But something has started, which may progress and in time supply this great need. Recently an untapped source of people who can give just the right kind of help has been found – they are the people who have themselves recovered from heart illness. They surely are the most able to understand the need, to lend the sympathetic ear, to dispel many unfounded fears, and from their own experience give hope and encouragement.

How it all started

In 1983, one of these ex-patients got together with a consultant physician and some hospital social workers to launch the "Take Heart" group for patients and their carers in Mansfield, Nottinghamshire, and its success led to the formation of other groups in Derby in 1984, in Chesterfield in 1985, and in Leicester in 1986. In June that year, over one hundred members of these groups gathered for a meeting.

Many more new groups have followed, and in May 1989 there were at least 25 known groups in England and Wales. A national network "CHSA-Interheart" links them informally together.

How do these groups work? After the initial setting up with help from social services departments, local voluntary services, doctors and nurses, they rapidly become autonomous. Each group is now run by a committee of members who organize activities and arrange publicity, fund-raising and so on. The actual work of helping heart people is carried out by volunteer ex-patients who, after a little practice and training in listening skills, visit patients in hospital and visit patients and their families in their homes. Once or twice a month group meetings are also held.

Someone to listen

When a heart patient, living in an area which has a group, goes into hospital, he is given a letter telling him of the existence of the group, and offering him a visit from someone who will listen to his worries and try to help him. The group aims to send the right volunteer to the right patient – someone who is about to have a coronary by-pass or a heart valve operation will like to meet someone who has had that operation and benefited from it. Incidentally, these visits are always made with the consent and support of the hospital staff.

Visits to families

The first visit is usually within three to four days of the patient entering hospital, and often he finds it helpful to tell his visitor the story of his attack. This way, he may lose some of his shock and bewilderment, and perhaps resentment. And seeing someone who has plainly recovered from a similar attack, the patient may become less depressed and anxious and take his first step towards acceptance – which is, of course, the first stage towards a good life in spite of some restrictions.

It is well known that carers and families are under as much strain, if not more, than the patients themselves, so home visits are offered by group members who try to allay fears and give reassurance to relatives and close friends.

Advice on medical matters is taboo – people are persuaded to discuss these with GP or consultant – but all practical and personal problems can be talked over and solutions are often arrived at. Carers are also given a telephone number which they can ring at any time that talking will help them.

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Meetings are helpful

Group meetings are usually two hours long, and half of this time is kept free for members simply to mingle together and talk to each other, and for greeting new members. Often there is a talk by a doctor, nurse, dietitian, therapist, social worker, welfare rights adviser, or perhaps a patient who has had a heart transplant. Cardiopulmonary resuscitation demonstrations are sometimes given. Relaxation routine demonstrations are popular, too. But these "serious" sessions are interspersed with a lot of fun, and social events and outings are also arranged.
After the first two groups (Mansfield and Derby) had been operating for a year, questionnaires were sent to all their members and contacts to find out their reactions to the hospital visits and the meetings. The result was that the largest number found both very helpful and reassuring. No one found them useless, and in fact everyone felt the work of "Take Heart" was worthwhile and should continue, even if they had not made use of it themselves.

New members continue to join all the groups. Half of these join as a result of receiving letters and visits in hospital, the other half learn about the groups from posters, local radio and press reports, or by personal introduction. Some members move on when their need for support has been met. Others stay on to help new members in the way they have been helped themselves.
The groups' work may well expand. Movement is now afoot for them to band together to press for the rights of heart patients in areas where society is felt to hold their condition unfairly against them. Examples of "worry" areas are employment, insurance and welfare benefits.
So I feel that "Take Heart" groups are here to stay, that they have shown the need there is for them, and have proved that they can fill that need. What must happen now is that they spread and multiply throughout the country, so that in time any heart patient anywhere can find the support he or she wants.

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THE PLACE OF RESIDENCE AS A HEALTH RESORT FOR RHEUMATIC PATIENTS

by Helmut Breitkopf and Vera Grunow-Lutter

This paper deals with institutional aspects of health promotion in relation to a research program comprised of five projects currently in operation in various regions of the Federal Republic of Germany. The aim of these projects, which are supported by the Federal Ministry for Research and Technology, is to provide locally based, interdisciplinary care for rheumatic patients throughout the course of the disease. Different organizational means are applied by the different projects to realize these goals.
The project described in this paper started in 1985 in Unna, a small town of some 60,000 inhabitants located in the Ruhr area. It involves intensive efforts in health promotion, the aim being to firmly establish self-help activities in everyday life. The following gives an overview of the project, its objective, structure and program – especially the "cure seminars" organized on an outpatient basis – and some of the difficulties encountered with regard to practical implementation and the long-term provision of health-oriented care. The last part of the paper deals with the research component of the model.

The aims of the project

Our aim is to build up an appropriate and comprehensive care system to meet the needs of people who live somewhere between illness and health. The kind of support we want to offer to rheumatic patients who wish to help themselves and try to improve their health lies in-between the sports club and fitness center on the one hand, and the hospital and medical practice on the other. It should enable rheumatic patients to live fuller lives in spite of their disease, to maintain their personal independence and their autonomy as long as possible, and to meet in self-help groups where they can discover that problems become easier when faced with others. Improvement of health and promotion of self-help are thus the key elements of our program.
We have two goals: (a) create a forum where every interested rheumatic patient can try out what has helped others, and (b) ensure that self-help techniques can be implemented in everyday life without an instructor. In this we also include complementary therapies. When selecting offers of help we take into account the following criteria: everything we offer must be medically supported, attended or supervised, and it must be possible to implement the activities locally and cheaply.

Organizational aspects

In order to be able to translate the above ideas into practice and achieve better cooperation between health care providers, a health association was founded which includes: the public health department, health insurance companies, the adult education center, around twenty doctors, one pharmacist, a sports club for the handicapped and other self-help organizations. Since this health association is not a legal entity of its own, the local adult education center accepted responsibility for the implementation of the health promotion program aimed specifically at rheumatic sufferers. The other member groups help the center with financial and personnel support and carry on tasks of public information.

Implementation of the project

"Learning health by experience" is our motto. It forms the basis of the specific rheumatism-related activities in our model. These include a number of courses such as special gymnastics, balneotherapy,

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occupational therapy, acupressure, proper nutrition, relaxation methods among which autogenous training and yoga, as well as fasting weeks, information sessions, the setting up (and follow-up) of self-help groups, and last but not least, "cure seminars" or *"rheumatic outpatient cures"* as they are occasionally called. These cures are the most important element in our model as they exemplify the fact that people can do something for their health locally, without having to travel to a health resort a long way away.

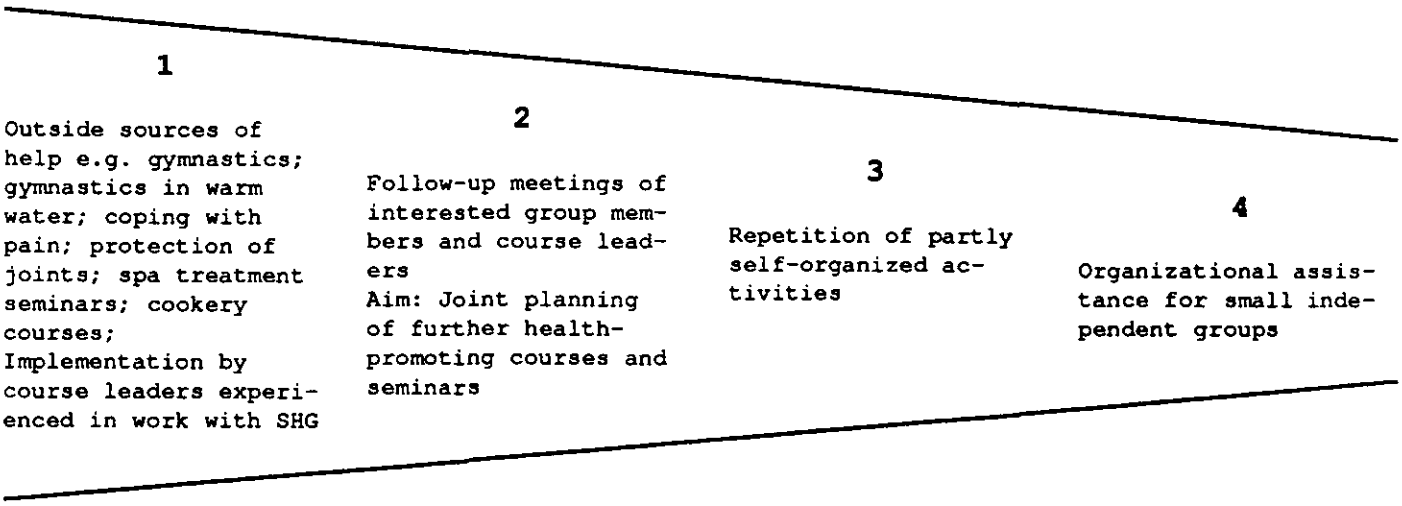
Patients attend these cure seminars for nine days, on a day-long basis and complete in their place of residence a program similar to that offered by a normal health resort. The morning sessions consist of exercises in warm water, individual treatment, sauna if patients are interested, and rest intervals. At midday a fully nutritional meal is prepared by the patients under supervision. The afternoon is for relaxation (yoga exercises), information (lectures) and social activities. One day is reserved for a visit to a nearby clinic for rheumatic patients. There, specific therapies are demonstrated such as cold-therapy or occupational therapy. There is also an opportunity to talk to doctors at the clinic, ask questions and receive advice.

By contrast with health resorts, where people separate afterwards, our aim is that group participants keep in contact and develop activities together. Self-help groups do not usually develop without some support. Empirical studies carried out at the University of Bielefeld (Breitkopf, 1982) show that only around 3% of the population is capable of forming its own self-help groups. Most people need encouragement and support in order to create a group or participate in an existing one. We have observed – and this is a very positive point – that during the nine-day cure seminar core groups are formed, whose members usually express the wish to continue to meet in future. We invite these people to discuss how to plan further group activities and how to put them into practice with our support. This support consists of providing rooms, materials for group work and guidance from experts if necessary.

One interesting outcome is the involvement of patients in the organization of cure seminars. This extends from women participants taking over the cooking of fully nutritional meals without the guidance of an instructor to the getting together of groups which organize by themselves a cure at their place of residence twice a year. Small groups of rheumatic patients are currently forming as a result of these self-organized seminars, who also meet independently of the project activities, e.g. to go to the sauna together, etc. In addition, a number of rheumatic patients have been stimulated to start self-help discussion groups.

This procedure represents a gradual development of the self-help potential, as shown in *Diagram 1.* The two lines that run together like a funnel show, in symbolic fashion, how the number of participants diminishes at every stage of the project. While a large number of groups are still formed at the seminars, fewer come to the follow-up meetings, and finally only a fraction of the people who originally came to our seminars attend small groups operating independently. We are trying to encourage more people to work in such undirected groups.

DIAGRAM 1 - STEP-BY-STEP SUPPORT FOR SELF-HELP GROUPS (SHG)



1

Outside sources of help e.g. gymnastics; gymnastics in warm water; coping with pain; protection of joints; spa treatment seminars; cookery courses;
Implementation by course leaders experienced in work with SHG

2

Follow-up meetings of interested group members and course leaders
Aim: Joint planning of further health-promoting courses and seminars

3

Repetition of partly self-organized activities

4

Organizational assistance for small independent groups

Some practical problems

What are some of the difficulties encountered with respect to the practical implementation of our program? Three main problems stand out.

Although our facilities can be described as being available locally, some of the participants nevertheless have difficulty getting to the courses and seminars. This is particularly the case in winter. We are thus encouraging people to set up car pools.

Another problem — in particular when starting self-help groups — is to ensure that participants have the ability to work in groups. What we understand by cooperation in self-help groups is mutual aid based on the fact that participants suffer from the same disease. To provide this mutual aid requires personal skills and experience that not everyone has. We are therefore endeavoring to inform the rheumatic patients about group rules and the principles of self-help groups.

Last but not least, it is difficult to involve rheumatic patients in education and prevention activities. If one assumes that the prevalence of chronic rheumatoid arthritis is 0.5%, in the municipal area of Unna, we reach just under 10% of those affected. This figure is on average the same or a little higher than the percentages achieved by other projects in the Federal Republic.

At present, we publicize our program through the Rheumaliga and the adult education program, and in daily newspapers. This is not sufficient, however, to reach all rheumatic patients. For this reason, we are trying to get more help from local doctors.

In spite of all the difficulties, we feel in a position to say that our idea of providing local, self-help oriented care for rheumatic patients has proved valuable. It seems that many participants gain strength and zest for life through our program. The joint activities and the exchange of experience in the groups has very good results. The dictum "the group can achieve more than the individual" is confirmed by our experience in Unna. It is most stimulating to work with groups of chronically ill people where the atmosphere is fully relaxed and where people laugh so much. One particular aim of our model seems to have been achieved: a fuller life in spite of chronic illness and handicap.

Obstacles to overcome for long-range planning

Two kinds of difficulties face the project in the future: financial and structural. The question of financing the project once the research funds have run out seems to have been solved. During preliminary negotiations, various potential funding sources, namely the health insurance companies, the town council of Unna and the district and regional leagues against rheumatism indicated their willingness to take over part of the cost. In the near future details on the financing of the local cures will be laid down in a contract with the health insurance companies, who will bear the main part of the cost.

The structural problems are associated with particular aspects of the German Federal system and difficulties in creating new structures at the local level to take over health promotion functions. Of all the institutions, groups and individuals forming our health association — health insurance companies, the public health department, self-help organizations, a sports club, pharmacists and doctors — the adult education center seems the best equipped for carrying out health promotion measures. Nevertheless, one may ask whether it is the function of an educational institution to help the chronically ill and promote people's ability to solve their health problems in small groups for which participants are responsible? Some of the practical problems include the fact that adult education centers (a) charge the same fees for everybody, yet must change this rule for participants in our project as their insurance status differs; (b) always have lecturers, in other words experts as teachers; (c) lay down a minimum number of participants per course and seminar; and (d) follow the policy that their programs must be open to everyone, i.e. there can be no closed groups; yet, self-organized groups of rheumatic patients want to meet independently of the time of year, determine the size of their group themselves, and work as a closed group occasionally; they also feel that a paid course instructor is often superfluous and contradicts the idea of self-help.

These, then, are the main difficulties related to the fact that our project is based with an adult education center. However, the difficulties would likely be even greater if other local institutions were to implement our health promotion program.

Some barriers to the establishment of self-help activities in everyday life

The research component of the Unna project is concerned with the main aim of the model, namely the development of the ability and willingness of patients to help themselves and to put into daily practice what has been learned through the project activities. This is of particular importance with regard to relaxation exercises which patients should continue to practice regularly at home.
We draw on two sources of data. One is the health diary or "passport" as we also call it. Participants are asked to fill in a form every month. This will go on for one to two years, so that later 12 or 24 monthly sheets will be available for every participant. These forms comprise two lists of questions concerned with (a) the frequency of self-help activities carried out at home, and (b) the use of the facilities available. The second source of data is also based on lists of self-help activities, used as part of a three-phase investigation aimed at identifying various development indicators. Data is initially collected when the patient first comes to the project — i.e. at a point where he or she has not yet participated in any of the project activities (T zero), — then a second and third time (T1, T2) at yearly intervals.
At the time of writing this paper, findings from these sources were still very limited as the period covered extended only over ten months. The qualitative interviews, on the other hand, provide interesting information. Patients were asked among other things about the obstacles, barriers and difficulties encountered with respect to the permanent establishment of self-help activities. The following are some of the negative factors cited:

- Lack of understanding of other members of the family with respect to certain self-help activities. This is encountered in particular when activities are of an "alternative" nature such as autogenous training for instance. For fear of "looking ridiculous", the patient stops carrying out these activities at home.

- Rebukes by members of the family. Physical activities in particular (such as finger exercises) are something patients like to do as a secondary activity (e.g. while watching television). Other family members find this disturbing and rebuke the patient.

- Time-consuming preparation. This is particularly the case with a nutritional diet.

- An inadequate domestic setting, e.g. there is often no quiet room for relaxation training.

- Problems associated with a change in roles. In the case of housewives, for example, the need to spend time on preparing a special diet is sometimes seen by other people as a neglect of housewifely duties.

- Obstacles due to social and health services bureaucracy. Many technical aids are not "automatically" granted by the insurance companies (particularly protection material for the joints). Often a number of certificates have to be brought by the patient, who is put off right from the beginning and does without the aid.

- No direct pressure caused by suffering. If the patient is momentarily free of pain and the joints are relatively mobile, he or she sees no reason to do physical or any other kind of exercise.

One important lesson can already be drawn at this stage: the likelihood and difficulties of establishing self-help activities on a permanent basis in everyday life must be examined for every such activity and for every patient separately as implementation depends above all on the everyday circumstances of life. Conditions in the family and daily routines thus need to be studied more closely. We know much too little about this aspect at the moment, and we are constantly being surprised — both in a positive and negative way - by our findings, especially in our practical work.

In conclusion

It is hardly possible to make generalizations on the basis of the experiences described, especially since the development of the project is influenced by local conditions.
This paper illustrates, however, some of the difficulties associated, on the one hand, with the reorientation of existing services towards a health promotion approach and, on the other hand, with the firm establishment of self-help activities in everyday life.

LINKING EVERYDAY LIFE WITH INPATIENT AFTER-CARE FOR CANCER PATIENTS

by Iris Bartkoviak

When cancer patients leave the hospital following a treatment that is often of a drastic and transforming nature, they have many fantasies on how life will be at home, ranging from "everything will be the same as before" to being panic-stricken by the fear of rejection. Often, before they return home, patients are sent to special clinics to facilitate the rehabilitation process. The Sonnenberg Clinic is one such center: it deals exclusively with after-care for cancer patients. It can accommodate a maximum of 270 patients whose stay is financed by various institutions. Most patients, however, have been at home for at least three-quarters of a year and come to Sonnenberg for the annual cure to which they are entitled during the three years following diagnosis. In case of metastases, relapses or renewed illness, more frequent cures are allowed. Thus, we deal with a mixed group of patients, some for whom cancer has already become part of everyday life and others who still have to learn how to cope with it.

The patients come from all over the Federal Republic of Germany, but mainly from the North and West Berlin. This means that their normal everyday life environment and relatives are on average 300 km away. Sometimes it is very beneficial to see one's own "normality" in perspective, to discover oneself and try out new things without being disturbed by familiar, and hence anticipated reactions from the environment.

However, a problem is posed by the return to daily life after a maximum of six weeks. Frequently, when the time comes to say goodbye the patients are afraid to go back home. There is a danger that the clinic becomes an "ideal self-contained world" for some patients, to which they think back with longing when they can no longer cope with their everyday situation. In addition, this "special world" gives rise to mistrust on the part of the partner and the family, if there is no attempt to deal with this situation.

Avoiding the split with daily life

To help provide a link between the distant after-care institution and normal everyday life, the Sonnenberg Clinic organizes an annual meeting known as the "Soodener-Gespräche" (Sooden Talks), to which the patients and their relatives are invited, as well as anyone who is interested. These have become a tradition and have been held for around ten years.

There is a specific theme each time – which in 1989, for example, was "Cancer and modern medicine" – and the meeting takes up a whole weekend. The participants normally arrive and register on the Friday afternoon, and on Saturday morning there are lectures by experts competent in the particular subject. In the afternoon, participants can meet in groups to discuss specific topics. There are also special discussion groups for relatives, for leaders of community self-help groups and for volunteer workers.

The positive response to these meetings shows every time the enormous need that exists for help of this kind. The lectures have to be held outside the clinic, as our own facilities can no longer cope with the large number of participants – up to 500 – who now attend.

With the "Soodener-Gespräche", we establish a link with the everyday life of our patients. The relatives who come receive a great deal of information and begin to understand the problems of the ill member of their family. The possibility of talking openly about problems to people in similar situations, i.e. to relatives or to other ill people, also eases the burden.

The meetings are organized by the "Friends of the Clinic", consisting of patients, former patients and friends who remain in touch beyond their stay at Sonnenberg. A regularly published circular maintains the contact and also brings new information from the Clinic into the patient's everyday life. If a further stay in the Clinic

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is scheduled, the relationship that has thus been created contributes to the success of the rehabilitation, also with respect to reintegration into everyday life.

Linking after-care with the acute phase

An attempt to link after-care with the acute phase of the illness is another step initiated by the Sonnenberg Clinic a few years ago through a training program for volunteer cancer workers. For three years this model was financed from a special fund. The idea came from the realization that there was a need for patients to receive emotional support at home following diagnosis, and later in the clinic treating the acute phase. Some patients voiced this need clearly.

It was also realized that there were several patients who were very willing to take on tasks and assume leading functions in promoting self-help upon their return home but they usually felt inadequately prepared to do so. Those who formed a group despite this handicap had reported considerable difficulties in providing proper leadership to the group.

We decided therefore to organize a course for interested patients or lay persons, consisting of two parts lasting a week each and dealing with (a) knowledge in the areas of medicine, nutrition and psychology, and (b) practice in leading discussions and groups. The theoretical instruction took place in the first week, the practical phase in the second week. Each time, we received more registrations than we could accept.

The lay helpers trained in this way have in fact created a number of groups in the areas where they live and have taken over the care of newly ill people in an exemplary fashion. Every time the "Soodener-Gespräche" are held, some of the lay helpers attend the meeting, so that the contact with the Sonnenberg Clinic is never broken off completely. This approach helps to forge a useful link between acute care, rehabilitation and everyday life.

CANCERLINK: "NO-ONE NEED BE ALONE WITH CANCER"

by Denise Winn and Mike Bieber

Marian rang CancerLink the day after she learned she had breast cancer. "I sat in the doctor's office at the hospital," she said, "and all I heard was that I had breast cancer and that he was booking me a bed. I can't remember if he told me anything about the treatment they were planning. If he did, I didn't hear it. I'm so terrified. Will I lose my breast?"

CancerLink receives around 450 calls every month, along with letters, from people who are anxious about some aspect of cancer. Very many ring because they were too shocked at the time of diagnosis to take in what their doctor told them about treatment.

Others feel loath to take up too much of a doctor's time with questions. Some are concerned by lack of information about their illness or treatment even when they ask for it. A doctor may mean well when saying, "You don't have to worry about that". But people do worry. As one man wrote to us, "I'm the kind of person who can cope with knowledge, but the unknown frightens me."

A caring network

It is to provide information and support for people with cancer, their families and friends that CancerLink was founded in 1982 by a group of four people with personal and professional experience of cancer.

CancerLink is a national organization. From its bases in London and Edinburgh it operates telephone helplines staffed by trained persons who provide support in whatever way they can for people whose lives have been affected by cancer. Staff answering calls have the time and information to discuss the issues that people with cancer – and those close to them – may not feel able to discuss in the normal health care setting.

CancerLink can often put people's minds at rest about some unanswered questions. Many worry because their doctors refuse to say how long they might live, for instance. We can assure them that doctors very rarely know. That usually helps people to feel less frightened and more positive.

Often we can supply or suggest helpful booklets. CancerLink produces its own range of booklets on aspects of cancer care. We also keep up to date with other books and pamphlets. Many callers would like the chance to talk with others in a similar position. We can give details of cancer support and self-help groups in their area. We can also help them to contact organizations for particular types of cancer affecting, for example, the breast.

Our main task: to listen

Very often, however, our role is not to talk but to listen.

Bill, a 45-year-old father of three, rang to ask a question but quickly his anger about having cancer began to come out. He said that he had told his GP several times that he had indigestion, but his GP had not referred him until recently for tests.

Charles was angry because he had only been retired for a year before his cancer was diagnosed. Now he was very bitter that the leisure he and his wife had long looked forward to might be cut short.

Clare expressed guilt and self-hatred about her breast cancer. "If only I had breastfed my children, this wouldn't have happened. I was too lazy to persevere and now this is my punishment."

The fears may not be realistic, or the anger may be misdirected, but the feelings are real. It is important for people to be able to express all kinds of feelings freely, in order to be able to grow through them.

Very many people who call us say they don't want to burden their families who are already burdened enough. Yet they are desperate to talk to someone who will not feel hurt by what they say. Their anger

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may be directed towards their own family at times. It is hard to understand or cope alone with these feelings.

For those who know that they have limited time left, there may be painful past events that prevent them from finding peace. Again, they may be reluctant to reveal these to those closer to them.

Sarah was distraught because she had lost touch with her brother ten years ago, after a family row. Now she desperately wanted to make amends and say goodbye.

Grief about unfinished family business leads many people to call us. Once that grief is fully expressed, they may be freed to see that it is still in their power to apologize or forgive and say goodbye in their hearts.

Often we are asked for help in how best to break the news of cancer to the family, particularly to young children. We are called upon to reassure many people who fear that they may have secondaries, after a cancer has been treated, but are reluctant to bother the doctor in case they are worrying unnecessarily. We can support them in their wish to have an early check-up, when appropriate, because worry is debilitating in itself. It is therefore sufficient reason to see a doctor.

CancerLink is regularly asked, by lay and professional people, for all sorts of practical information. Some people want to know what side-effects or different treatments to expect. Some enquire about diets or about complementary treatments. Some need to know where to find nursing help, financial help, or prostheses.

Whatever the question, whatever the cancer, each individual's circumstances are taken into account and there are no stock answers. To every single person who calls us, we will listen as long and as often as they need us.

An important source of support: the self-help groups

CancerLink also puts people in touch with their nearest cancer support and self-help group – there are over 300 of these in the United Kingdom with more being formed every month. There they can meet and talk informally with others who have undergone the same feelings and experiences. Many people with cancer who join self-help groups become far less anxious and depressed about their illness. "There's certainly nothing depressing about our group," says one woman. "We're all just so pleased that we're still here! We give each other confidence. If you have been very ill, it helps to see others who were that ill before and are now so well."

Some people join groups because they want a safe place to express their feelings, to air doubts, fears, ask questions and be helped to come to terms with what is happening. Others may feel that by helping others they will also help themselves.

The groups undertake a wide range of activities. It is up to each to decide how far they wish to spread their net. Important for virtually all are the informal regular open meetings when the group may listen to a speaker and welcome new members. Also important are smaller drop-in evenings when members can offer and receive more extensive support.

We support new and established groups in four main ways: training courses for group members, publications, information exchange, and giving support and information to groups on particular issues. We also fund the National Conference of Cancer Self-Help Groups, which is organized by an independent committee.

The aim of the training courses is to help group members to reach a fuller understanding of what they want to achieve and to give.

"I went on the very first training course that CancerLink had ever run in 1983, recalls a group leader. I felt that they were moving forward on something that just hadn't happened before in this country and that is still just as necessary now."

Another group leader recounts how she ran into difficulties when she started setting up a self-help group a few years ago: "I had felt very alone with many anxieties after treatment for ovarian cancer. I had just finished going back and forth to the hospital for chemotherapy and I felt awful a lot of the time. It struck me that a support group for people with cancer would be a good idea and I threw all my energies, what I had of them, into getting one going. But it was such a huge commitment that I quickly started to feel worn down and over-burdened. Then I heard of the training offered by CancerLink and went on it. It taught me to realize my limitations, among much else. I no longer think I have to have all the answers and I don't offer more than I know I can give."

Many plans for the future

CancerLink has achieved a great deal since it was set up in 1982. But there is still much to do.

An office has been opened in Edinburgh to bring CancerLink's services closer to people in Scotland. At first it will concentrate on individual information and support. Support for cancer self-help groups will be developed in the future. This is an exciting way forward for CancerLink as it helps to bring its services closer to those who need them.

New publications are being planned. Some of these will be for people with cancer and their relatives and friends: the most recent is *Body Image, Sexuality and Cancer* which discusses the problems a changed self-image brings about. Others will be for health professionals, to keep them up to date with the information CancerLink has gathered, such as *Cancer Support and Self-Help Groups – A Directory* which lists all the self-help and support groups in England, Scotland, Northern Ireland and Wales. CancerLink also publishes a quarterly newsletter *Linkup*. All publications are free on request to people with cancer, their families and friends.

As more and more cancer support and self-help groups are set up, CancerLink plans to increase its work as a resource for them. It will be spreading the word about new ways groups have found to offer support, and will be encouraging and assisting groups throughout the country.

CancerLink also wants to carry out much-needed research, to find out the best ways to offer support and information. We want to find out about people's differing needs, and how best to meet these: people living in towns and cities and in the country, women and men, people from different ethnic groups, older and younger people.

Finally, CancerLink has been invited to several international meetings linked with the World Health Organization. This is important, and CancerLink would like to continue to reach out in this way, to learn from and share the experiences of others in different countries who are offering support and information to people affected by cancer.

FOCUS ON THE FUTURE

Community action should be strengthened to:

- inform people of alternative forms of health promotion in their local communities, in part through setting up accessible and effective networks of information to help patients find the treatment facilities they need;

- promote patient-to-patient and self-help activities, making use of experience from existing groups and encouraging businesses to develop heart groups and other kinds of support for chronic patients;

- foster the capacity of community services to help families and self-help groups to promote health, specifically to develop means to decrease the mental and physical burden placed on the family as principal caregiver (as in such community services as hospices and telephone services); and

- facilitate the active participation of people with chronic illness in social life by providing adequate facilities (such as the Munich Health Park with its program of leisure and creative activities which promote the health of healthy people as well as of those living with chronic illness).

8.

DEVELOP PERSONAL SKILLS

Health promotion action means:
to develop personal skills

Health promotion supports personal and social development through providing information, education for health and enhancing lifeskills. By so doing, it increases the options available to people to exercise more control over their own health and over their environments, and to make choices conducive to health.

Enabling people to learn throughout life, to prepare themselves for all of its stages and to cope with chronic illness and injuries is essential. This has to be facilitated in school, home, work and community settings. Action is required through educational, professional, commercial and voluntary bodies, and within the institutions themselves.

Ottawa Charter

AN EDUCATION PROGRAM FOR PATIENTS WITH CHRONIC PAIN

by Carmen Franz

Sometimes, there seems to be a tendency towards idealizing or romanticizing the patient. I would like to take a provocative line and say that chronic illness can be a fortunate condition because, with proper effort, it leads almost of necessity to self-realization. I have myself "enjoyed" to a sufficient extent the patient's position to know how difficult it can be. I went through many years of gloom before I could accept the wheelchair and understand that this illness also had a positive side, that it was also an opportunity for me to develop as a person. This was and will continue to be a path with many setbacks.

How difficult it is to progress along this essential path of change is something I experience with chronic pain sufferers in the course of my daily work. This has led to the development of a patient education program at the pain unit of the Göttingen University Clinic.

The treatment of chronic pain: a very difficult task

There are many complex factors to be taken into account with patients who come to us. These factors, which have been reviewed in chapter IV, make it extraordinarily difficult to provide treatment that is adequate according to our view of the problem, i.e. which gives due consideration to: (a) the physiological components; (b) the fact that people quickly learn that certain benefits can be derived from a pain condition and thus develop a "pain memory"; (c) the need felt by patients to legitimize their pain vis-à-vis the outside world by giving it a somatic cause; and last but not least (d) the very "personality" of the patient, taken in its broadest sense, i.e. his concept of the world, his past experience, his lifestyle, etc.

The "experts" involved in the treatment of chronic pain patients know that the psychosocial element in pain is frequently more important than the somatic complaints. Telling this point-blank to the patient will, however, provoke resistance. I will take as an example patients with chronic low back pain. Their chief aim in life is usually acknowledgement by the outside world – acknowledgement as hard-working, ambitious, constantly active persons. Leisure tends to be a bad word as far as they are concerned. There is no balance in their life between activity, work and relaxation, leisure and enjoyment. They are very norm oriented: many such patients, when referred to a psychologist, feel this as an attack on their integrity. They realize that a stigma is usually attached to people who have "psychological difficulties" making them unable or scarcely able to function, and there is the great fear of no longer being "normal", of no longer being able to swim with the tide. The tide is normality. Patients with back pain would never acknowledge their inability to swim with the tide as this would imply recognition of their psychological problems.

Another difficulty stems from the fact that the patient has usually been sent to us by the doctor treating him, and thus has no freedom of choice in the matter. He will also often suspect that when the pain goes, what is possibly an equivalent of the pain – namely depression – will take its place and he instinctively feels: "I need this pain", and instinctively he defends himself against our kicking away this "psychological prop".

I have sometimes the feeling that the problem of treating chronic pain patients is over-simplified: people seem to think – and doctors are no exception – that when other treatments have failed, a "talk" with the psychologist will be the answer. We just need to discuss things quietly with the patient and then everything will go smoothly. The patient will have a so-called "aha-experience" and will say: "It's great that I could talk to you. Now I understand, and from today I will change my life". In many ways, it is neither psychologically nor economically possible

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for someone to pack his suitcase and say: "Well, now I'll go out into the world and lead a contented life". In fact, the patient has to rely on his self-competence to build the bridge leading to the "promised land". But achieving self-competence is precisely very difficult for pain patients. Their lack of awareness of their "self" is one cause of suffering and there is no easy solution. Only persevering efforts will help.

The message does not get across: why?

In order to overcome these difficulties, we have tried several approaches. First we developed a brochure for our patients. In it, we introduced ourselves as a team, so that the patient would know from the beginning that we work on an interdisciplinary basis, i.e. the doctors, the psychologists and the physiotherapists treat the patient together and work with him together. We described who we are, what we do, and the forms of treatment we offer. We also discussed the physiology of pain in a very simplified form and the factors influencing pain perception. Our aim was to minimize resistance to the psychological talk and to strengthen compliance.
After having used the brochure for a certain time, we asked patients whether they had understood the various texts and diagrams and how they reacted. We found that the brochure was much too scientific although we thought we had presented things very simply. We realized that we had made intellectual demands that were much too high. In general the cognitive area was over-represented in our approach.

The movement towards change remains blocked

As a result of these findings we developed a second brochure - "Pain, what is it?" - in which we proceeded less "scientifically". The result was definitely better, yet what patients retained was mainly related to the body, to anatomy and physiology, and not to the psychological or social aspects.
We first looked for the mistake in the didactic material itself. But the mistake was elsewhere. Our patients are mainly from the lower classes. They are not used to dealing with printed matter and are ashamed to admit it. This was at the root of the problem. So we changed over to another medium and developed a slide series with a soundtrack. One advantage was that the information could be presented by a team member and the patients could ask questions. This provided an opportunity for discussions and patients started to think about aspects unknown to them. However, while the information improved the patients' knowledge, it seldom led to new ways of looking at the pain problem as a whole. There remained, as someone put it, a "cognitive frigidity" and the movement towards change was blocked.
This brought us to what is, for the time being, the last step in our endeavors to produce an "education program". With the support of the Federal Center for Health Education and of the South West Baden-Baden Television, we developed a film telling the story of a patient with chronic back pain.

Getting the patient emotionally involved

Our approach was inspired by the strategy which Milton Erikson uses with his patients: "If I want them to talk to me about their sister (mother, father, etc.), he says, I will tell them about mine." In other words: telling you about my affairs will bring you unconsciously in contact with your own. Discussing this approach, we realized that we had a wealth of experiences on which to draw in our daily work. In group therapy sessions, patients often describe situations in such a vivid manner that the audience can nearly "feel" the pain. Often group members would say: "Oh, that's just like me, I do exactly the same thing!" Or they would be deeply affected while listening to another person telling his story. We realized that if we could stimulate the patient's imagination, we would likely be more successful in our attempts to "teach" about chronic pain.
We listened to the hundreds of biographies that we had recorded on tape and integrated the main elements into the story of the life of a man. We included all the aspects that we assume can lead to chronic pain: learning conditions at an early age and later on in life, and reinforcement by the medical and the social systems.
While working on the film, the new concept evidenced its potential impact. The movie staff members, who knew nothing about the story, listened very attentively, asked spontaneously many questions and told us about their own pain experiences. On the other hand, there were some heated discussion with doctors who came to see what was going on as the film was being produced in our Clinic. Most of them were "peripheralists" – i.e. they believed that pain per-

ception results from a peripheral lesion and that cognitive and emotional factors are only side effects. Therefore, if you repair the lesion, the pain will disappear.

Finally, the day came when the movie was shown on television. The reaction was immediate: we received thousands of letters in which patients told us about their pain problems and asked for help. This fully confirmed our feeling as we were progressing with the movie: we had nearly every day the proof that this was the right way to enter into a vivid although often difficult discussion with pain patients in order to bring out fundamental issues which they had never talked about or never related to their suffering before.

FAMILIES WITH A HANDICAPPED CHILD: DEALING WITH PAIN IS ESSENTIAL IN THE HEALING PROCESS

by Joseph Lebeer

Most families with a handicapped child suffer from chronic mutual pain. The author's experience with 85 families with a brain-damaged child indicates that a majority of parents have suffered from chronic psychosomatic problems of one kind or another since their child was born: these range from toothaches to back pain, peptic ulcers, musculoskeletal pain, etc. Numerous other studies show a high level of stress in all families with brain-damaged children as a result of permanent conflicts between expectations and disillusions (Zucman, 1982; Rees et al, 1982; Knott, 1979; McAndrew, 1976; Kogan et al, 1974a). It seems very likely that the chronic somatic pain is a translation of the life-pain associated with the upbringing of a handicapped child. Pain, according to de Vries (1983; see also p. 128) is a symptom of broken integrity, of broken dreams.

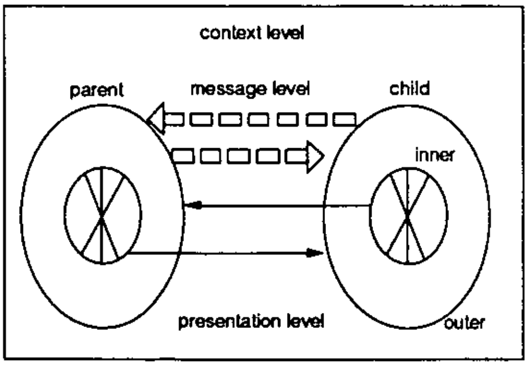
Sources of pain in families with a handicapped child

1. In the first place, *at birth, or at the time of diagnosis of a handicap.* Parents anticipated a normal baby and they are now faced with a sudden collapse of their expectations. Very often, the newborn baby is separated from its mother for various reasons (reanimation, infection, prematurity, etc.). Depending on the cause, it may not be possible to make a clear diagnosis immediately. Meanwhile, there is a feeling of uncertainty which really never disappears during the child's life.

2. Secondly, *as the child grows older.* It is very, very painful when a child does not develop normally, does not move well, suffers from numerous complications and has to undergo surgery, etc. As the years pass, the parents realize more and more that their child cannot keep up with peers and the pain is constantly revived: at the time of entering kindergarten; then primary school; the first use of a wheelchair; the decision to institutionalize the child; later, at the time of adolescence: finding proper employment, integration in society, or finding a place to live and people who care. Our data indicate that the degree of pain is not related to the objective degree of handicap. Sometimes the contrary can be observed: the smaller the difference between a normal child and the handicapped child – like in the case of a minimally brain-damaged child (Tikkanen, 1984) – the more often painful situations occur.

3. Saying that *the chronic pain is mutual* relates to the fact that the child also experiences "pain" at the time of brain damage: the lack of oxygen and nutrition and the separation bring to an abrupt end the intrauterine symbiotic environment and must be associated, as recent research indicates, with intense feelings of discomfort by the child (Verny & Kelly, 1981; Leboyer, 1974). Later, in the course of development, the conscious child constantly has to face his or her lack of ability. The less conscious or mentally retarded child can also detect chronic disappointment in his environment, to which he often responds non-verbally with "pain", in the form of aggressive, self-mutilating or difficult behavior.

This interaction entails a continuous transfer of signals with regard (a) to the pain feelings themselves, and (b) to the way both partners deal with these feelings, i.e. cope with their own pain and with the pain of the other. This interaction can be presented as follows:



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The concept of this interaction process is derived from the system theory outlined by Boszormenyi-Nagy (1973). One of its basic assumptions is that in an interaction process two (or more) persons enter in contact with the inner world of the other(s) through the medium of the outer side. In such interaction, there is a continuous (mutual) interpretation of the outer side of the partner(s). For instance, the parent may react to the "pain" of the child by denying it, by trying to stop it, by comforting it, or perhaps by staying in contact with the pain and trying to interpret its significance. The child may react to the parents' pain by suppressing his own feelings, or by withdrawing, or by over-reacting with nervousness, etc.

4. Part of the pain is *iatrogenic*. The physician who has to bring the bad news often gets all the rage of the parents, resulting from their feelings of powerlessness. It is important that physicians dealing with brain-damaged children learn to cope with these feelings, which is not easy. They have to gain insight in their own pain feelings in the first place. At present, this is still lacking in medical education. In addition, the physician can aggravate the parents' pain by formulating a negative prognosis, for instance: "Your child will never walk", or "He will only be fit for an institution". Such statements are based on a rather static model of brain damage, leaving little room for individual freedom and the unpredictable course of human healing systems. Yet, current research in neurology indicates that the brain has some faculties of recovery which can be positively influenced by the environment (Lund, 1978; Cotman, 1978; Walsh, 1981). A model of *brain plasticity* recognizing this fact would provide a more accurate description of reality. It would be most welcome by parents who want their child to improve and often are willing to contribute to this improvement. At the same time, we must be cautious not to create false hopes.

5. The pain of parents and children is also *triggered by reactions of the environment*, frequently expressed in well-meant but pain-provoking remarks like, for instance, underestimating the child. Gradually, the child becomes "invalid", not so much because of his objective disability, but because of the *lack of validation* by society. Another source of pain comes from the fact that the child with a handicap has difficulty in competing with "normal" peers in one or another skill. This is painful as competition is indeed an integral part of childhood.

Ways of dealing with the pain

Sources of pain are one thing, but dealing with them is another matter, and a difficult one, because modern Western culture, including its medical establishment and professionals, have a tendency to dismiss pain, to deny it or to attack it. Physicians have difficulties with their own life-pain and they are seldom able to offer sound help. In the case of families with a handicapped child, understanding the sources of pain is essential for the developmental process of both parents and children. For instance, if a child who has difficulties in moving wants something to eat, he will often ask someone to bring him the food. It is very frustrating when your body refuses to do what you want it to do. So the child will express his pain and anger in various ways. When a parent cannot see this pain or avoids facing it by giving the child what he wants, a vicious circle starts which will leave the child helpless in the long run. This is how children *become handicapped.* Tinbergen, a Nobel prize winner, who spent the last 20 years of his life studying autistic children, uses the phrase *"learned helplessness"* (Tinbergen, 1983). To break this circle, both adults and children have to learn to deal with their pain and frustration. Loving the child sometimes means resisting its immediate wishes, but helping it to solve problems by himself. This has been beautifully realized for children with motor disorders in the Peto Institute in Budapest (Hari, 1975). The results are amazing: the children appear to attain a much higher level of independence than is the case in most institutions.

A parents' course entitled "Acceptance is something else than resignation"

At the Academy of Health Promotion in Antwerp, which organizes various courses related to health promotion, one project aims to help parents of handicapped children become more aware of the healing process and to take a more active part in it. As all healing starts with recognition of the pain, focus is placed on enabling parents:

a) to become conscious of their chronic pain feelings, of which they are often unaware, but which they translate into all kinds of somatizations; and also to accept the pain and to understand its significance;

b) to allow feelings of pain and rage to be expressed; such feelings are often suppressed in the presence of professionals or other people; parents must become aware of the effect that their suppressed anger and pain may have on others;

c) to deal with reality by acknowledging the fundamental uncertainty of life and by accepting the limits of human power;

d) to see where parents' real power lies – often it is more a matter of *how* to deal with reality than to change it – and to gain insight in their freedom and (re)call their creativity and inspiration; here, it comes to a matter of "responsibility" in the sense of giving "response" to the challenge of having a handicapped child, of making a conscious choice to take up this challenge and to express the values which one wants to uphold;

e) to be in relation with pain in all kinds of daily situations; and to become aware of the way they react to their child's pain.

So far, 85 families have participated in the course, which consists of 10 weekly meetings of 3 hours in its current experimental form. The course is too recent to allow for an evaluation of long-term effects, but the experience is rewarding. Some parents really started to do creative work, to experiment with new ways of dealing with their child's disability, and they have discovered new potentials in their child and themselves. *When parents stop seeing their child as helpless,* they are able to give meaning to their reality and to influence this reality, even on the biological level. For example: an older mother had a child with Down's syndrome, suffering from severe mental retardation and heart problems; she had lost her other "healthy" child in a car accident and she decided to set up an intense stimulating program that would bring forth all the potential in her child. She eventually succeeded in making the child participate for two hours daily in a normal class where she was doing reading, mathematics and sports together with her peers (who were on the average three years younger than her). Another mother had a child with cerebral palsy who was bound to a wheelchair at the age of four; she gained new courage and belief, took her daughter out of the wheelchair and started to teach her to crawl and creep: she is now teaching her to walk. Many others have taken similar initiatives. However, parents usually have difficulties in taking up their responsibility, as it means that the burden can no longer be shifted. Being in relation with pain without any possibility to escape it is very difficult: one has to be attentive to each and every event in order to foster the child's independence. Our experience is that most prents find it difficult. The more so that society has a tendency to increase the helplessness of handicapped people.

Another problem encountered in the course comes from differences in the level of energy of parents. This is related to the age of the children. Parents of older children display more feelings of powerlessness and tend to consider that their children's potential is lesser; in fact, many of the older motor-handicapped children have more rigid bodies. On the other hand, parents with younger children have plenty of energy, which enables them to have confidence and to experiment. As the goals diverge, it might be preferable in the future to organize two different courses: one for parents of young children and the other for parents of older children.

The process of growing is closely related to transformation; it is like breaking out of a cocoon to become a butterfly. The healing process associated with having a handicapped child and enabling that child to grow is quite similar and it is painful. Yet, at the same time, it can be very meaningful. It requires a choice in favor of patience, hard work and efforts to solve problems. It is certainly not the easiest way. It is much easier to resign. But going through this process can give a sense of aliveness and vitality. Whenever there is an experience of meaning – which really reflects a choice – the chronic pain might not be dissolved but it can be accepted as an inevitable step towards inner growth.

CREATIVE MEDIA AND CHRONIC ILLNESS: CLAY MODELING AS AN INTEGRATIVE THERAPY

by Michael Rinast

Creative media such as painting, music, pottery, but also movement in the form of dancing and pantomime have been used for many years in psychotherapy and in helping people understand themselves. The creative media can be used in a number of ways in working with the "chronically ill": they assist both patient and therapist with self-exploratory processes that can involve experience directly related to the illness (such as conflicts) but can also lead to a deeper understanding of the illness itself or help the patient to cope with the illness.

Expressing oneself through a creative medium such as pottery or painting can be a help when language does not yet lead – or no longer leads – to further understanding. Creative media can help actualize certain subjects. A picture of a heart or of the back modeled in clay can give more direct contact to feelings about the body, emotions, inner images and ideas than a story about the heart or the back.

Work with creative media can promote the development of self-awareness, but also awareness of the environment and of fantasies and projections.

Thus the expression of the "disturbance" in the lump of clay, the shaping of this expression as a sculpture, can be used in the first place to concretize projections, fears or hopes, in order to examine them more closely by subsequently talking about them. The concretization and the dialogue which may follow (for instance, between the "sculptor" and his heart) facilitates for the patient the process of "reowning" that part of himself that has become alien to him, or even threatening.

Work with creative media can lead to an increase of the possibilities of expression and hence an increase in "ways of responding to the world". If one starts from the assumption that in our culture adults are limited almost entirely to verbal expression, increasing the possibilities of expression already represents an opportunity for developing the personality. This increase alone may have certain healing or coping values. And the work with creative media, such as paints or clay, helps patients to express ideas vividly.

Prelinguistic inner experience or inner experience that cannot be expressed in language can be communicated very well in this way: symbols are developed and pictures or sculptures are created that say more than language ever could.

Work with sculptures or pictures does not only permit the expressing of inner experience, but records it in its "fleeting character". Non-temporary media such as clay, pictures, puppets, masks, etc., allow contents to be preserved and help both therapist and client in the process of exploration.

("Exploration", in the context of this paper, means always more than mere investigation. Self-exploration in itself already has integrative qualities and work with creative media always includes a "working-through" and a possible reorientation.)

Clay modeling

Work with clay modeling can start at many different points. It is possible to concentrate directly on the affected organ or the part of the body giving pain. It is also possible to start with feelings about the illness or the reactions of the environment. The shaping should always come from inner experience. The client attempts to put his emotions and moods, impressions and inner images into the clay and give them a shape. As a preliminary step to the modeling, it is advisable to start with an awareness exercise, which increases perception of the inner experience. This can be a meditative "journey through the body", but also a brief moment of "unspecific contemplation" or a physical exercise with the aim of improving contact with one's own body.

Sculpturing clay often leads the person concerned to express himself with his

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whole body: "Hands, face and sometimes the whole body express what is going on inside the individual. Currents of energy come from inside and are visible in bodily movement. Facial expressions clearly reflect feelings. Inner emotions are expressed in the clay through the movements of the hands."
Clay as a soft material, workable but not infinitely so, allows the expression of the widest variety of emotions: from the direct expression (through simple motoric skills) of psysical impulses such as throwing, hitting, smashing or tearing, to the fine chiselling of a filigree clay sculpture, there are a great number of expression possibilities. This property of clay as a medium enables the representation of a wide spectrum of emotions or impressions as well as symbols, concepts and ideas.
Thus the simple expression of sorrow or rage at chronic pain or lost ability is just as possible as a symbolic representation of the patient's network of social relationships with all its nuances and possible ambivalence.

Discovering the meaning of the sculpture

The possibilities offered by clay modeling, outlined here, basically apply as well to other artistic "products", such as pictures, masks, puppets, collages and other objects.
The client should be helped to experience the sculpture as intensively as possible, in order to make feelings and memories available in the here and now. The concretization of the model brings the client in contact with his inner images, with his physical impulses and impressions. The work with the sculpture, and talking about it, makes it possible to connect "the language of images with the language of reflective rationality", so that a vivifying interpenetration can take place. This interpenetration, which also serves to harmonize pictorial intuitive thinking with rational analytical thinking, has in itself a therapeutic quality according to findings from more recent psychotherapy research.
The client can look at his sculpture in four ways:

1. The sculpture as a whole: what does the sculpture mean as a whole, what is its significance, what is the message of the total product (e.g. if this sculpture is my heart or represents my heart, what does it tell me about my heart?)

2. The different parts or the sculpture: what parts does it consist of and what do the individual sculpture elements mean to me?

3. The atmosphere resulting from the sculpture as a whole and from its parts: what emotions and moods does the sculpture generate as a whole and/or with its individual parts?

4. The "missing" parts, the gaps: these also can contain information for the client and the therapist (e.g. what does it signify for me if I model my body in clay but "forget" the head or the hands?)

Identification with the sculpture

The client can identify with his sculpture in a number of ways. He can say "I, as the sculpture, now feel ..." or "I now feel ...". When the client speaks "as the sculpture" he has the opportunity of verbalizing part of what it is expressing (and hence the feelings he has put into the sculpture). Through this process of identification, he comes to "recapture" his *self*. With the help of this Gestalt therapy identification technique it is also possible to allow individual aspects of the sculpture to enter into a dialogue with one another (e.g. the damaged parts of the body speak to the healthy parts). And it is possible to conduct a dialogue with the sculpture ("My heart tells me what it thinks of me and what it wants from me ... I talk to my rheumatism about our common views of life" etc.). These dialogues can be apparently superficial but also deeply emotional and frequently they make profound understanding possible. This process leads to an insight into the connexion between somatic illness and the psychosocial or intrapsychic dynamics which, otherwise, remain often inaccessible for the client. Current medical education of the patients, e.g. in heart infarct clinics, is also not very conducive to such insight. And "education by experts" is probably not the way either to inform people of the delicate and not unintentionally rejected connexion between psyche and soma.
Working with clay sculptures (or pictures, etc.) and the identification technique described here allow the client to get closer to the subject in a manner and at a pace that suit him.

Creating fantasies

The client can also invent fantasies in connexion with the sculpture or individual parts of the sculpture. The therapist can also help the client with self-exploration by asking him to explain the fantasies in his sculpture.

If the process is taking place in a group, the other members of the group are also helpful sources of fantasies which can help broaden the experience. During this procedure it is extremely important to treat the fantasies as fantasies which contribute to intersubjective understanding between client and therapist and other group members. They are on no account interpretations and explanations with a claim to truth. Only as fantasies can they help the client to discover new aspects in the sculpture, or aspects of which he was not aware, or to look at various aspects of the illness as a result.

The sculpture-drama

When in the course of the self exploration process several sculptures have been created, e.g. a whole-body sculpture, an organ sculpture, symbolic sculptures, etc., there is a possibility of bringing these sculptures into dialogue with one another. The client can identify with the different sculptures and bring them to life. The different sculptures possibly depict different aspects of the personality which thus come into conscious contact with one another. By this approach, ambivalent attitudes can be dealt with, as well as splits in the personality and aspects or consciousness that are censored.

Integration: the final objective

The concept of "integrative therapy" serves as background to the work with creative media. This "integrative" process acts in a number of ways: integration of various aspects of the client's personality, integration of his life-history, and also of the history of the social environment and the ecological context; integration as well of lost and regained, or newly acquired abilities; and last but not least, integration of disturbances and damage that are irreversible.

From the point of view of theory and methods, integrative therapy is also an integration of various approaches: from the active psychoanalysis of the Hungarian school (Ferenczy, 1970) and the Gestalt therapy of Perls & Goodman (1979) to the existential philosophical tradition of Merieau-Ponty. The holistic approach of the integrative therapy concept puts emphasis on understanding the person with all his corporeal attributes, all his forms of perception and expression, and his way of talking about them in the therapeutic process. Working with creative media is one of the means employed. As indicated briefly above, it is linked with verbal discussion but also with other forms of expression and response such as exercise, dancing, music, pantomime, therapeutic theatre, contemplation and meditation. Another means, that is still employed too infrequently, would be working together: working on a specific object, working on projects, active participation in social and ecological "healing projects".

The various approaches of integrative therapy largely combine the different media with one another: clay sculptures are translated into movement and dance, poetry therapy and music therapy permit specific forms of expression and exploration that go further. And as they make the integration of illness and coping with it possible, so these approaches also help the client arrive at a different understanding of illness. An understanding where illness is also perceived as an expression of a life process that cannot be removed by therapy. Where illness describes the foreseeable end of life, where one must confront one's finite nature. Where it is no longer the courage to change but the willingness to accept that is required.

When language fails...

In my experience, the creative media in particular, and also "mediating work", can be used and are helpful where language can no longer express "inexpressible, unspeakable suffering". When a person is speechless with fear, rigid with panic and paralyzed with grief, non-verbal methods are often the only possibility of communicating, making contact and establishing a relationship.

TRAINING PATIENTS WITH CHRONIC POLYARTHRITIS TO COPE WITH PAIN

by Uwe Prümel, Silke Eggerichs and Bettina Bunge

The project developed by the Schleswig-Holstein League against Rheumatism in its model center at Kiel aims to promote the interest of people suffering from chronic polyarthritis in activities that are complementary to medical provisions and focus on self-help. Five categories of measures from the area of psychotherapy are offered:

- telephone consultations to discuss problems;
- support through self-help groups and discussion groups;
- individual consultations in the case of psychological problems;
- leisure activities;
- training courses aimed at the alleviation of pain (training in coping with pain).

The courses in coping with pain are organized by the model center in close cooperation with the local associations of the League. First, an introductory lecture is given on psychological problems associated with chronic polyarthritis and the potential help to be derived from psychotherapy.

The prime aim of the courses is to enable the patients to deal more effectively with the considerable stresses resulting from their chronic illness, in particular their pain. The patient should be helped to lead his life in a satisfactory way and to improve his general well-being. Patients always have the hope, sometimes expressed openly and sometimes kept secret, that the pain will vanish as a result of participation in such a course. This must be relativized at an early stage. It must be made clear that with the help of pain coping techniques, people can increase control over their pain and thus reduce the feeling that they are at the mercy of constant suffering. A further aim is to improve the patients' spirits, their self-image and ideas about their body. Through the experience of pleasant bodily sensations during relaxation and visualization exercises a change is initiated in attitudes to one's body, which has perhaps been perceived for years merely as a source of pain and as increasingly immobile. On the behavioral level the aim is to enable patients to achieve appropriate healthy behavior; this involves the capacity to observe and take body signals into account. A longer term objective is the reduction of medication.

Three stages in developing coping skills

These aims can only be achieved if the patient is highly motivated and works with the therapist. Sufficient time is therefore allowed, in the initial stage of the course,to establish motivation and correct inappropriate expectations. The courses in pain coping are given in 1 1/2 to 2-hour sessions over a period of 10 weeks. The group consists of 6-8 participants, so that a group process can develop. The group atmosphere reinforces the relaxation experienced by the individual and the relatively small size of the group also makes it possible to deal more intensively with the needs and problems of individual patients. The exercises involved in developing the capacity to cope with pain are divided into three groups:

- stage 1: progressive muscle relaxation (Jacobson);
- stage 2: journey through the body;
- stage 3: visualization exercises.

The progressive muscle relaxation, based on Jacobson's method, is an active relaxation method which meets the need of patients to influence their situation actively. The method enables them, for example, to become sensitive to the perception of tense and relaxed states. Once this objective has been achieved, there is

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a change to a passive relaxation method, the so-called "journey through the body", which enables many participants to have a deeper relaxation experience; it also serves to prepare the patients and puts them in the right mood for the subsequent visualization exercises. The accompanying fantasy focuses on images which give the patient energy and peace. It is a suitable form of introduction to the visualization method as it starts with the visualization of an external environment which most patients can easily achieve. This is followed by an exercise related to the inside of the body: the patients imagine a pleasant, reviving liquid which loosens the muscles and washes round the joints, cleaning and maintaining them.

In addition to the exercise phases, participants are given sufficient time in the course sessions to exchange experiences about their training.

Difficulties and successes with the newly learned techniques are dealt with on an individual basis. Daily life problems which produce stress are usually brought up by the patients themselves, since coping with pain is also understood as coping with stress. The individual thus becomes aware of personal coping strategies that have already been developed and these are made available to the group through discussion with other course participants.

A client manual, which describes the individual relaxation techniques and how to practice them, helps the course participants to exercise at home. The patient is introduced to relevant literature and at the end of the teaching on progressive muscle relaxation, in the fifth course session, the participants receive a cassette for practice at home.

(In the first fifteen courses with 115 participants, 96% were female and 72% between 50 and 70 years old.)

A PSYCHOPHYSIOLOGICAL THERAPY PROGRAM FOR MIGRAINE SUFFERERS

by Michael Falkenstein and Helga Falkenstein

This medication-free program is based on behavioral therapy and uses a multidimensional psychophysiological approach to understand and influence the migraine process. It attempts to teach patients cognitive, behavioral and physiological self-control strategies that can be used in everyday life.

In recent decades there has been a marked increase in psychosomatic disorders, which is not just the consequence of improved statistics. From a psychodynamic and a behavioral-medical point of view, migraine is a typical psychosomatic disorder. We start from the assumption that migraine is usually caused by a number of factors. Using the diathesis-stress paradigm of behavioral medicine, we find two important components leading to migraine, namely a constitutional predisposition (diathesis) and stress (in the widest sense).

Stress is caused by the cognitive evaluation of environmental stimuli and the subjective assessment of one's ability to cope with the situation. When stimuli are perceived as threatening, and the ability to cope is considered (subjectively) as inadequate, this situation gives rise to stress.

With migraine sufferers, the regulation of the blood vessels in the head is unstable. This means that these patients tend to react to stress with a particular sequence of changes in the blood vessels, which brings about the symptoms of the attack.

A diathesis-stress model of this kind seems to apply to most psychosomatic disorders, i.e. it is assumed that the patients have physiological "weak spots" which are the first to give way under stress and result in illness symptoms. Even in healthy people, but to a much greater extent in migraine sufferers, stress causes the blood vessels in the brain to constrict. This is followed, possibly as a reaction to reduced circulation, by marked dilatation of the large vessels in the brain. At the same time the pain threshold of the vessel walls is reduced by the release of pain provoking substances. This is the cause of the migraine pain. In other words, it is assumed that a negative reaction to environmental stimuli leads to stress, which in turn leads to pain as a result of faulty vessel regulation in the brain. The disposition to faulty regulation is probably inherited, but negative reaction to environmental stimuli is learned.

On the basis of this model, it would appear useful to apply the migraine therapy at various points of the conditioning network. Since the subjective evaluation of a stress factor is what turns it into stress, multidimensional therapy should start here.

The first stage of our therapy program is hence:

Stress coping training

Migraine patients, like almost all patients with psychosomatic disorders, are usually less able to deal sensibly with stress factors. This is characterized in particular by insufficient expression of emotions and anger, especially in their relationships with superiors at work and with their partners.

Stress coping training is carried out in small groups of 6 to 8 patients or in individual sessions. The patients should first learn to identify environmental stress factors and factors initiating an attack. The patients then report how they currently deal with these stimuli, i.e. what thoughts, feelings and actions follow. In further sessions an attempt is made to discover the extent to which these thoughts, emotions and actions are justified and how efficient they are as methods of coping with stress. In order to explore alternatives, the patients first practice these in the group or in therapy session by means of role playing, and then try to apply them in everyday life instead of their previous inadequate behavior. Their experience with the new behavior is discussed in the next therapy session, whereby possible adjustments to the behavior can be motivated and once again practiced.

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By changing thoughts, emotions and behavior in response to critical environmental stimuli, migraine patients can successfully learn to deal in a more effective way with factors initiating attacks and as a result, the attacks will become fewer. Since it has been established that migraine patients react excesssively to stress with resulting vasoconstriction, the next element in our therapy program is:

Relaxation training

The best-known relaxation methods are autogenous training and progressive muscle relaxation. Comparative studies have shown that combining elements of both methods produce better results than either method alone. In our relaxation training we therefore combine autogenous training formulas with instructions to tense and relax individual groups of muscles. The relaxation training, like the stress coping training, can be conducted in small groups or individual sessions. What is important here is not just the relaxation but learning a better perception of the body (e.g. when there is an increase of tension) in order to detect quickly the onset of stress-induced stimulation and reduce or eliminate it by employing the relaxation techniques that have been learned.

The third element of our training program starts at a more peripheral point in the causal chain that leads to pain. As already described, one of the conditions for the development of migraine is the dilatation of large vessels in the brain. In order to treat attacks, medication is usually taken to constrict these vessels (ergotamine preparations). The problem is that these drugs must be taken at an early stage, since they only take effect slowly. Because of this delayed action, often the migraine cannot be stopped. Taking the drug too soon or even prophylactically can very easily lead to misuse and, in the case of mixed preparations, to pronounced side-effects such as the development of a permanent headache. For this reason, the third part of our training program deals with:

Vasoconstriction training

This training is concerned with helping the patient develop the ability to influence the width of the vessels, directly and voluntarily. In this way the patient can acquire the ability to work actively against the onset of vasodilation in an attack.

Here, the width of the temporal artery is measured and continuously reported back to the patient in visual form (biofeedback). In the training sessions the patient should try to voluntarily constrict the artery, whereby he can use the feedback picture to help. In this way he can gradually learn voluntary vasoconstriction, increasingly without feedback so that he can continue to practice constriction at home. By constantly practicing vasoconstriction, successful patients are able to repress migraine attacks at their onset and markedly reduce their frequency as well as the taking of medication.

Self-control skills prove successful

The three skills are thus complementary and are applied at different points in the causal chain that leads to migraine pain. They all attempt to increase the ability for self-treatment by teaching patients new skills which enable them to intervene at all behavioral levels (cognitive, emotional and physiological) in the migraine process. These self-control abilities serve partly as a preventive measure and partly to arrest attacks. Comprehensive studies in which the three methods were used parallel to one another show a marked reduction in the frequency of attacks and the taking of medication, which is clearly linked to the acquisition of self-control skills. The three methods are currently being applied in a combined training program conducted in individual sessions for outpatients.

THE USE OF VISUALIZATION IN GROUP THERAPY FOR CANCER PATIENTS

by Iris Bartkoviak

An innovative approach to the treatment of cancer patients was developed in the late 1970s by a small group of US psychologists. Based on their experience with cancer patients, Simonton, Matthews-Simonton and Creighton proposed a therapy concept inspired by the view that treatment should include (a) the psychological elements of illness and recovery processes taken in the widest sense, and (b) measures aimed at stabilizing the patients or influencing them in a positive way, whenever necessary. In addition to the usual medical treatment, their patients received intensive psychological treatment.

This approach stemmed in part from the positive experiences reported in the field of cognitive psychology. This approach was being taught to managers with respect to their attitudes to success or failure. The Simontons felt it should be possible to influence in a similar way the immune system which, in their view, was closely connected with the development of cancer. (The thesis regarding the role of the immune system in relation to cancer has still to be further proved scientifically.) In addition, the Simontons' own observation suggested that coping factors such as inner goals or purpose in life, the hope of a cure and confidence, had an influence on recovery processes. This is how they came to use an exercise known as "visualization" which also took into account the well-established influence of deep relaxation on the regulation of immunity. They combined it with deliberately produced inner images of the tumor which was being fought by the body's defense as well as by medical treatment. The elements of the exercise are described below.

Instruction for relaxation and visualization

Sit down and make yourself completely comfortable. Put everything aside that might disturb you. Close your eyes. Start to relax. You are already becoming calmer and aware of how you are sitting, the contact you are making with the chair.
You feel how the upper part of your back is touching the chair.
You are sinking yet more deeply into the chair and sense how your entire back comes into contact with it.
You are sinking deeper and deeper and becoming aware of how safe and securely you are sitting, how the chair is fully supporting you and that you can now fully let yourself relax.
You feel the contact between your thighs and the seat. Further and yet further down towards the feet. There you can feel how the soles of your feet are touching the earth, making contact with the earth.
Perhaps you also sense a current, flowing from the center of the earth through the soles of your feet into your body.
You are connected with the earth and its gently flowing current.
Your arms are feeling heavy, very heavy.
Also your legs are heavy, very heavy.
You are breathing quite calmly and regularly, deep down into the lower abdomen.
Soon you will see a stairway before you – your stairway and it has ten steps.
And with each step, you will become more and more relaxed.
Now you see your stairway before you. You are taking the first step. Then the second step and further ...
the third step is bringing calmness
the fourth step brings peace
the fifth step – now you are half-way
the sixth step and still further on
the seventh step is to feel free
the eighth step is as if you could fly
the ninth step, you are almost there
the tenth step, now you are deeply relaxed.

The body is totally and deeply relaxed, yet the mind is wide awake and clear and alert to what is to be experienced.
You now enter into the body, irrespective of how and where.
Very slowly, according to your rhythm and pace, you go exactly to the place that you had intended to go. There, just where the tumor, the metastasis exists, where the weakness, the problematic point of your body lies. You look at everything exactly,

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the color, the structure, what is happening.

Perhaps, you can also see how your own body's defenses are flowing precisely to the place where they are most needed.

You watch and consider everything that is happening.

Now, slowly you move away from this picture and return once again to your stairway – this stairway with its ten steps. But this time, with each step, you will become more and more awake:

the tenth step
the ninth step: more and more
the eighth step: quite distinctly, you are becoming aware of
the seventh step: how you are in this room,
the sixth step: also, quite clearly, the chair,
the fifth step: how you are sitting there, together with the others,
the fourth step: the contact of your body with the chair, you can now feel it more and more distinctly,
the third step: more and more conscious and wakeful, you are becoming aware of your surroundings,
the second step: you already feel how your body wishes to move,
the first step: and now you are awake, you open your eyes, you have returned to full consciousness.

This exercise is never to be isolated from the overall context of the treatment, which is always a comprehensive program of psychotherapy since illness occurs in the context of people's surroundings and relationships as well as it relates to their personal biography. Other aspects are therefore just as important as visualization. They concern:

- the patient's responsibility for himself;
- secondary gains from the illness;
- the need to identify causes;
- the "healthy" (strong) elements in the patient;
- overcoming "inner resentment";
- creating a future, setting goals;
- making contact with one's "inner advisor";
- coping with pain;
- engaging in physical activity;
- coping with the fear of a relapse and death;
- receiving support from the family.

Dealing with these aspects counteracts the feeling of helplessness. It aims to help the patient regain his ability to deal with the disease, and helplessness thus shifts towards action and self-determination.

The deep frustration resulting from the dysfunction of the body – which may coincide with a deep frustration with life in general, already existing before the disease – often triggers a personality crisis which makes comprehensive psychotherapy a matter of urgency.

The Simonton approach is based on a broad concept. Unfortunately, it has often been reduced by others to the mere exercise aspect and its application equated to treatment with medication: doctors tend to give the book to patients – as they would give a prescription – and advise them to read it and do the exercises three times a day. At first, patients see in the book a psychological prop but soon they become discouraged. A printed text does not provide opportunities for dialogue and they feel left on their own, with the result that they often abandon.

Some criticize the Simontons for their all-too euphoric and simplified view of the way it is possible to influence the immune system and the successful cures that will result. The success figures they quoted could never be reproduced and this is certainly a cause for complaint from the methodological point of view.

In our experience patients who have studied the book do not merely concentrate on the exercises but are just as interested in regulating their lives, learning how to cope more effectively and get along better with their family and their partner.

A shift in the approach

Our answer to the needs shown by our patients was first to provide intensive person-to-person treatment in which we could take into full consideration the individuality of each patient. In the process, we gained experience with the exercise described and discovered that more patients than expected responded well to the method of visualization. Initial alienation on the part of "beginners" vanished rapidly, to be replaced by a positive attitude to their bodies and the pleasure which they experienced in the joint interpretation of images.

Very soon we moved away from the original, somewhat rigid, instructions for visualization to a more open form of guidance which provides a great deal of scope for the individual elaboration of images. Drawing on the "Katathymen Bilderleben" –

a form of therapy in which the patient is asked to imagine particular scenes such as a meadow with wild flowers, the entrance to a cave, etc. – we broadened the intrinsic aim of visualization. We now have a joint interpretation of the images with the patients to improve their understanding of themselves. The systematic conditioning of the immune system has given way to a psychotherapeutic concept whereby an attempt is made to reveal the intrapsychic attributes of the illness with the idea of always making connexions between conflict areas prior to the illness and the illness crisis itself.

If there is a connexion between psychological factors and the occurrence of cancer, a psychosomatic theory seems more appropriate to us than the idea of conditioning of the immune system. The positive reactions of the patients to visualization, the interpretation of the images and the therapy dealing with the general and everyday problems of life have led us to realize that creating or restoring the quality of life should be the main objective in coping with cancer. We focus therefore on essential topics which can be dealt with sensibly and effectively in the limited treatment period at our disposal (see article p. 202).

Moving to group therapy

We have now developed a group concept which provides an orientation both for us and for the patients but allows sufficient scope for variation in individual cases. This group therapy is comprised of eight sessions of 1 1/2 to 2 hours each; this gives sufficient time for therapeutic work, yet avoids giving rise to a feeling of anxiety which untrained patients experience when sessions are too long. The group is self-contained and consists of six to a maximum of eight patients. Next to visualization and interpretation, topic-centered discussions take up most of the time. The following topics are suggested: origins attributed to the tumor by the patient; how the illness is experienced; stress factors in the patient's history before the illness, and strategies used for coping with them; the current stress situation in everyday life and how the patient copes with it. The table which follows this article lists the topics proposed for each session.

Each group formulates different focal points so that it is possible for other topics to be introduced, or fewer points to be discussed more intensively. The "artificial" situation of the limited inpatient stay, remote from everyday life, makes it particularly important to ensure that the tension created within a group declines towards the end. Every patient should have reached a conclusion with respect to his individual problem. If a patient does not develop easily, individual therapy is undertaken parallel to the group therapy.

The results are positive

Such an approach can only help to take small steps on the road of health promotion, but experience has shown that these steps can later on be transferred to everyday life.

We have not been able until now to carry out any accompanying research or systematic follow-ups, so that the effectiveness of the therapy is limited to our clinical observations.

Our seven years of experience with this method indicate that important changes can be achieved. This is confirmed by the statements of the patients returning at regular intervals after having taken part once or several times in such a group. Patients have become aware of feelings of inadequacy and helplessness and of poor coping strategies. The treatment has enabled them to become active again and to come markedly closer to coping with the illness and with life, which is the objective of the therapy.

Session No.	Subject	Aim
1.	Introduction	First familiarization with the method
	Getting to know each other	Introduce the group process, create an atmosphere of confidence
	Expectations of participants	Make clear the personal involvement
	Short feedback period	Come into contact with one's current condition and learn to be conscious of one's own feelings
2.	First trance with fantasy travel	Introduction to techniques using stabilizing images
	Present state of body and mind	Attach importance to the body, first steps towards personal involvement in the recovery process
	Discuss which body areas will be the topic of the visualizations	Preparation for the following exercises
	Short feedback period	
3.	Trance with body image (tumor)	Strengthening of the immune system, self-confidence, active recovery, etc.
	Detailed discussion of stress factors before becoming ill	Learn to recognize reactions of helplessness and to develop helpful counter reactions
	Short feedback period	
4.	Trance with body image	
	Painting together	Reduction of fear through painting; promoting the value of knowledge
	Detailed discussion	Further, more intensive steps towards having an occupation
	Short feedback period	
5.	Residual images	Discussion of the images
	Trance with body image	
	Short feedback period	
6.	Trance with body image	Considerations on current life relationships and psychic energy; development of a positive attitude towards one's life and, perhaps, the possibilities of changing; setting realistic aims in life
	How best to "budget" the use of one's energy	
	Short feedback period	
7.	Residual energy "budgeting"	Discussion
	Short feedback period	
8.	Reflection on the past: what was important?	Departure from the past and realistic outlook towards the future
	The future	How will one get on at home again?
	Short feedback period	

"BODY AWARENESS": A NEW FORM OF THERAPEUTIC EXERCISE FOR HEART PATIENTS

by Wolf-Dieter Fischer

Therapeutic exercise for heart patients implies much more than physical training. Physiotherapy, bicycle ergometer training and going for walks contribute to restoring health but the fundamental needs of heart patients cannot be met by mere leisure activities and sports nor even by efforts to control and suppress personal and environmental stress. Insight is needed. Body awareness aims precisely to provide such insight.

The "inner experience" produced by the introduction of a meaningful task in the therapeutic exercises and the "physical movement" associated with the task are conceived so as to have a significant influence on the behavior of the heart patient and lead to change in daily lifestyles (Fischer, 1986b).

In the therapeutic exercise center of the Waldburg-Zeil clinics in Isny-Neutrauchburg, in the Federal Republic of Germany, body awareness is incorporated in the physical therapy program.

What is "body awareness"?

This is a therapeutic principle which is applied to exercises with the body at rest or in motion. The unity between inner perception and physical exercise is the basis of interaction between the inner world of behavior, relaxation and experience, and the outer world of everyday activity (Fischer, 1986a).

Body awareness is not meant to be used as an independent form of therapy but integrated into existing exercise programs at appropriate points. A sensitization phase of around 4-6 weeks is nevertheless necessary. Through the body awareness approach, the patient comes to relate what he momentarily experiences, senses and feels in performing a wide variety of exercises with aspects of his private or working life and potential negative impacts for the future.

In order to explain how body awareness functions, the three most important areas of exercise will be described:

a) *Dealing with risk behavior*
The patient is encouraged to try out individual behavior alternatives through personal confrontation with, for instance, aggression, hectic behavior and impatience, competition and urge to dominate, and achievement-oriented perfectionistic behavior patterns.

b) *Practicing the ability to relax*
When working towards a state of "inner harmony", we distinguish between direct and indirect relaxation. In direct relaxation, breathing, meditation and deep relaxation exercises are practiced by the patient on his own, with the aim of reducing the vegetative excitation level or achieving muscular balance. Indirect relaxation for the heart patient aims at developing poise, relaxedness and composure through exercises connected with the formation of a group: introductions, making contact and loosening up.

c) *Experiencing one's own body*
The way in which the patient handles his own body as a whole is influenced by making him aware of habitual movements or posture (walking, running, standing, sitting, lying), by his learning to recognize body signals that influence stress (physical and mental work), by training the senses (seeing, hearing, feeling), and by creating a sense of nearness or distance (body contact).

Body awareness: why and for what purpose?

There are three reasons for integrating body awareness in therapeutic exercises and in the process of improving health.

a) Classical as well as psychosocial risk factors represent a threat to a healthy life.

Classical risk factors (e.g. excess weight, high blood pressure, cholesterol, smoking, lack of exercise) can often be successfully controlled through programs

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of therapeutic exercise aimed at changing the body's metabolism or at bringing about cardiac relief through more effective movement. Since, however, it has been proved (Bräutigam, 1975; Schäfer, 1982) that psychosocial risk factors (e.g. time pressure, occupational stress, family worries, environmental and industrial civilization problems) are playing an increasing part in the occurrence of illness, we must consider how they can be influenced by therapeutic exercise programs.

b) Therapeutic exercise, which is primarily function-oriented, must be complemented and widened by experience-oriented exercise.
Two main aims of therapeutic exercise (improvement in the functioning of the postural-support apparatus on the one hand and physiological relief of stress on the heart and the circulatory system through movement, on the other) are concerned with restoring physical fitness. The exercises used for this purpose have often been designed without thinking through all the problems and there is a great danger – according to the personality structure of the patient – that the "type A behavior" risk factor (e.g. achievement orientation, prestige-oriented thinking) will be reinforced if the therapy concept does not take experience-oriented aspects into account.

c) In order to achieve a state of health, thoughts, feelings and actions must be taken equally into account.
The aims of individual or group discussions in achieving health (also in therapeutic exercise programs) are to inform and motivate the patient, and optimally, to bring him to the point where he is prepared to rethink or change his behavior.
In the discussion situation, a patient finds it difficult to see what he can do about problems arising from how he behaves and how he ought to behave. On the other hand, when the problem is demonstrated in exercises and experienced as individual behavior, the discussion becomes much more meaningful and possible solutions can then be explored.

Some practical examples lined with "type A" behavior

From my experience, the following exercises help with the integration of body awareness into traditional exercise and training programs (Binkowski, 1984), an approach which makes it easier to recognize and deal with conspicuous "type A" personality traits.
Decision as to when the body awareness exercise is incorporated into the therapy unit and whether the experience of the patient is to be discussed at the same time or at a later point (Grössing, 1977) is left to the judgment of the therapist, according to the focus of the treatment.
The exercises are designed in such a way that patients can understand quickly what is important for them. We try to make sure that there is an experience before there is a purely intellectual insight.
The process includes three steps: preparation for the exercise; facilitating precise and full perception during the exercise; and description by the patient of what he has perceived and experienced. We do not attempt to interpret the experience of the patient as this would be the task of a trained therapist specializing in this particular area, such as a clinical psychologist or psychotherapist. As exercise therapists, however, we encourage the patient to reflect on his experience and on the feelings perceived during the exercise (Stolze, 1985).

The problem of resistance and denial

"You know", said one patient, "at first I thought it was all nonsense. But now I realize this represents for me one of the most important elements of the treatment."
Another patient made remarks about kindergarten and sandpit games and expressed a complete lack of understanding for the program that day; only when another patient asked what was actually so bad about being a child did he become thoughtful.
Resistance, defensiveness and denial are personality traits that should not surprise us in cardiac infarct patients. They represent protective mechanisms which serve to repress illness-related fears of profound losses or irreversible failures in the widest variety of areas. We must of course pay attention to these traits, since they have a crucial influence on the cooperation of the patient and the effect of the therapy.
For this reason it is particularly important with newcomers in the inpatient rehabilitation clinic, or with outpatients in the heart groups – who have often a very stable "type A" behavior with its illness-inducing characteristics reinforced by society – to change the "being used to a different way of doing things" into

“physical movement”. This can be done by briefly indicating the idea behind the exercise before starting or by proceeding in a highly structured way with specific rules. The therapy procedure can also be tied to known patient expectations and have a content tailored to their particular needs. The aim is to be as comprehensible and intelligible as possible and to produce distinct, visible and successful outcomes for those concerned.

As mentioned above, the body awareness exercises are integrated into existing programs with keep-fit exercises and games, or bicycle ergometer, walking and running training. Heart patients who are taking part in the “normal” program are therefore also offered the body awareness exercises. In Isny-Neutrauchburg, we found that even after the above-mentioned “sensitization phase”, some patients were neither willing nor able to accept these exercises.

Qualifications of the exercise therapist

Meaningful, health-promoting practical work with body awareness and in particular its appropriate integration into exercise programs for heart patients will always be influenced by the personality and training

TABLE 1. DEALING WITH RISK BEHAVIOR

Agression		Hectic behavior/impatience	
Duration: 5-10 min *Equipment:* Foam-rubber batons *Participants:* In pairs *Used with:* Exercises with a baton *Note:* Precise “hitting” instructions	*Fencing duel:* A duel with foam-rubber batons, standing on the spot and with movement (forwards, backwards, sideways). The partner may be hit.	*Duration:* 5-10 min *Equipment:* none *Participants:* Open arrangement *Used with:* Walking/running training/and gymnastics	*Pace tempo:* In the time alotted (30/60/90 sec) the participants count their steps, maintaining the same tempo. The therapist then sets the number of steps to be made in the same time unit as before (30/60/90 sec). *Note:* First, let the participants determine their own number of steps
Competition/dominance		**Perfectionism**	
Duration: 5-10 min *Equipment:* Balls/chairs/rings *Participants:* In pairs *Used with:* Exercises with hand equipment *Note:* Timely intervention in case of overtaxing	*Imagination:* Each pair chooses two of the available types of equipment and thinks up an exercise which all the other pairs can do in competition. Participants are asked: “What points must be taken into consideration?” (Time points; distance; requirements for the exercise)	*Duration:* 5-10 min *Equipment:* none *Participants:* In pairs *Used with:* gymnastics	*Drawing figures:* One of the two stands still, the other one walks, outlining a figure on the floor: the standing partner has to guess what it is *Suggestions:* 1. An animal 2. A number 3. A symbol *Note:* After completion of the figure, partners can change places and repeat

or the further education qualifications of the therapist (Fischer, 1986a).

In my opinion the therapist should fulfil the following requirements:

a) personal and practical experience over a period of months or years (body awareness aspects are currently being more frequently included in further training organized for physiotherapists and sport therapists);

b) since the physical process – at least during the practice of the exercise – is foremost, the therapist too must have accepted his own corporeality: he must be flexible, lively, expressive and sensitive;

c) in order to promote the patient's trust and cooperation, the manner of presentation is crucial: voice, language, imagination and understanding are important factors;

d) the capacity to assume the role of leader, to guide the treatment process and to act as observer and partner is essential;

e) the basics of discussion and communication such as listening and being able to make oneself understood are among the tools of the therapist working with body awareness.

Keeping in mind the contents and aims and above all the potential of the body awareness approach, therapists who are searching for more effective rehabilitation means or would like to explore new therapy concepts with heart patients should remember the words of Stolze (1985):
"There is only one real danger with the application of methods and techniques in the area of experience-oriented exercises and that is the inadequately prepared and inadequately trained therapist."

THE FELDENKRAIS METHOD: AWARENESS THROUGH MOVEMENT AND FUNCTIONAL INTEGRATION

by Ulrike Apel

The Feldenkrais method is the result of many years of research by an Israeli engineer, doctor of nuclear physics and judo champion, Moshe Feldenkrais (1904-1984).

In the thirties, his interest in the characteristics of man, the dynamics and statics of the human body, led Feldenkrais into the areas of behavior therapy, neurophysiology and neuropsychology.

His method is a *learning method* which aims to promote a more conscious direction of the self – conceived as a whole incorporating body, mind and spirit – through a more sensitive, better use of the body.

The Feldenkrais method is not concerned with physical fitness but with the "plasticity of the brain".

By contrast with animals, man has few instincts. He has to learn his behavior and patterns of movement in the course of his development after birth. The development of movement in the child proceeds hand-in-hand with psychological and intellectual development. With every new movement (rolling, crawling, sitting, standing, walking), the child extends the scope of his action and his experience; in this way, he develops his self-image as an autonomous person.

The aim of Feldenkrais is to take the adult back to this point – where learning is not restricted and embarked on with a specific aim, but takes place in a spirit of play and discovery accompanied by curiosity, joy and laughter. Often, in the course of socialization, such an approach becomes disconnected from "learning" (in the cognitive sense).

Creating awareness first

Lessons in the Feldenkrais method focus on the kinaesthetic sense of movement. They usually take place in a lying position, with effort and speed reduced to a minimum. The aim is first, to create awareness of *how* one makes certain movements. *What* do I usually do? Intellectual knowledge is replaced by sensory awareness.

The students become conscious of wrong patterns, bad posture and tensions acquired over the years in order, then, – and this is the second step – to make way for more economical, lighter and new patterns, which are more appropriate to the person and the particular situation.

Have you ever thought about *how* you get up from a chair? Where does the movement begin? How do you shift your weight? What is your head doing? And your neck? What is your breathing like? You have already made this movement hundreds of times but you will discover that it is not conscious.

The body functions automatically. Normally this will not bother you unless pain, a relearning process after an accident, an illness or paralysis forces you to concentrate on the way the movement takes place. Or, perhaps, just the feeling that "it could somehow be lighter, more elegant and more flexible".

In a Feldenkrais lesson you learn, for example, what effect shifting the weight of the pelvis has on the organization of your knees and feet; how, by conscious observation, you can release tension in your neck and how you can improve the action of standing up and make it gradually become lighter and effortless. With a minimum of energy and effort you achieve more effective, more elegant movement than through the use of willpower and muscle power.

One of Feldenkrais' basic principles is: When you know what you are doing, you can do what you want. If there is only one way of doing things available to you (namely the usual, unconscious way), then you have no choice. To make full use of our potential requires, according to Feldenkrais, that we know everything in three, four, five different ways – or more. Then, he says, our brain will be used as a brain! This freedom of choice, this conscious action, is what distinguishes man and makes him different from animals, governed by instinct; this is what constitutes human dignity.

Health, in Feldenkrais terms, is not a static concept (= absence of illness). It is defined as a "dynamic process" and the ability to "recreate" oneself and achieve

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wellness. Health is something that must be constantly brought into equilibrium and constantly regained – just like posture. Feldenkrais does not attempt to teach "*the* correct" posture, but gives criteria for a good, upright posture. Movement is carried out according to Feldenkrais requirements when the work is done only by those muscles that are necessary to maintain the balance and carry out the desired movement. To do more is a useless waste of energy and damages the whole system.

Two forms of teaching: verbal and non-verbal

The method is taught in two forms, either with verbal or non-verbal means of communication.

"*Awareness through movement*" is the verbal technique. It is taught in groups of a wide variety of composition. Coordination and a feeling for movement are promoted by means of cautious, sensitive experimentation with movements; sensitivity is increased, and the pupil uses his energy more economically.

Since the body is inseparable from perception, thinking and feeling, mental attitudes improve along with the physical posture. Old patterns disintegrate, new ways of doing things are communicated to the brain. There is no "right" or "wrong"; it is rather a question of the Feldenkrais teacher guiding the pupil in learning by trying things out and trying himself out – as in play.

People of all ages, the handicapped, persons with degenerative illnesses, pain sufferers, and also sportsmen, musicians and dancers take part in the lessons in order to enlarge their "movement vocabulary".

Functional integration is taught individually, and the teacher communicates non-verbally by means of touch. Through gentle movements he makes the pupil aware of functional connexions; he gives impulses to the nervous system via the skeleton and the muscles in order to produce a better organization of the body system.

Both methods are complementary; people with pain conditions or special problems often take a whole series of individual lessons and subsequently join a group.

Both methods are conducted without pressure to achieve, without reaching the pain threshold or producing stiff muscles; after the sessions, the body feels lighter, more pleasant and often "new" and relaxed. The discovery of fresh possibilities by using latent abilities gives self-confidence, increases general well-being and shows each individual new ways of tackling his problems and difficulties himself.

Life is movement. What Feldenkrais shows is a better and more intelligent way of using the enormous potential that exists in everyone – independently of age, handicap or illness.

Note: The expressions "The Feldenkrais method", "Awareness through movement" and "Functional integration" are patented and can only be used by trained Feldenkrais teachers.

A HEALTH DIARY FOR THE CHRONICALLY ILL

by Hermann Baert, Peter Gielen and Mieke Smet

"When did your illness start? What were the first signs? When was the illness diagnosed? Who were the people with whom you came into contact? What fears did you experience? How did the people around you react?"...

These are questions heading a number of blank pages in the *Health Diary* where patients are invited to write down their personal experiences and to note the happy as well as the difficult moments.

Being chronically ill is a "total" experience influencing all facets of life. The person who is ill for a long time is therefore confronted with a broad variety of problems, including the necessity to interact with many professionals and to undergo diverse treatments.

How the idea developed

This difficult situation brought a number of self-help groups in Flanders, the Dutch-speaking part of Belgium, to develop a health diary. The idea was implemented through the Working Group on the Chronically Ill, which is comprised of several self-help organizations concerned by the problem, and Trefpunt Zelfhulp, the Flemish Self-Help Support Center. Technical and financial support was provided by the King Baldwin Foundation. Patients, as well as professionals and people specifically interested in the subject were involved in the drafting of the diary, which was first tested with a group of some 50 patients belonging to 13 self-help groups, each concerned with a different type of chronic illness.

The diary is intended as an aid for patients, as a reminder to collect useful data regarding their chronic illness. It is also meant to serve as a bridge between the individual who is ill and the specialized care services. The diary provides the chronically ill person with a means to share his experiences with professional workers who are seldom informed of these personal aspects and unable, therefore, to take them into account. In the final run, it is the chronically ill person who must keep track of what happens and of what different professionals tell him. By using the Diary, the chronically ill person is able to gain an overview of his situation and to meet with professionals as an independent and self-reliant person.

Addressing the patient, the editors, Mieke Smet and Hermann Baert from the King Baldwin Foundation, explain in the introduction:

"The diary is just like an ordinary diary – you write down whatever you like – but in this case, you write specifically about your experiences regarding your chronic illness. The diary has several parts: the first part provides space for useful addresses, contact persons, and indispensable data about your health status. The second part is entitled *My diary* and has blank pages where you can write down just anything. This is the private part of your diary. In the third part, you have a number of sections corresponding with specific aspects of being ill: self-help and self-care, physical and psychological complaints, experiences with professionals, the treatment, hospital stay, heredity, and financial cost related to the illness. There is also space for notes of all kinds. The fourth part is an informative section intended to familiarize you with health and social care services."

An example

Each section of the diary aims to help the patient develop personal skills to better cope with the illness and to participate more actively in the healing process. The section on self-care and self-help gives an excellent example of the approach used:

Everything you do yourself to maintain and improve your health and well-being is called self-care. In other words, caring for yourself.

How you take care of yourself is closely

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related to your personal attitude towards being ill:

- do you feel you have the right to refuse certain things, to say no?

- do you consider justified in being unable to cope with certain things?

- can you congratulate yourself on your efforts, and can you accept that certain efforts are not always possible?

- can you decide for yourself what is good for you and what is not?

- can you talk about your difficulties with others?

- can you ask for advice?

- are you willing to explore new possibilities?

- are you looking for new hobbies?

Self-care also means taking your own destiny into your hands. This is reflected, for instance, in the relationships you develop with professionals:

- do you, each time you visit your doctor, prepare a list of questions and queries, and do you ask him/her for clear explanations?

- do you ask questions concerning your treatment?

When you write down your own experiences and reflections this gives you an insight into your personal attitude towards self-care. Keeping a health diary is already in itself a form of self-care.
Being ill is experienced differently by each person and the influence of the illness on the daily life is also different. Does the illness occupy a central place in your life or do you push it in the background? Is the outside world familiar with your health problems or are these hidden as much as possible? The following questions may help you to become more aware of various aspects of your health problems:

- how do you experience your illness?

- how does it affect your life?

- what are the difficult and hard moments?

- are there any pleasant elements in your illness?

GAINING INSIGHT INTO COMPLAINTS			
	Complaint	Complaint	Complaint
Was I confronted with the complaint before ?	☐ yes ☐ no	☐ yes ☐ no	☐ yes ☐ no
If yes, when was the first time ?			
When did it occur last ?			
When is the complaint present ?	☐ always ☐ mostly ☐ seldom	☐ always ☐ mostly ☐ seldom	☐ always ☐ mostly ☐ seldom
When does the complaint occur ?	☐ morning ☐ noon ☐ afternoon ☐ early evening ☐ evening ☐ late evening ☐ night	☐ morning ☐ noon ☐ afternoon ☐ early evening ☐ evening ☐ late evening ☐ night	☐ morning ☐ noon ☐ afternoon ☐ early evening ☐ evening ☐ late evening ☐ night
During what activities does the complaint occur ?			

- what aspects are not as positive as they could be?

Besides self-care, there is also self-help. A self-help group consists of people facing similar problems who come together to do something about it:

- do you know of a self-help group?

- do you feel it would be interesting to get to know a self-help group?

- what do you think a self-help group can offer you? We can perhaps help you answer this question.

Further on the diary provides space to note impressions on meetings attended and suggestions for the following meetings. The section on "complaints" helps the patient to get a better insight into the difficulties resulting from his illness. He is invited to reflect on the occurrence of symptoms, possible causes, consequences, and ways to improve the situation. The table on the previous page is very helpful, both for the patient and for professionals caring for him.

Relationships with professionals, the effect of the treatment, as well as changing habits are also the subject of special sections, where questions and advice mingle. The diary deals just as thoroughly with practical aspects related to a stay in hospital *("don't forget your health insurance documents"!)* or the cost of being ill, as it does with such delicate matters as hereditary factors.

A source of valuable information

Throughout, emphasis is placed on the fact that the diary is the property of the patient and that it is up to him to decide what sections he would like to fill out, what he will write in it and how he will use it. It has been conceived so as to be of support to chronically ill persons (a) in moments of insecurity and (b) when they are in contact with professional caregivers. It is a source of valuable information that can be consulted at any time — to provide data of a private nature, or data that can be useful to doctors or other professionals.

FOCUS ON THE FUTURE

Personal skills should be developed to:

- provide patients, families, self-help groups and other community groups with accessible and effective technology for learning and applying techniques and skills of health promotion, according to: (a) the needs and preferences of people with chronic illness; (b) the changing body of scientific knowledge on treating and caring for people with specific chronic diseases; and (c) cultural differences and needs;

- ensure that the approach to skill development is holistic, while acknowledging the specific problems associated with different chronic conditions;

- ensure that key people in the patient's social network are included in efforts to educate people in coping and communication skills; and

- use educational methods that foster active participation and strengthen motivation for and awareness of the potential for a better quality of life.

9.

REORIENT HEALTH SERVICES

Health promotion action means: to reorient health services

The responsibility for health promotion in health services is shared among individuals, community groups, health professionals, health service institutions and governments. They must work together towards a health care system which contributes to the pursuit of health.

The role of the health sector must move increasingly in a health promotion direction, beyond its responsibility for providing clinical and curative services. Health services need to embrace an expanded mandate which is sensitive and respects cultural needs. This mandate should support the needs of individuals and communities for a healthier life, and open channels between the health sector and broader social, political, economic and physical environmental components.

Reorienting health services also requires stronger attention to health research as well as changes in professional education and training. This must lead to a change of attitude and organization of health services, which refocuses on the total needs of the individual as a whole person.

Ottawa Charter

9.1 TRAINING: NEEDS ARE ON TWO LEVELS

Training needs cut across the three groups of chronic illnesses covered in this book. These needs are on two levels: (a) adequate knowledge of recent scientific findings with regard to cancers, cardiovascular diseases and chronic pain; and (b) an understanding of the concept of health promotion and its implications in the field of chronic illness.

Effective interventions demand careful listening to the patient to discover his/her sources of threat, harm and distress. This is something often almost absent in medical practice, namely: a real concern and awareness of the patient's emotional life.

It is urgent to reorient training for professionals in supporting people living with chronic illness and pain, and to change attitudes through the introduction of appropriate knowledge (psychosocial and behavioral) in the education of physicians, other health professionals and social workers. An understanding of the many factors influencing the coping process is essential for helping people with chronic conditions. The goal should be to develop in health care providers the skills to enable patients to cope, and to support them, the family and self-help groups, without endangering self-reliance and independence.

This section includes a background paper which discusses training needs as they relate to the subject of chronic pain and gives examples of new teaching programs.

MEDICAL TRAINING: A SERIOUS DEFICIT

by Rieke Alten

About one person in ten lives with a chronic illness or disability. In the Federal Republic of Germany alone there are about three million people who suffer from chronic pain or rheumatic diseases specifically. Their usual treatment consists of anti-inflammatory and analgetic drugs. The predominant feature of the lives of these patients is pain. Yet, during my basic or specialist medical training, never did I once encounter this topic otherwise than in reference to drug treatment.

This reality reflects not only a serious deficit – which cannot be altered by just adding another course to the existing curriculum – but also the way medicine has developed over the centuries and its inability to focus on "health".

Medicine is predominantly concerned with collecting data on pathological conditions, their description, their course and their outcome. Medical students are confronted in their first year with dead bodies. Only a few allow themselves to realize their feelings while the majority switches over to defense mechanisms and sarcasm. As the educational process develops, feelings of compassion are replaced – step by step – by organ-oriented analyses of diseases aimed at making a correct diagnosis. In universities and teaching hospitals where this process takes place, there is, from the start, a negative selection of special cases and rare diseases which do not mirror at all the general practitioner's reality in everyday medicine.

While nearly all social sciences acknowledge the role and influence of the investigator during the investigation process, most of those working in the medical field have so far ignored these findings and their implications. Patients are human beings – with a biography that constitutes their unique way of experiencing reality, including bodily systems like the immune system, and their mode of experiencing pain, hopes, fears and other "irrational" feelings. Medical doctors also are human beings; as such they act as subjects and are submitted to "irrational" feelings which are part of their individual biographical data and of their perception of the world.

In the interaction between the patient and the doctor, both have to face the difficult task of forming a common reality that will enable them to develop mutual confidence and understanding.

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TRAINING: NEEDS AND POSSIBILITIES

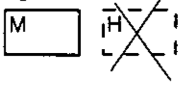
by Robert Lafaille

This paper reviews training needs as these relate to chronic pain, the possibilities and problems, the ingredients of a comprehensive approach and various training programs developed on the basis of these concepts.

1. The medical and holistic approaches to pain: five options

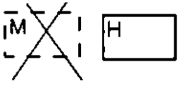
We can distinguish in the different sciences of medicine two broad approaches to the topic of pain: a medical approach on the one hand, and a holistic approach on the other. With regard to medical training, we need to answer a very fundamental question: which combination of these approaches is the most fruitful in relation to the level and the context of the training program? Logically, there are several possibilities:

Option 1



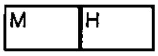
- monopoly of the medical approach (M)

Option 2



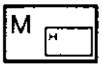
- the inverse situation, monopoly of the holistic model (H)

Option 3



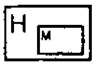
- linkage of the two approaches, but without theoretical or practical integration; juxtaposition in a sequential order

Option 4



- inclusion of the holistic approach in the medical approach

Option 5



- inclusion of the medical approach in the holistic approach

So there are mainly five different options. Within the last two, the approach itself can vary according to the emphasis placed on one or the other component, for example:

It is very important to be aware of the possibility to choose between these different options and to make the choice clear and explicit before starting a training program. The author prefers option 5 which seems to be the most appropriate choice at this moment of societal development:

- options 1 and 2 are not very realistic, although both approaches exist; from the point of view of the public and of the vast group of pain patients, the polarizing of approaches in training programs in this manner is not satisfactory;

- option 3 has many didactic disadvantages;

- the choice, then, lies between options 4 and 5; option 5 seems preferable since the holistic approach has a broader scope than the medical one; this choice, however, is not merely a logical one, but in essence a choice based on values.

Because of the momentary dominance of the medical approach, it is essential to explore views or alternatives.

2. Ingredients of a holistic approach

An overview of models reflecting a holistic approach to the problem of chronic pain and its treatment were provided in chapter 4. My own investigations focused in particular on the theories developed by Metz, de Vries and the psychosynthesis school. These theories provide very promising ingredients for a holistic approach. What is needed now is:

a) further extension of each model and supportive research to make new developments possible;

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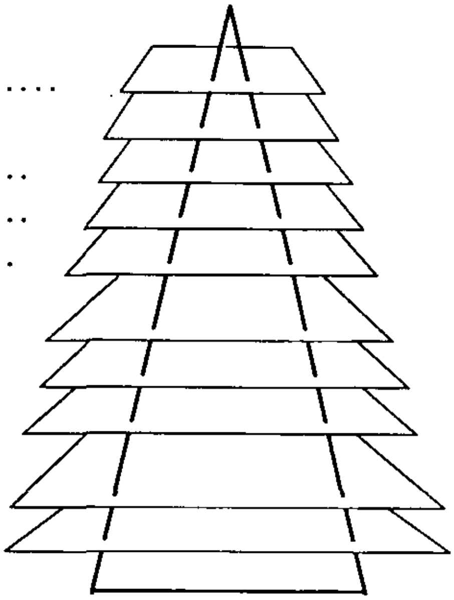
b) serious efforts to make new syntheses on a metalevel: to what extent are these models compatible? What will be the outcome if the values and empirical findings of each model are integrated in a new metamodel? What new hypotheses will occur? What will be the consequences at the level of therapy? Based on the material of our investigation, we can mention three – complementary? – ways of integrating knowledge on a higher level.

The *first synthesis* is inspired by the ideas of de Vries (1985; see also p. 128). The general system theory offers a good framework for integrating insights from diverse sources. If preference is given to a dynamic model, various processes will be found at different levels:

Levels	*Sublevels*
Transpersonal level	Social relationships
	meaning of life
Level of consciousness	mind constructs
	emotional awareness
	stress response
Biological level	organ systems
	tissues
	physiological transmitting processes.
	cells
	molecular and atomic sublevels



These processes are partly autonomous and partly interconnected. With such a model it is possible therefore to interrelate very diverse scientific findings. New hypotheses, especially about the interconnexions between the different levels, will emerge. Another advantage is that the different existing therapies can be given a place in this model. Each of them is influencing one (or more) process(es) on a certain level and can generate effects on other levels.

The overall effect of a specific therapy plus the total sum of effects can explain the success of a given therapy. It is also easy to see that there are different pathways leading to the same result. Different therapies (at different levels) can have the same outcome, namely the reduction or relief of pain. Thus, a kind of natural openness for different therapies and alternatives is a by-product of the general system approach.

The *second synthesis* uses the biography of the patient and its relation to the social context as an integrating framework. Different approaches provide material for such an integration:

a) *Behavioral theories:* How does the human mind organize life experiences including pain experiences? Which factors have a conditioning effect? What is the role of socialization? To what degree is pain and chronic pain a "learned" response to difficult situations?

b) *Interaction and communication theories:* What is the role of the social environment? To what extent does the pain experience of the patient and the response of the social environment form a kind of "system"? What meaning does this have at the biographical level? How does the patient choose this relationship (and the reverse: how does the environment choose this relationship with the patient), and are there biographical roots for these choices?

c) *Psychosynthesis theories:* Is there a relationship between pain experiences and the "inner biography"? How can processes which "include" pain in life be stimulated? What is the role of "unconscious" processes?

Within this second frame of reference many questions about pain can be studied:

- what is the place of pain experiences in the dynamics of projection and introjection?

- what is the relation between pain experiences and (a) the organizing of life processes and (b) the development of consciousness?

- what is the relevance of the inner biography – especially as reflected in visualization exercises or meditation – for understanding the meaning of pain?

The *third synthesis* has a historical and anthropological basis. Although many authors refer to the historical and cultural dimensions of pain and mention that the experience of pain differs in different historical periods, very little research has been carried out on this topic. The findings of medical anthropology (Prince, 1982) are relevant, but there is a lack of (empirical) research. As a consequence, there is no existing body of scientific knowledge by which one can decide whether the ideas outlined are pure speculation or grounded in reality. Yet, such knowledge is absolutely necessary for developing a more empirical theory of pain.

3. The need to relate personal experience and scientific knowledge

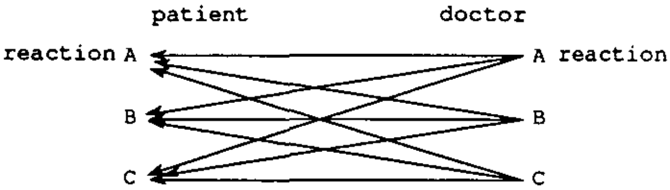
The relationship between doctor and patient is very complex. During the last decade, new models have been developed to better understand this relationship. The general system theory, the communication theories and psychosynthesis have played a leading role in this respect. For the first time, different types of relationships and their effect at different levels are being experimented by role playing, gaming, simulation, meditation exercises, etc.
These experiments show clearly that the way in which the helper deals with his own feelings or problems is transmitted – consciously or, mostly, unconsciously – to the patient.
This is of great importance, especially in dealing with pain. The Institute of Ecological Health Care has developed a general typology of response to illness, which can also be applied to pain. This typology contains six stages (Rijke, 1984). For our purpose, we will concentrate on three main reaction patterns:

A. Being a *victim* of the pain. The patient sees the pain as something that "happens" in his life, something that disturbs his pattern of existence from the outside. Like an accident. The pain patient feels powerless to do something about the pain. He seeks help in the medical system with the expectation that *"they"* will solve his problem.

B. *Rebellion* against the pain. Mostly because the expectations towards the medical system are not fulfilled. The patient then comes into rebellion against the pain: "It is not fair", "It is not just", etc. He seeks his own solutions: more sleep, warm and cold water applications, alternative medicine, etc.

C. Positive and active *acceptance* of the pain. In the third stage, there is the insight that the pain is there, and that one has to accept it. The relationship with other life values also comes into question: "What is the meaning of pain and am I willing to let pain take the mastery in my life, or is there another part of my life in which I am the master?"

Once pain is accepted, its meaning changes. And this change in meaning affects in many cases the pain itself; its character is modified and the pain may even disappear.
These types of reactions are not only biographically bounded, but they are also related to culture. As already stated (see p. 109), the dominant style of coping with pain in most Western cultures is the type A reaction: being a victim and handing oneself over to the medical system. From the side of the helper/doctor, we find the same reaction patterns to pain. There are therefore nine possibilities:



The therapeutic process should encourage the patient to achieve the type C reaction. Yet, this is very difficult if the doctor's own reaction pattern belongs to type A or B. The patient is dependent for cure on the integrating power of the doctor which, in turn, is influenced by his capacity to integrate his own pain in his life.
The coping possibilities of the patient are also influenced by similar processes in his social environment, especially the partner relationship. Lebeer applied this observation to parents with a handicapped child. His experience indicates that healing resources can be stimulated in the handicapped child by changing the atti-

tudes of the parents towards their own pain (see p. 215).

Although it is not usual to select students on personality traits or personal capacities, it would be in the interest of pain patients to select doctors who are able to integrate their own pain feelings in their life and to use this ability for healing. Doctors have to learn that it is absolutely necessary to relate personal and scientific (medical) knowledge to achieve the right treatment. Medical knowledge alone is not sufficient to help the patient.

At the moment, different models are being developed. There is no reason to hesitate any longer to bring this subject matter in medical training programs. The only question is: How? What is the best formula from the didactic viewpoint? We will deal with this question in the coming section.

4. Training possibilities in the medical curriculum and post-graduate courses

The design of a medical training program on the topic of pain and chronic pain raises questions which are interdependent. We discussed at the beginning of this paper two fundamental questions concerning the approach and the ingredients of holistic models to be used in transferring knowledge and skills. Other key questions include:

- What is the optimal place for dealing with the topic of pain in the current medical curriculum and in medical post-graduate courses?

- Do we need long or short training programs?

- At what moment should the training be given: should it merely be scheduled as part of an official training program or should it relate to the inner growth of the student and his personal experience of pain, for instance in connexion with a "burned-out" period?

- Are special training programs needed for family doctors and medical specialists?

- Is the subject of coping with pain to be limited to medical training or is it also a subject for health promotion training?

- How many trained professionals do we need?

Place of training on pain in current medical curricula and post-graduate courses

In *principle* one has to say "yes" to the question: "Should there be a place for the topic of pain in the normal medical curriculum?" In a certain way it is obvious that doctors should be trained in a subject that is at the core of their work: the pain of their patients.

In *practice*, however, there is great resistance on the part of students to look at the subject of pain (cf. the experience of the universities of Rotterdam and Antwerp, p. 250). The question of how to bring the subject of pain in the curriculum needs more exploration but there are nevertheless possibilities for immediate implementation:

- the subject of pain can have a (larger) place at the theoretical level; medical students must be informed about all the possibilities of pain relief; good *textbooks* which integrate classical and holistic approaches are an important preliminary condition for progress;

- the subject of pain can have a (more) important place in case studies;

- the subject of pain can have a place in such courses as "methodical practice", initially developed by the Free University of Amsterdam (van Aalderen & Hollenbeek Brower, 1981) to train students to work in a methodical way with patients, i.e. to explore systematically their problems and possible solutions and to place the patient at the core of the helping process.

These various possibilities tend to integrate the subject of pain in the medical curriculum in a very organic way. However, this is not enough and there is a certain consensus that the best place for such teaching is at the post-graduate level, when students have been in contact with the pain of their patients. The Commission on Pain of the Dutch National Health Council (1986) also subscribes to this opinion.

Consideration should be given to cooperation with psychotherapeutic training institutes and university departments dealing with human sciences (psychology, sociology, anthropology, etc.) in developing courses on pain. It is very important that the knowledge of these different fields become integrated.

Should courses be long or short?

The experience of therapeutic schools indicates that there is no shortcut in working through one's own pain. In most programs, a one-year period is required for experimental learning.
The experience also shows that in many cases it takes still longer (two or three years) to integrate pain feelings in one's inner life. It is not very realistic to require such long training for a vast category of people. Furthermore, a clear and free choice on the part of the trainees to go through an emotional process of inner growth is needed for such a training program. This leads to the following questions:

- Who should be selected for short or for long training programs?

- What should these short and long training programs cover?"

- What can be the place of one's own experience in short training programs?

- What is the best relationship between short and long programs in terms of admittance, training requirements, qualifications, possible certificates, etc.?

At which moment should the training be provided?

If personal experience with pain is taken as a starting point, then one has to wait till the student is confronted with pain, for instance when he experiences the so-called "burned-out" syndrome. Although such an approach can cause very difficult organizational problems, it meets the fundamental need to relate courses on pain to the personal growth of the student.

Special training for family doctors and specialists

The Commission on Pain of the Dutch National Health Council (1986) makes a distinction between the need for training family doctors and certain medical specialists who need more extensive training in pain topics, namely: anesthesists, neurologists/neurosurgeons, psychiatrists/clinical psychologists and physical rehabilitation physicians. The Commission considers that this group should undertake to transfer its knowledge and competence to others by giving courses and advice.
The question remains whether it is desirable to develop different training programs for different medical specialities, and to offer both short and long-term training programs. It seems evident that for medical specialists who work very intensively with pain patients a long-term program is desirable.

Pain: a subject for medical training only or for health promotion as well?

A totally different approach is to start with the general public, rather than look at the medical professions, and to ask: What knowledge do people need in order to cope effectively with pain? This is the area of lifestyle programs, health promotion and self-care techniques.
A crucial element here is to enable people to deal with emotions, to create meaning in life and to learn how to cope with societal power which tends to influence and limit them. Although this is perhaps the best way to prevent the development of severe problems, there is a great lack of knowledge, experience and pilot studies in this area.

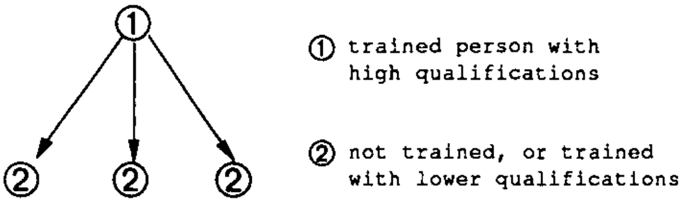
How many trained professionals do we need?

If we divide medical personnel in two categories, i.e. those who have much contact with pain patients and those who have relatively limited contacts, we can try to elucidate questions regarding training needs for these categories.

	short courses		long courses
	in curriculum	post-graduate	post-graduate
little contact	a	b	c
very much contact	d	e	f

Which are the optimal proportions: $^{a}/_{b}$, $\frac{a+b}{c}$, $^{d}/_{e}$, $\frac{d+e}{f}$ and $\frac{c}{f}$?

How can the expertise of the new trainees be of use for other medical personnel?



What are the organizational consequences of these options?

And, finally, is there not a need for a minimum of trained personnel at the different levels of qualification?

5. Examples of training programs based on a holistic approach

The following examples represent some of the pioneer initiatives which hold promise for further progress in developing holistic medical training programs.

The Institute of Ecological Health Care, Rotterdam

Post-doctoral courses in ecological health care were started by Professor Marco de Vries in 1979 at the Erasmus University, Rotterdam, under the name of "medical synthesis". The courses are now offered by the Institute of Ecological Health Care, whose program covers research, training and counseling. It views "health" as an individual, creative and meaningful way of living, which includes a healthy way to deal with illness and healing processes, and "ecology" as the experience of man's dynamic, complex and interdependent reality, both internally and as part of larger systems (de Vries, 1985). The models and methods the Institute has developed are the subject of a variety of teaching programs.
Basic course in ecological health care. The purpose of this course is to help health care professionals to become aware of their own development and health status; it combines experimental approaches with theories and models and lasts five days. The course has been given 21 times in Holland and twice in England: some 300 health care professionals have participated, including approximately 150 physicians, 100 nurses and 50 other professionals such as physiotherapists, health educators, social workers, etc.
Two-year training programs. This program is meant to help health care professionals achieve greater insight into the subjective processes involved in health, illness, and healing, as well as in the dynamics of promoting health and healing. The program consists of 16 weekends, 16 individually-supervised sessions and two courses of four days each in connexion with a summer school; about 100 professionals – mostly nurses and general practitioners – have participated in this program.

Summer school – Each year a summer school offers various courses as a "creative retreat" for health care professionals.

Short courses – About ten times a year, two-day courses are offered on specific topics like the "burned-out" syndrome, medical counseling, the language of the body, etc.

Specific projects – Short courses have been developed for health care centers, focusing on a health-oriented approach, interdisciplinary cooperation and further development; a group of community nurses was guided for a year in developing greater awareness of subjective and intersubjective processes in their daily practice.

Individual counseling – This type of activity is offered to health-care professionals, in particular for people suffering from "burn-out".

"Netwerk" – This bulletin is published bimonthly and provides information on ecological health care for health care professionals.

Dr Rudy Rijke

The Institute of Family Medicine, Antwerp

The Institute of Family Medicine offers since 1980 some short-term courses on the topic of pain as part of the normal medical curriculum. The same program is included in the nursing curriculum.
This initiative was prompted by research findings indicating that more than 40% of the complaints in the Belgian population concern pain problems. Analgetics represent seven of the ten pharmaceutical products most prescribed. Patterns of prescription vary greatly among doctors: 10% rarely prescribe major analgetics and 10% prescribe 80% of the analgetics.
The program deals with (a) theory, (b) the

approach in specialized medicine, and (c) the craftsman approach at the primary health care level. Teaching is based on the general system theory and develops the view that the manifestation of pain is dependent upon an interplay of factors at different levels. Pain is presented as a relational phenomenon (Metz, 1964). It stresses the important role of the primary health care worker and the need for specific attitudes, skills and therapeutic possibilities (one can learn to sleep without hypnotics and to relieve pain without analgetics). Illness careers are strongly determined by the attitude of health care workers and the first contact can be decisive.

There is a tendency to reduce the topic of pain in the teaching programs when organizational change introduces new priorities.

Dr Hugo Stuer

The department of general pathology of the Erasmus University, Rotterdam*

Teaching in the subjective experience of illness and disease is given at the department of general pathology. Attention is drawn to the meaning people ascribe to disease and the way they choose to cope with it: videotapes of conversations between patients and practitioners, so-called patients' "papers" and personal experiences (e.g. letters) are compared with medical reports. The theoretical basis of the teaching stems from the general system theory (von Bertalanffy, 1968; Laszo, 1972) and is extended to medicine (Engel, 1980, de Vries, 1985).

In their first year of study, students are introduced to the subject by four two-hour lectures and four training practices. In the beginning of the fourth year, the transition is made to the clinic setting: students attend two or three practices each week (maximum of 18) and 12 two-hour lectures (half of which are optional). Optional lectures include a double-hour lecture on pain which covers: the cartesian paradigm and its explanation of acute pain; a medical reconstruction of pain; pain as a signal of tissue damage, as a symptom, and as a disease. Referring to the general system theory, it is shown that the classic view is limitative and that essential information is lost. Findings from pain research are introduced (i.e. Wall's views (1979) that pain is not a perceptual phenomenon). Examples of "inexplicable" or "chronic" pain are given, which do not fit the classical model.

The anthropological view is then discussed: the experience of pain is related to a "way of being" in which the body becomes the center of one's "life-world" (Metz, 1964). Pain reflects a sort of existential distress and its *meaning* is at that level.

Referring to the general system theory, the body is presented as an open system, in which problem situations in the subjective sphere can lead to physical pain experience if the person cannot cope. These notions are illustrated by the latest neurophysiological findings.

Although students have been introduced to the phenomenology of disease in previous courses, their first reaction is usually to *resist* the anthropological paradigm of pain and even to express crude disbelief. A *dialectic* approach often leads to a paradigm-shift among some students, but others persist in their disbelief. Acceptance of the classical paradigm is so strong that some students even reject examples of patient behavior and healing processes which do not fit classical explanations.

Only 5% of the students take pain as a topic for examination, which indicates most probably that they find it difficult to replace the classical paradigm by the anthropological view. They are more likely to accept the recent neurophysiological findings which ascribe an important role to human memory in the pain experience. Although immediate acceptance of alternative views is poor, it is generally assumed that there will be a shift later on during the professional career. This is supported by recent evaluation of medical teaching programs which indicate positive attitudes towards alternative views in medical science among 50% of the students.

Dr Mariet A.E. Vrancken

The Center for Health Studies, University of Antwerp

The Center for Health Studies, which was inaugurated in 1986, offers a university training program which comes under the Department of Family Medicine and, as such, is part of the Medical Faculty at the University of Antwerp. Its task is to develop teaching and research in the area of health-promoting lifestyles. It is the

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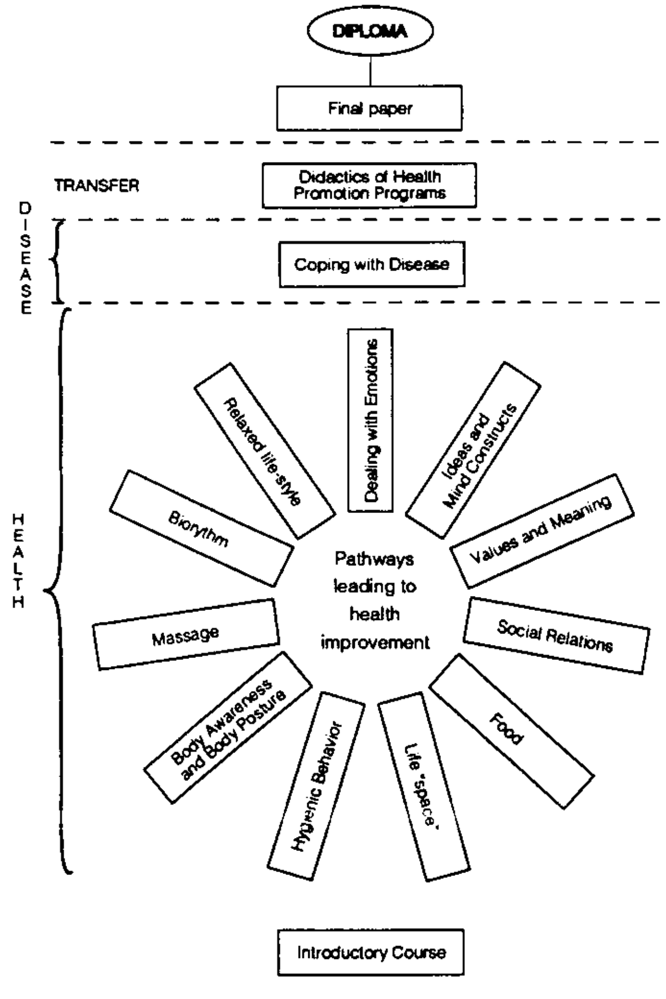
* The course described here was discontinued shortly after the Bad Honnef Symposium, due to economic reasons.

first such center *within a medical faculty,* where doctors and other professionals in related services are being trained in developing healthy lifestyles for people *in a holistic framework,* while at the same time such courses are offered directly to the general public.
The program is based on five steps, which every student can follow as a whole or only in part. It forms a certain "carousel" structure: the student can enter where he chooses and can continue to progress through the program at will, in close relation to his choices, and to his own biography and development. This process is being guided cooperatively by a specially designed "intervision group". The course modules are in the hands of Belgian and Dutch trainees working together on a multidisciplinary basis.



The program presents health as an open concept and rejects any monopoly in this area. It considers that specific methods and techniques for health improvement should be linked with one's personal biography; hence, this "carousel" structure which provides for a maximum of choices.
The Center's training program takes up the issue of pain in the course on "Dealing with emotions". This is a course of ± 40 contact-hours which is part of a much larger program lasting ± three years. The underlying philosophy is that health promotion has to prepare the individual to deal with severe problems if and when these occur in life. The preventive goal of health promotion is to prepare people for the long voyage of life and to teach them how to preserve their health, even in dangerous and risky situations. Applying this principle to the field of emotions, trainees discuss how we usually deal with emotions in our culture and the possible consequences. Attention is drawn to measures that will foster a more optimal attitude towards one's emotional life. Pain, and how to deal with it, is discussed in this context.

Dr Luc Debaene

6. In conclusion

It is very important, in exploring the different possibilities in medical training, to develop programs offering an integral view covering health promotion, health education, lifestyles, self-care and self-help. We should also find ways of stimulating medical personnel to follow certain training programs. Pain specialists, in particular, should follow a long (psychotherapeutic) training program. The question of how to bring the subject of pain into the normal medical curriculum needs further study.
We must recognize that knowledge on dealing with pain is very scarce in many societies. Even in therapeutic "temples" like some of the well-known therapeutic schools, knowledge about pain feelings is still limited and most of the sound information has been imported, especially from the Eastern traditions of meditation (Yoga, Zen, etc.). Nevertheless, as reflected in the examples of pioneer initiatives in medical training reported in the previous section, new theories and new approaches are being developed and experimented.
There is a pressing need, therefore, to communicate the different experiences and it would be of great value to form international, national and/or local networks of trainers in the field of pain, possibly linked with the different centers for pain relief. Such networks would greatly facilitate the acceptance of a comprehensive approach in medical training.

Community-oriented education: a response of academic institutions

In 1979 a network of medical schools was started by the deans of medical schools in several countries with the aim to promote community-oriented education (COE), i.e. an approach to teaching and learning that derives its objectives from an empirical analysis of the major health hazards in a given population and looks at the future tasks of health professionals.

COE represents a response of academic institutions to the observation that conventional education does not provide graduates with the intellectual equipment and skills relevant to priority health problems in their communities and which would enable them to influence the existing health care delivery systems and make an impact on health conditions. Today, the "Network of Community-Oriented Educational Institutions for Health Sciences" has a membership totaling over 100 full, associate and corresponding members who all have COE programs. The Network focuses on (1) solving the problems associated with the development of community-oriented education curricula and (2) introducing change in established medical schools and offering suitable alternative strategies adapted to the specific conditions and challenges that prevail in different countries and even in different schools within the countries.

Those interested in the Network can contact the Secretariat of the Network, Rijksuniversiteit Limburg, Post Office Box 616, 6200 MD Maastricht, The Netherlands.

A NEW APPROACH TO MEDICAL EDUCATION

by Robert Wiedersheim and H. Christof Müller-Busch

This is a brief description of the Herdecke Medical School and its University Hospital. Founded by a group of 12 physicians, the hospital, which was inaugurated in 1970, aims to strike a balance between medicine as a science and medicine as an art. Less aggressive methods with regard to patient interventions and more emphasis on patient care are one of the principal objectives of hospital staff.

The hospital has 500 beds, an up-to-date diagnostic equipment, a nursing school and a unit for music therapy. Occupational therapy follows the usual pattern. There are artists as well as specialists in handicraft and design who work with the patients. A riding school set up by the hospital is used for therapeutic and recreational purposes. A rehabilitation unit deals primarily with paraplegic patients.

The idea to have a State-independent university was in the minds of those who founded the hospital already four decades ago. After years of negotiations the Government agreed in 1983 to the setting up of a private university. The first faculty was the medical school. The goals of the university include:

1. To attempt to "bring back" some of the objectives that had prevailed in European universities during the 19th and early 20th century, i.e. more emphasis on general knowledge, especially history, medical ethics, philosophy and mathematics. A special department has been set up to organize these "fundamental studies" where about ten professionals offer courses for students coming from all faculties.

2. To adjust educational policy to the needs of society.

The medical faculty has been set up with the following concerns in mind: (1) a more attentive system of nursing care; (2) more time for physicians to deal with patients and with students; (3) more emphasis on what the World Health Organization would describe as "extended medicine" and a more critical utilization of pharmaceutical products; (4) greater encouragement to students to take into their own hands the learning process and the development of their personality; (5) learning situations which develop student attitudes for a critical appraisal of their own activities during their years in the medical faculty and thereafter.

Students must have six months experience in nursing care before they enter the medical school and become familiar with the special nursing care applied on the wards of the hospital during four additional weeks.

Unlike any other of the West German schools, Herdecke has an admission and a curriculum committee, an audiovisual and an evaluation unit. Student representatives are part of all assemblies, committees or units except the admission committee.

Admission to the medical school takes place once a year and is regulated by the school itself (no other German medical school is allowed to do likewise). Not more than 25-30 students are accepted for the first year out of 1600 candidates. The total length of the medical course is six years.

Government restrictions have been, and still are, the greatest problem for the medical faculty. Within this straitjacket we have modified a few aspects of medical education, in particular:

1. Students are taking part in hospital medicine from the first day on, beginning as nursing aides and after the second semester continuing as apprentices with the physician.

2. Behavioral concepts – intended to introduce, and then to intensify, patient-student interactions – are incorporated into the medical course from beginning to end.

3. Students are given a more active role in the teaching-learning process. Seminars and papers to be read by the students are more common than lectures.

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4. According to the organ system concept, the structure and function of the human body are jointly dealt with by the preclinical departments, together with the respective clinicians and the patients. Although the subject matter becomes more complex through a multidisciplinary approach, it presents itself in a more comprehensive way leading to better understanding of pathophysiology and the nature of diseases.

5. The required courses to learn clinical medicine are arranged as block systems, thus allowing students to stay several weeks on a ward or clinic, working with physicians and patients. This is not done in the other German medical schools where clinical instruction is given in the form of lectures, i.e. each day one hour of internal medicine or surgery with very little or no opportunities for students to examine patients.

6. Students may interrupt the course for maximally one year (electives), preference being given to those who want to acquire more experience in the health field within or outside the country.

7. In cooperation with social and welfare institutions of the region, the students are encouraged to participate in social medicine and health care projects so that they will become aware of the social aspects of medical care and health promotion.

In short, we do not entirely follow the German system of teaching first the premedical and preclinical subjects in isolation and only thereafter to begin bedside teaching. An article recently published by a young physician starts with the heading: "Jetzt darf ich alles tun aber ich kann fast nichts." (Now I am allowed to act as a physician but I know almost nothing of practical medicine). This sad fact is the consequence of an almost total separation between the teaching of natural and medical sciences on the one hand and experience to be gained in clinical medicine or general practice on the other.
The most pressing problem that must be faced is: How can a new approach to medical education develop in view of the restrictive Federal requirements? Especially the examination patterns are likely to force even the most gifted students to start rote learning before they have time to understand the complexities of health and disease together with the related problems they are supposed to solve in their professional lives.

The most poorly educated

At least a beginning has been made and we hope to avoid for our students the predicament which Sir William Osler, the cofounder of the Johns Hopkins Medical School, denounced already in the twenties: "The medical school accepts only the most gifted students and then exposes them to an educational process so rigid in its horizons that, on graduation, the medical student is the best informed but most poorly educated of all graduates. This system, which is designed to eliminate the incompetent, also often succeeds in stifling the inventiveness and imagination of the most competent and signally fails to develop those intellectual attitudes necessary for continuing self-education."

HEALTH PROMOTION FOR HEALTH CARE PROFESSIONALS: A PRESSING NEED

by Rudy P.C. Rijke and Johanna Rijke-de Vries

In dealing with chronic diseases, many health care professionals seem to suffer from a chronic burned-out state. This ussually leads to a gradual decrease in their creative use of caring skills, of knowledge and of personal qualities.
In the past eight years we have seen several hundred health care professionals (mostly general practitioners and community nurses) for intensive, experiential courses (cf. Lafaille, p. 245).
It is our experience that many people, both patients and health care professionals, are caught in a rather blind approach to the fight against disease and death. This is certainly the case with chronic diseases. This situation can block a meaningful exploration into health promotion with chronic diseases, and certainly does not stimulate it. It also proves to be exhausting for health care professionals, in particular when health promotion is not part of their working habits, which it rarely is. Taking (emotional) distance from patients, working less, etc., is often a way of fighting exhaustion but it is not an effective means of health promotion.
Generally speaking, meaningful relationships, a supporting environment and a certain degree of inner autonomy are conducive to health promotion, both for the patients and for the health care professionals.
However, to be meaningful, the approach to health promotion in chronic diseases requires more than skills:

- it requires insight into the processes that people with chronic diseases go through, each at a different pace and in his/her own, individual way;

- it requires knowledge of ways to help people connect to their inner experiences (physical experiences, feelings, insights, images, intuition, etc.);

- it requires knowledge of ways that may help people to connect to their inner resources;

- it requires the ability to differentiate between "healing" and "cure" (cf. Lerner, p. 84) and the knowledge, skills and personal resources to be used accordingly;

- it requires the ability to help people improve communication with relatives, friends, health care professionals, etc.;

- it requires insight into the interdependent nature of people's autonomy: their inner freedom needs to be respected without forgetting they are part of a family, a community and of society;

- and above all, it requires compassion.

The first step for health care professionals is to develop these necessary insights in relation to themselves and their own lives. In our experience, this is crucial, both because it is essential for the well-being of health care professionals, and because neglecting this step may easily lead to the use of health promotion as a new weapon in the fight against disease and against death. Yet, health promotion and the promotion of the quality of life, including methods to fight diseases *(but not vice versa)*, should lead to a more meaningful health care system, in which the various disciplines would be able to discover more easily, and to implement, innovative approaches.
An essential step in helping people with chronic illness is to enable them to develop a dialogue with their inner reality. This is largely determined by the willingness and ability of the health care professional (in whatever field) to be in dialogue with himself and to acknowledge his own vulnerability and limitations, his own pain, as well as use his sense of discrimination and his intuition. Then a collaborative exploration into the experience of illness and the alleviation of suffering can become a meaningful enterprise.
We believe that health care professionals need above all to feel compassion in carrying out the often difficult task that

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they are willing to face. Denial, repression and avoidance of pain, sadness, anger, fear and anxiety are quite prevalent today. Yet these feelings are not conducive to health promotion, whether for patients, for health care professionals, or for our society (and for societies) as a whole. The difficulty of this task is partly reflected in medical statistics which show that working as a health care professional is a major risk factor for one's health.

We would like to say that health promotion for health care professionals is one of the necessary steps towards health promotion in general, in particular in relation with chronic diseases.

"OPEN LEARNING": A NEW APPROACH IN DEVELOPING PROFESSIONAL KNOWLEDGE AND SKILLS

by Tom Heller

Open learning study packs offer an educational method which fulfills the variety of updating and training needs of those working in the health and social welfare fields.

A wide range of packs and study materials have been developed by the Department of Health and Social Welfare of the Open University in Great Britain, in association with experts and practitioners in the fields of nursing, clinical psychology, social work, medicine, the social sciences, policy analysis, and educational techniques. Materials produced are designed for maximum flexibility. They can be adapted for individual use or for inservice training.

Study packs typically consist of a main workbook, other reading materials, a study guide and audio-visual material. There are also optional assessment packs which enable students to register and submit work to a tutor. For inservice use there are supplementary group work packs. People study at their own pace, but typically between 20 and 30 hours should be allowed for each pack.

Although workers in primary care are the main target audience for these packs, they can also be used in undergraduate teaching and for the training of hospital-based workers. The packs have been developed by multi-professional teams and have been explicitly designed for multi-professional use – an approach which seems especially appropriate for health promotion work.

Five main problem areas

The following issues have guided us in the production of the teaching materials. Although many of the comments focus on medically trained people, they probably also apply across the whole range of primary health care workers.

1. *Health workers do not have much detailed knowledge of health promotion issues.* Much of our work has convinced us that doctors, in particular, are very poorly informed about the concept of health promotion. Much of their advice tends to be based on rather vague generalizations. Their ways of helping people who consult them rely on knowledge which is often only slightly better than that of the average Sunday newspaper reader. We have to presume that this is because of the poor level of teaching in preventive subjects and the low status of such subjects at the undergraduate and postgraduate levels.

2. *There is still a lot to do in order to develop teamwork within primary health care.* Here again our observations indicate that the notion of integrated teams working together towards common objectives has not yet been achieved in the British primary health care system. Too often the existing teams are a collection of disparate, distinct specialities in loose approximation, sharing neither values, goals or status. In particular, we found that in many cases different members of the "teams" had only scant knowledge about the skills, training or value systems of the other members.

3. *Record keeping is disorganized and not helpful for preventive activities.* Many recent surveys have shown the lack of organization and poor record keeping systems of present day primary health care. It seems to us improbable that a satisfactory standard of preventive activity can possibly be undertaken without more attention to record systems and the basics of administration and management of primary health care.

4. *There is enormous variability between the best and the worst in present day primary health care.* It seems apparent to the groups in charge of developing teaching materials that there are enormous differences: the best have taken to heart the notions of preventive work, patient-centered medicine and multi-professional

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working, while the worst are self-centered and determined to resist any change or even notions of change. The size of these very different strata and whether the overall picture is getting better or worse is indeed a matter for debate.

5. *Health workers need help in the skills of interviewing and assessment.* Although these skills may be considered the basic "tools" of the trade, consumers consistently complain about the failure of health workers to communicate effectively or even to develop a satisfactory relationship with their clients.

Starting a process of improvement

All the above statements seem to add up to quite a catalogue of disaster. Yet, the teams developing the teaching materials firmly believe that change is both necessary and indeed possible. We remain committed to the provision of high quality teaching materials which can actually address some of these unsatisfactory areas and be part of a process of improvement.

The Department of Health and Social Welfare of the Open University has now become a well-respected institution for the training of professional workers throughout the United Kingdom. In 1988 almost 30,000 new students enrolled for our courses. These students are usually postgraduate workers already involved in the day-to-day care of people. The courses for health workers have the following components:

a) *helping with the basic knowledge-base:* the courses contain all the information that health workers need to know about the subject areas concerned; we always commission a series of articles from the foremost experts in the field and these are included in the teaching packs;

b) *exploring attitudes:* in a structured series of activities the students are asked to look at their own health attitudes towards health promotion issues; in this way they are guided to examine their own feelings and beliefs before examining those of their patients;

c) *looking at the community:* in this section we ask the students to look further than their own team and identify the particular features of their community that may actually result in health problems; in addition, we ask them to look around their area with another purpose in mind, namely to discover that they are almost certainly not alone in attempting to help people remain healthy or cope with disease when it should occur;

d) *evaluating one's own organization:* in this section we ask people to look at their own methods of practice and the structures in which they work; to identify features that could be better organized, and how it might be possible to implement change;

e) *assessing one's own skills:* in these sections which are backed-up by a videotape, we ask the health workers to look critically at their own skills in dealing with people; they are encouraged to think about ways in which their skills could be improved and ways of ensuring that they can further develop and improve their skills.

The following are examples of two packs relevant to the content of this book. Further training materials on health promotion are in production, including a pack produced for Europe-wide use in the prevention of cancers.

Coronary heart disease: reducing the risk

Study pack P575 – This pack, produced in association with the Health Education Authority, is designed for members of the primary health care team – general practitioners, practice nurses, health visitors and district nurses. It is also suitable for occupational nurses, practice managers and receptionists, community physicians, district medical officers, health education and promotion officers, dieticians and members of health authorities.

The pack is intended to help the reader: become well informed about the issues involved in reducing the risk of coronary hart disease; review evidence for the risk factors of CHD and the effectiveness of interventions aimed at reducing them; develop a more effective approach to risk assessment and management, and the special records such work requires; make use of community resources and consider what opportunities exist to contribute to wider community-based health promotion.
The materials are flexible and modular and contain elements for both individual study and interactive group work.

Mental handicap: patterns for living

Study pack P555 — The aim here is to respond to, and support, the changes occurring in the lives both of children and adults with a mental handicap, and of their families, as the emphasis on community-based services and "normalization" takes effect. It offers information, guidance and support to help people work out, through their own experiences, the implications that these changes will have for them.

The pack is primarily designed, in content and style, for parents and inservice residential and day staff, particularly those without qualifications, but it is also suitable for other groups. There is an emphasis on improving understanding between different groups, particularly parents and staff. Some of the material is for use in mixed group sessions, and guidance is offered to encourage the setting up and coordination of such groups.

An important new approach

Commenting on the pack on CHD, Professor Geoffrey Rose, professor of epidemiology at London University's School of Hygiene and Tropical Medicine, stated: "Primary health care teams find themselves in a very unsatisfactory situation. It is agreed that within the Health Service, theirs is the central responsibility for prevention. Yet, doctors were not equipped when they were at medical school with either the knowledge or the skills to practice prevention. That is one chief reason and basis for the Open University courses: to enable doctors to discharge their preventive function, and make a good job of it."

There is no doubt that the entry of the Open University into the postgraduate teaching of prevention should herald an important new approach to bringing about major changes in the way we combat disease and promote health.

SOME PRIORITIES

- Determine what knowledge and skills need to be transferred, at which points of the curricula and over what period;

- introduce in the training program of the medical and nursing schools knowledge on the specific needs of cancer patients and how to meet these needs;

- explore the best ways to bring the subject of pain in the normal medical curriculum and how to develop an understanding of the many factors influencing the coping process – a knowledge that is essential for helping people with chronic conditions;

- provide additional training in advisory functions to doctors, nurses and social workers, to facilitate a shift in roles, from directive to supportive, and develop the capacity of professional helpers to maintain continuous support to families and self-help groups in a way that fosters self-reliance;

- develop training programs linking the theoretical and scientific knowledge with personal experience;

- ensure that doctors develop adequate knowledge on how to follow a comprehensive and socio-ecological perspective in treating cancer patients, heart patients and other chronic conditions.

9.2 HEALTH CARE: A COMMUNITY BASE IS EMERGING

Reorientation of medical care entails a critical assessment of the social and physical milieu or environment of the care setting, particularly architecture, design, esthetics and the organizational set-up of the institution (e.g. where people eat, socialize, relax, grieve, etc.). Emphasis should be on moving the care setting back to a more "normal" daily environment for both the caregivers and the care seekers, with a de-emphasis, although not an elimination, of the "bricks and mortar" approach to institutionalized care. Places where care is given should not, however, become a "substitute world" for the chronically ill – one where they might be more comfortable than the environment to which they must return.

Community action is a vital key to a new concept of health services reflecting the Ottawa Charter. Although the community base of care is emerging in some areas, the dominant health service model is largely underpinned by the hospital, with its highly hierarchical system emphasizing the sick role for the patient. Control of the patient and the staff are the hallmarks of such institutions. It is not designed for humanistic medicine.

The issue of levels of care and disease specificity demands further study. Some chronic problems, e.g. CVD, may require a rather rigid structure at least in some phases of the disease. There, an emphasis should be placed on continuity and linkage between levels and types of care.

The development of new institutions of care, e.g. the health center with geographic responsibility for a community's health, is well worth exploring. Such new structures would require, however, a change in the perceptions of health care workers. A system would be needed which rewarded and provided prestige to those working in primary care, expressing a health promoting spirit.

This section presents examples of innovative approaches to providing care that focuses on the total needs of the individual and is based on the community.

COMMON CONCEPTS IN CONVENTIONAL AND COMPLEMENTARY MEDICINE

by George Lewith

Growing numbers of people are seeking treatment with complementary therapies. What motivates them to do so? We recently carried out a study at the Centre for the Study of Alternative Therapies and surveyed, over a period of one month, all the new patients attending our clinic in Southampton. Sixty-five patients were thus seen at the initial interview and 56 of these were followed up some two months later. Although 20% of the clinic time is spent seeing patients who are socially disadvantaged, either free of charge or for a nominal fee, the largest group of patients attending the Centre were in Social Class II, married and female, aged between 26 and 50 (Lewith, 1985). The services offered by the Centre include acupuncture, manipulative medicine, homeopathy, clinical ecology, biofeedback, psychotherapy, the Alexander technique, and hypnosis.

Patients came with a variety of problems, most of which had been present for a long time. Only three patients had been referred to the Centre by medical colleagues. The vast majority stated that failure of conventional medicine was their main reason for seeking complementary therapies, although they had a good relationship with their general practitioner and felt that they had received satisfactory treatment through the National Health Service. Patients interviewed after the first consultation said that the complementary therapist understood their problems and could, as a consequence, provide a successful and effective form of therapy.

We felt that these patients were not cranks and had not lost confidence or interest in conventional medicine, but were seeking a solution to an unresolved long-term problem. Our study showed that approximately 60% of patients attending the Centre felt much better after therapy. An important reason for this apparent satisfaction, and clinical success of complementary therapies, in this study, may have something to do with the therapies themselves. If this is correct, then the concepts underpinning these therapies deserve close examination as they may have a valuable contribution to make to our understanding of some illnesses.

A significant shift in the attitudes of practitioners

Doctors, particularly those in general practice, are also becoming far more interested in complementary therapies. A study from the Institute of Complementary Medicine suggested an increase of 20% in the provision of complementary therapies by non-medically trained practitioners between mid-1983 and mid-1984.

A survey recently completed by a general practitioner and the author, funded by the Research Council for Complementary Medicine, looked at the attitude of a random sample of 195 general practitioners in the Avon region, in relation to a number of complementary therapies, namely spinal manipulation, acupuncture, hypnosis, herbal medicine, homeopathy and spiritual healing. Over half perceived these therapies as either useful or very useful and were regularly referring patients to complementary therapists. Approximately half of those referrals were to registered, but non-medically qualified, people (Wharton & Lewith, 1986).

Thus, it would appear that a significant shift has already occurred in the attitudes of both patients and general practitioners, in their approach to this area of medicine.

It is less than a decade since the General Medical Council effectively rescinded a ban on referral of patients to non-medical practitioners, and a surprising number of general practitioners in our sample now often do so *(Table 1)*.

Moreover, in some cases they have met the practitioner, and a few keep in regular contact. This indicates the development of a professional relationship that a decade ago would have been unthinkable. It seems likely that many referrals to non-medical practitioners are less formal than to doctors; in some cases general practitioners said that they simply suggest to the

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TABLE 1 - REFERRAL PATTERNS FOR COMPLEMENTARY TECHNIQUES
(Figures indicate the number (with percentage in brackets) of those responding to questionnaire*)

	Never refer	Refer to doctors	Average No of patients referred to doctors/year	Refer to non-medical practitioners	Average No of patients referred to non-medical practitioners of complementary medicine/year
Spinal manipulation	23 (16)	77 (51)	6	62 (43)	13
Acupuncture	57 (37)	44 (28)	3	45 (30)	4
Hypnosis	47 (33)	66 (44)	4	40 (28)	4
Herbal medicine	131 (92)	2 (2)	1	9 (6)	2
Homeopathy	57 (40)	68 (42)	4	18 (13)	2
Faith healing	115 (80)	2 (2)	2	25 (18)	3

* Not all respondents were able to answer each question with a clear positive or negative response, and some gave more than one answer, so the figures do not add up to 145 (100%).

patient that a particular technique might be useful and offer the name of a reputable practitioner.

Thus, the investigation has shown that most general practitioners now view and use these techniques as complementary to conventional medicine and see them as beneficial to the patient's health.

The fact is that conventional medicine is often powerless in providing relief to patients whose complaints pertain to the category of "undifferentiated" illness. Such patients often present a vague group of symptoms such as headache, malaise and abdominal distension. They are rarely, if ever, seen by hospital specialists as they simply do not fit into a defined disease pattern. Detailed investigations in such patients are almost invariably normal and the general practitioner is often left with a patient who is unwell but without a clear diagnosis.

Towards understanding and cooperation

The Royal College of General Practitioners has developed an excellent model for training GPs to deal with such illness. They consider the interrelated triad of the social, psychological and physical aspects. Such an approach requires a complete understanding of detailed family relationships and involves viewing the illness over a period of time in the context of its environment. This allows for the illness to be considered and managed by combining a range of primarily psychological and pharmaceutical approaches for particular patients and specific problems.

The clinical ecologist has a similar model for illness. A reaction to what may produce symptoms varying from an undiagnosable illness to a clearly defined migraine or an active and serologically positive rheumatoid arthritis. Furthermore, the symptoms produced by specific foods may change with time. An individual with milk intolerance may develop eczema as a small child, asthma at about the age of six and finally migraine in the mid-twenties. All of these symptoms or diseases could potentially be resolved by avoiding milk. The clinical ecologist's approach does, however, take into account more than just simple food intolerance. If a patient who was previously stable and well controlled on a food exclusion diet suffers from considerable emotional stress, then the symptoms may return and sometimes new or more complex food intolerances develop. In other words, psychological pressures can have a clear and often reproduceable effect on clinically measurable disease (Lewith, 1987).

Both the clinical ecologist and the general practitioners therefore view undifferentiated illness as a complex problem in which physical, spiritual and psychological stressors play an interrelated and often changeable role in the development and natural history of the condition.

A detailed understanding of complementary medicine may allow the conventional practitioner to develop a much more accurate understanding of the cause of a particular illness, and, as a consequence, a much better grasp of its treatment.

The complementary practitioner, who does not have a formal medical training, would also benefit from a more detailed understanding of conventional medicine as this would add substantially to both his understanding of illness and his diagnostic abilities.

The basic concept of biological energy

One of the main ideas that underpin all complementary therapies is that of biological energy, or in the case of traditional Chinese medicine, *chi*. The homeopath, osteopath, naturopath and acupuncturist all view the manipulation of this indefinable vital force as the central aspect of successful therapy. All primitive, and by implication intuitive, medical systems have had some idea of vital force as the basis of their medical systems. Conventional medicine does not have such concepts and therefore finds great difficulty in defining health (Lewith, 1988).

However, the traditional Chinese view of illness cannot be sustained as a theory if it fails to produce adequate results in the context of clinical practice. Therefore some attempt must be made to analyze the substance of traditional Chinese medicine in terms of treatment outcome. Such research, particularly in the field of acupuncture, has unfortunately been bedevilled by a number of misunderstandings. All too often, conventional doctors have seen acupuncture purely as a stimulation technique that involves the insertion of needles in or around a site of pain.

Research protocols designed to evaluate complementary therapies must take into account their whole philosophy. This lack of understanding has led to many inadequate research projects and made comparisons between different therapeutic approaches difficult if not impossible.

Modern pharmacology is firmly rooted in conventional reductionist views and as a consequence finds it very difficult to understand the underlying principle of homeopathy, based as it is on the assumption that infinitesimal doses of a substance may have a dramatic effect. However, there are reports that rats given a dose of carbon tetrachloride that would normally cause severe liver damage and death, can be protected by the prior administration of a 15C potency of carbon tetrachloride which does not contain any material medicine and therefore, when analyzed, would simply be pure water. The effects of a dose of copper which would normally stunt and destroy the growth of wheat seedlings can apparently also be overcome by preloading the seedlings with a 15C potency of copper. Such experiments suggest that there may be more to homeopathy than our logical approach to pharmacology may at first allow us to accept (Mouriquand et al, (1975).

Three requirements for progress

Although therapeutic fashions change, the underlying ideas behind how we approach illness tend to remain consistent. There are many strong conceptual similarities between conventional and complementary medicine, but the need for new thought processes is paramount if conventional medicine is to progress. The complexity of acupuncture and the therapeutic conundrums of homeopathy may represent fundamental truths through which we can find new ways of looking at illness and its treatment. However, without adequate support and research funding, the complementary therapist will continue to be outmanoeuvred academically and this may ultimately mean that patients lose out on potentially valuable treatments.

With the prospect of increasing demands from patients, general practitioners will play a pivotal part between the conventional and complementary establishments. This can be of benefit to all concerned provided that there is mutual respect between these two areas of practice and that this respect is allied to proper professional standards and the carefully controlled regulation of complementary practices.

AYURVEDA: A LONG TRADITION OF PREVENTION

by Hans Schäffler

Ayurveda, the science of life, is one of the oldest health systems; its body of medical knowledge has endured for thousands of years and is still valid today; some consider it as the source of all natural healing traditions. The classic Ayurvedic texts reveal a holistic understanding of man and his relationship to nature that has an inner logic, unity and direct applicability.

Ayurveda is based on the Veda, a comprehensive system of knowledge and findings concerned with the fundamentals of the cosmos and its gradual development into visible creation. The statements of the Veda largely coincide with the latest research results of quantum physics, which sees the "unified field of all natural laws" as the starting point of all material and energy fields. The so-called "supersymmetric unified quantum field" corresponds on account of its properties to the basic condition of consciousness. Thus Ayurveda is holistic in the original sense of the word. It embraces all human existence both in the "vertical" plane, from the concrete forms of expression of life to the most abstract area of consciousness, and in the "horizontal" plane where it includes mind, body, behavior and environment in its ideas and practices.

Here the primary goal of Ayurveda is not just curing illness, but rather actively reinforcing health.

Here, mention should be made of the work done since 1957 by the Vedic scholar Maharishi Mahesh Yogi, together with leading Ayurvedic physicians in various parts of the world and Western-trained scientists, with the aim to fully restore ancient Vedic knowledge and interpret it in modern scientific terms.

Ayurveda is based on comprehensive fundamental principles which present a dynamic picture of man as a unity of mind, body, behavior and environment. This makes it possible to determine the effect of all aspects of the internal and external environment such as nutrition, behavior, emotional states, climate and seasons on the individual's psychophysical balance.

Prevention and therapy in Ayurveda

1. Basic prevention

a) *Individual health counseling* – The first step in prevention is designed to adapt nutrition, behavior and daily activities to the physical and mental condition of the patient. Thus not only are risk factors eliminated, but a healthy lifestyle is developed at the same time. The physician trained in Ayurvedic practice first determines the individual constitution of the patient and disturbances of the psychophysiological balance. Ayurvedic diagnosis, which can detect homeostatic disturbances at a very early stage, should be complemented by laboratory and technical examinations, if necessary. Then a balanced diet and daily activities can be recommended, appropriate to the individual's personal condition so that disturbances of the individual balance recede and a stable state of health develops. The Ayurvedic recommendations also take into account the influence of circadian rhythms and of the changing seasons and age. In addition to these personal consultations there are seminars providing detailed health education and counseling.

This procedure is extremely successful. Ayurveda starts with the assumption that our physiology tends to compensate for homeostatic disturbances of its own accord by creating a need for particular foods and forms of behavior. Unfortunately our inner intuition is usually obscured by our way of life, tradition, environment and much else.

In exploring the psychophysiological constitution of the patient, the physician trained in Ayurveda can identify these natural needs. For this reason, rules for a balanced diet and behavior do not appear strange to the patient but are accepted as corresponding to his own inner needs. The often lamented problem of compliance is thus considerably reduced.

b) *Psychophysiological prevention* – This level of basic prevention would be incomplete without an equivalent spiritual

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approach, whereby Ayurveda traditionally goes back to the systems of yoga. As Western medicine is increasingly doing, Ayurveda sees imbalance in the intellectual and emotional spheres as a basic cause of all illnesses. Balance on the level of consciousness stands as an important means of achieving stable health and is thus a central concern of Ayurveda.

Here, Maharishi Ayurveda recommends transcendental meditation (TM) that has been established for decades in the West. This technology of consciousness enables the mind to identify itself with the unified field that is subjectively experienced as the area of pure consciousness. This results, as it has been shown, in harmonious and integrated spiritual growth as well as in more stable physical health and improved social behavior.

The effects of transcendental meditation have been documented in thirty years of research, evidenced by the reduction of substantial risk factors, improvements in a multitude of mental and physiological disorders and a comprehensive development of body, mind and behavior in the direction of perfect health.

The first level of prevention is also the basis of the therapy.

2. Ayurvedic purification processes

At the second level of prevention it is possible to remove deeper-seated disturbances the psychophysiological balance which are no longer accessible to health counseling alone. Ayurveda uses highly differentiated purification methods by means of which physiological impurities are removed from the body and the balance of the basic physiological and mental forces is restored. This purification treatment is not only effective at the prophylactic level, but represents also the basic therapy for many chronic illnesses.

In the Maharishi Ayurveda Health Center at Schlederhausen, we have treated around 500 patients up to now with the Ayurvedic purification methods. We believe that this treatment, together with health counseling and the Maharishi technology of the unified field, provides a holistic approach.

The second level of prevention also involves a further specialty of Ayurveda, the so-called "Rasayanas". These are nutritional additives consisting of herbs and minerals, produced according to classical methods of preparation. These are traditionally given to the healthy person to make him or her more resistant to the influence of illness and aging. These nutritional additives are, appropriately, applied following the purification treatment.

3. Ayurvedic therapy

Although Ayurveda places the main emphasis on prevention, it is often successful in the field of therapy, in particular with severe, chronic degenerative disorders. Here, in addition to traditional medication, purification processes, yoga, diet and behavioral counseling, such approaches as Marma therapy (Marmas are sensitive points on the body surface) and Gandharvaveda (music therapy) may also be used. These authentic forms of therapy closely follow the classical texts.

4. The aspect of collective health

The recovery of health by the individual cannot be separated from the recovery of health by human society as a whole. Controlled studies indicate that group practice of TM leads to a high order of functioning of the brain in the individual and of the collective consciousness of a society.

A dynamic concept

Ayurveda offers a widely varied health program that enables primary prevention both at the level of the population and of the individual, with his specific case. The particular strength of Ayurveda lies in its dynamic concept of three basic psychophysiological functions by means of which all areas of life can be analyzed. Disturbances of the functional balance can be recognized at an early stage, long before the outbreak of an illness, by means of refined methods of analysis, and then corrected with corresponding adjustments of lifestyle and nutrition, and the active cooperation of the patient.

Ayurveda is useful in developing knowledge and intuition about one's own particular health needs and places the individual – not the disease – at the center of medical thinking and action.

HELPING THE PATIENT SING HIS OWN MELODY

by Marina Schnurre

This delightful title is unfortunately not my own idea. I discovered it in a book by Leshane. It appealed to me so much that I made it the motto of my work.
My first contact with the Moabit Hospital dates back to the time I was myself affected by cancer. I was once a perfectly normal housewife, mother and artist. I illustrated children's books and did not think I should worry too much when, one day, I discovered a lump in my breast. I went to my doctor who diagnosed it rather "reluctantly" as being "probably breast cancer". That was how the work I am doing today started.

My experience as a patient

When I woke up in hospital, I asked "Is it cancer?". The doctor was standing at the foot of the bed with my husband, and my husband said, "Yes". The doctor, typically, said, "But you still have your breast, you still have your breast." After a third operation, when I was lying in bed, the doctor came in and just as he was about to leave he asked: "Mrs Schnurre, when is your husband coming?" - "This afternoon. Why?" The doctor replied - at the door, "That's excellent. We want to talk about things with him, something has been found again. See you this afternoon then." I think that was more or less the worst moment of my so-called "patient career". For the first time, I was scared to death. I thought: my case is so bad that they dare not talk to me anymore. They have to talk to my husband. That means I am so critically ill that they have to leave me in peace." And I really thought of jumping out of the window.
When I went with my husband to see the doctor in the afternoon, he put himself at a great distance from me. The barrier between doctor and patient was always, and still is, the desk. But here it was even worse: the doctor moved around and rummaged about, did something or other and did not look at me at all. He said with a movement of his hand, "I don't know what to do with you anymore." And it was my third operation. I thought: now I will have to die, he doesn't even know what to do with me. First he wants to speak to my husband, now he doesn't know anymore what to do with me. And when I asked, "What would you do, then, if I were your wife?", he looked at me and said quite innocently, "I would send you to the Heidelberg Tumor Center". I clung onto that, and thought: I know someone in Heidelberg, I will go there right away."
And that's what I did. There I discovered that things could be done quite differently: I was treated as a person, explained what was the matter and given every opportunity to participate. For the first time at the doctor's round - that was in the meantime my fourth operation - I experienced that the doctor might sit for a moment on the bed, or put his arm round me when I cried. I did not have the feeling of lying there completely defenseless, with a doctor on the right and a doctor on the left batting Latin words at each other and me, lying in the middle, and not knowing what it was about at all but suspecting it was something very bad. Heidelberg gave me a great deal of courage to think about what I would actually like to do when I would be through with my illness. It was another negative sentence that led me to work with cancer patients. This negative sentence was actually meant positively by the doctors, who kept saying: "Just live as you did before." At first, I found it a very reassuring sentence as I thought, "life will go on". But after five operations, this sentence was not right anymore. I began to question what was actually wrong with me. Why did I get this illness, and why just at that time? And why me? I could also have got stomach ulcers or something else. But it was cancer, breast cancer.
That was the moment when I thought a lot and looked for other people who had been through the same problem. I thought it would be a great help to find out how other people had coped with their illness. But there was no-one to be found. Then I came across an article where the first self-help group that had been established

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in Berlin was advertized. So I went there. I even bought a tape recorder, thinking, "This is fantastic, I'll record all this and one day I'll turn it into a book". I entered a room where twenty women were sitting, knitting and crocheting. It was November. I can't knit, which didn't help. Anyway, I wanted to talk. I wanted to ask, "How did you cope with this illness? What did you do? What help did you find?" But fancy that, the women all apparently had no difficulties. Apparently they were all happily married, and in this group they didn't talk about illness, I was told. "We have survived it, we only want to think positively." Thank goodness, another young woman in the room felt like I did and together we founded a new group, the "Self-help group for working women". I was in this group for two or three years and I came to realize that people who join self-help groups are always motivated and really want to do something for themselves – in other words, they are exceptions. But then, what happens to all the patients or the people who never join a group, who never get any help?

At that point, I felt I should go a step further, another step into hospital. I persuaded a fellow group member to join me and we put together a program, then we tried to sell it. We met a lot of nice people. They reacted quite positively to our suggestions but they always told us: it isn't possible. I even wrote to the president of the German Cancer Foundation who replied, "My dear young lady, you must first have a proper profession in order to be able to work in a hospital. Commitment alone is not enough. We are already supporting a lot of programs and practicing high tech medicine. What you propose is not something we can imagine. What is done has to be done by the doctors. They cover that very well."

Thank goodness we encountered a woman doctor in the Moabit Hospital, where I had had chemotherapy, who said, "Yes, I came across something like this when I was in America. I have had very good experiences with it, and I am all for your setting it up in Moabit for a year, on an experimental basis."

Our work at Moabit starts – and also many problems

So we entered the Moabit Hospital very naively. And I must say: thank goodness it was very naively! We had some great projects but not the slightest idea how to put them into practice. One thing was clear in our minds, we did not want to be answerable to any senior consultant. It just so happened that we were asked under which department we wanted to work. The surgeons? No, we didn't really want them. What about the gynecologists? No, that would be too limited. Then we asked, "Do we actually have to come under anyone? We would really like to be a department on our own." The atmosphere was very relaxed and we sounded so sure of ourselves that the director of the hospital said – which made a tremendous impression on me, "All right, it doesn't make any difference whether I spend seven million or seven-and-a half million a year. So we'll do that, and you are a department on your own." We were allocated two positions: one for a social worker and one for a psychologist, each on a half-time basis as we had asked, and two beautiful rooms. Then the work started.

I should say: then the difficulties started. We visited the patients and they all found it fantastic. But the doctors and the nurses felt disturbed and said so very plainly. Wherever we went, we were asked, "What are you doing here? Why aren't you wearing white coats? You can't parade around here like peacocks." We always dressed in a very lively fashion, with earrings and nail varnish, etc. And that met with resistance. Then we thought: "Well, we're going to paint our fingernails whatever, but we see the point about the white coats." White coats are a kind of identity card. You can go anywhere in a white coat and have access to all the files. By the way, I would just like to say that it's a myth, data privacy. If I want any data, I lift the receiver and say, "I am so-and-so- and I am calling from Moabit Hospital." I get all the data on the phone. Only once a woman from some authority said to me, "Give me your telephone number and I will call you back." Fantastic, isn't it, data privacy!

When we came to the ward the first thing the sister would say, was: "What are you doing here?" – "Well, our program also includes educating the nurses and forming Balint groups." – "What? Balint groups? Talk about difficulties with senior doctors and ward doctors? We don't do that! We're not doing that!" So we worked our way in, very slowly. First we developed a very thick skin, and second, we used the stick and carrot approach: we were intractable with regard to what we wanted to achieve but very friendly in our approach. We invited the doctors, we even cooked for them sometimes, we listened to their problems. But when we had decided to accomplish something, we stuck to our point and stood with it.

This approach eventually turned out very positively. But meanwhile, we had to face more than one problem. For example, the social work department. It also rejected us at first because we were taking over areas of its work and challenging it to be more active, more daring. The social workers would never attend discussions on the ward nor go on the doctors' round, much less share concerns with a senior consultant. Once I asked a doctor, "I was here in your hospital, why did'nt you ever send a social worker to me? I knew nothing about a cure or what social provisions there were." He looked at me very shocked and said, "But my dear lady, you aren't a social case." This idea is still very deeply rooted among the doctors and I think it has to do with the way social workers, psychologists and therapists see themselves. They need to change their own attitudes to be able to work differently in the hospital.

That was our first negative experience. The second one was when the doctors said to us, "You know, we don't really see what you want to do here. All our patients are in the picture, they are coping adequately with their illness and are all fine." And then I dared to say, "Yes, but Professor, on your ward, where I've now been working for two weeks, some patients say exactly the opposite." He was absolutely astonished, and very angry, and shouted, "Tell me the name of these patients and I will go and have a quiet little talk with them." He simply would'nt accept what I said.

Over six years have passed since we started and the atmosphere in the hospital has slowly changed. We've changed too, incidentally. Perhaps we've settled down mid-way. It may be of interest to go a bit in detail over the activities I carry out.

Three main tasks

It is essential to speak to the patients right at the beginning, in other words almost before they are given the diagnosis, and if possible to be there when it is given. There I had some very strange experiences. We all have been told that "patients must be put in the picture". Some doctors now do this so radically that the patients often have no chance to grasp the full meaning of what is happening to them. And if the doctor feels unsure, then he doesn't leave the slightest opportunity for questions. He immediately slaps on therapy: "And then we'll do this and this, and we'll give you this treatment. "The patient sits there and gradually collapses, thinking, "I can't cope with this at all. What is all this? I can hardly separate one thing from another." When I notice this, I stay with the patient, go back with her to her room and simply give her time to draw breath and then, very slowly, encourage her to ask questions. I try to put the doctor's statement into ordinary words that she can understand. That helps a lot. So that's my first task. The second task in that initial period is to make the patient more familiar with the hospital. If you are a person who has a full working life and know your way around, coming to hospital as a patient is a shock: you are treated as if you were incapable of managing your own affairs. You hand in everything to the sister at the front when all the papers are filled out and you're popped into bed even if you don't want to. When you say, "But I would like to receive the doctor sitting up in my dress when he comes," you're told, "No, no, please lie down, it's better." So you lie there like a lamb and wait for what's coming to you. To be there when the patient has the feeling, "I need help, I need someone to explain things to me, to tell me what's happening", that is my second task.

My third task consists very often in accompanying the patient for treatments as in the case of radiotherapy for a tumor, for example. Radiotherapy is something that frightens people. It has been shown in a negative light by the media, with people who have been burned or other dreadful things. So most people are afraid of radiotherapy and need to be reassured. It's always very good when I can say, "Come with me, we'll go down the day before and have a look at the instruments. And I'll introduce you to the team with whom you'll be working." The patients are always nicely surprised and say, "Oh, is that possible?" And I reply, "Yes, of course." Then we go down and look at the apparatus. I explain that people stay alone for a moment in the room where the radiation takes place, but may have contact with others. They can communicate with me by microphone, for example, as I stay in the adjoining room. I tell them they can ask for music. All this helps to bring things back into proportion a little.

An essential role: listening to patients

My work with the patients is something that develops quite slowly. I do not come to suggest therapy but to listen. I am simply a listening ear. Most cancer patients are sent to our hospital by their general practitioner, who suggested they go "for an examination". He usually hasn't told them what is wrong, but they sense it. Studies show that 80% of people who haven't been told are fully aware that they have something serious. The difficulty is this inability to talk. The doctor knows, the patient suspects. The patient acts as if he believed the doctor had nothing to say. It's a game of hide-and-seek. Here, we are at the other extreme in the doctor-patient relationship. Listening to patients and giving them the possibility to express what they feel is most important. Patients will say things like, "It's strangling me. I've got a band round my head. There's something lying on my stomach, it's a stone." Usually patients come very quickly to the point where they tell you why they think they got sick: "I had to get this illness because ... I think it's a punishment ..." According to the milieu, the education and the background of the patient, you sense in which direction your help is needed. Thus, every day you have to put your imagination to work and every day you experience something new.

In the course of time I have learned to wait, because I have noticed that these steps I'm claiming to take don't come from me, but from the persons with whom I'm working. The images they share with me show me how far I can go. They are symbols that the patients offer. Often the patients will use a flowery language and I respond in the same manner. I work a great deal with dreams, with fairy tales, with visualization exercises, I do what is important at the given moment. Sometimes I go for a walk with patients. Recently I went jogging in the park with a patient who was very depressed, almost out of her mind, and I suddenly discovered that she could run much better than I. After that, she felt exhausted but was back with both feet on the ground.

I have noticed that the patients are different every day. At the beginning, I thought, "Now I've got it, now I know how to work with patients." Then I always fell flat on my face, because every day things were different. There's no point in being there, for instance, when the doctor comes by, saying, "You've got good results, everything is OK", if you don't notice that in spite of these good results the patient, today, simply doesn't feel well at all. So one must look at the situation afresh every day and always be on the lookout.

The family-patient relationship: communication is arduous

Let me now come to the family. I must admit that I do not always rate the family as positively as some people do. Many times, I have found the family very disturbing and burdensome. The family was often the cause of the illness and the family has not changed but goes on as it was, and the difficulties which originated in the family continue in the hospital. I encourage the patients to express their feelings and say so when they don't want a visit. It is always sad to see a husband coming every day, just because he thinks it's his duty, not really because he wants to be with his wife. And the wife lies there, feeling guilty because she can't take care of their home anymore, cook, wash the shirts, and then her husband comes every day, the poor man. I encourage wives to say once in a while, "Edouard, stay at home, I would like to be alone for a day, I need that." I also try to support the husbands, encourage them to talk, and make it clear that they need to do something for themselves too. Nothing is more frustrating than to lie in hospital for three months and Edouard comes every day and doesn't know what to talk about, because nothing happens to him. He goes home and washes his shirts and does the housework after a fashion, comes again to the hospital, and the moment is very soon reached when husband and wife just don't know what to say to one another anymore. It is terribly important therefore to support the husband or the family and to say, "Please, live your own lives, then what you bring into the hospital is all the more colorful. And above all, share your lives with the person who is in hospital."

Sometimes illness blocks communication in other ways. I can remember a woman who always told me about her positive life and her fantastic marriage. Her husband visited her every day and always lovingly sat on the bed. But he looked at her so sadly and spoke with such a low, soft voice, that it created a very depressing atmosphere. Yet, he would never really show his feelings. "As soon as I want to talk about dying, or when I indicate that I'm worse, he turns away and tightens his mouth. But

I don't know what he feels, if he is really deeply affected ..." I was able to talk to the husband and give him the courage to show his feelings. It helped a lot. So, encourage people to express their feelings.

Incidentally, I sometimes cry too when I'm visiting the patients. When people tell me a very sad story, I have found myself putting my arm round them and shedding a few tears, and I don't actually see why I shouldn't. But I also laugh a lot with them. At the beginning, a nurse remarked, "I don't know why you're always so cheerful, this is a ward where there's nothing to laugh about." That's simply not true, life isn't just grey, we make it grey. And if we look at both poles, the colorful and the sad, we can be quite different with one another.

Another task I have set myself is to be there right to the last moment. In the early days, this was incredibly difficult for me to accept because I always lost a part of myself as well. Perhaps it had also something to do with my own illness. I have learned since to be less afraid of death. I used to hesitate at the beginning when the nurses would say to me "Go in, the woman's in a coma. Actually, you don't really need to go in anymore." But soon I discovered this was not true. I realized it was necessary for me to go in – for the patient and for myself.

The difficult process of change – for professionals and for patients

I try to work successfully with the nurses on the wards. I join in the coffee break. Coffee and a bite to eat, that always unites people and relaxes the atmosphere. Then, sometimes, you can bring up issues that are important and talk about difficulties on the ward. Nurses have learned that they must leave their emotions outside the hospital, put on a particular expression with their white uniform and neither smile nor be sad. On the wards where things are going well, we try and alter this attitude. For example, we suggest that the nurses might bring a cake for the patients, or sit down for ten minutes on the bed and play a game or listen to a cassette with them. In other words, do things that are not part of the hospital routine.

One of my dreams is to give every patient the opportunity to select the paintings she wants to hang on the wall of her room. Our director first said, "Wonderful idea, go ahead." But the question of insurance came up and that was found too costly.

There are other difficulties. For example, with the senior consultants. They often say, "We're open to your work, it's fantastic what you're doing." They send us patients and ask us to see what they call "difficult cases". Then they ask, "What have you achieved?" But you can't achieve things immediately and above all, what we achieve is not always what the senior consultants want. We try to help the patients become a little rebellious, to use their illness to change something in themselves and to live differently. If you want to do that, you can't just pull a program out of a drawer marked "Gestalt therapy" or "visualization" or "breathing therapy", and pass it on to the patients as you would pass on a recipe. It doesn't get to the root of the problem. The patients need to change their lives, because their lives have caused their illness. But when you've been going in one direction for thirty or forty years, it's very difficult to suddenly do an about-turn.

What is very important for the helper is to know that the steps taken are very small and that there are always some setbacks. But these very small steps are a progression along a particular path and when you go along this path with the patient, after a certain time – not just one or two weeks but after a longer period – you really see a change. Patients as well as people who attend self-help groups confirm this again and again. When you meet them after a long time and they say, "You know, this work you're doing, it really helps. It has enabled me to cope better with my illness", then you feel really rewarded.

This paper is a transcription of the recorded presentation made by the author at the Symposium.

THE DUO-FORMULA: A BALANCED COOPERATION BETWEEN PROFESSIONALS AND PATIENTS

by Maria A. Bremer Schulte

This paper describes research on innovative ways to promote the practice of self-care by people with a chronic complaint. Considerable interest in the subject exists. It was confirmed by interviews with patient groups and with a random sample of general practitioners, specialists and community nurses. The answers, however, reflected some uncertainty regarding *how* to carry out self-care effectively. The study reported here is part of a wider program of research on the area between conventional health care and self-care, including the development of training programs for medical professionals and lay people.

Public interest in self-care, self-responsibility, and self-help has been revitalized as one response to alter the existing health system. Individuals are demanding more health information and education, a better understanding of disease processes presented in lay terms, and more control, responsibility and management over their own health. Therefore, as needs with regard to future health care evolve, it is imperative to consider ways of further developing self-care/self-help technology. There is an increasing awareness of the imbalance that exists in our present health care delivery system. The one-sided professional and individualistic approach for the treatment of medical problems is no longer considered adequate by many patients seeking health care. This is especially true for chronically ill persons, who constitute a majority in current morbidity. In fact, since the beginning of the seventies, experimental studies on self-care in relation to chronic disease have demonstrated the importance of combining professional knowledge and experiential insight of patients as a means of promoting health.

In many countries, there are signs of growing interest in finding new ways of helping patients to cope with chronic disease (Hasler & Schofield, 1984). There is particular concern about the increasing reliance on self-medication to reduce symptoms of stress or cope with problems which might be given more effective solutions (Katz & Bender, 1976; Levin et al, 1979); Hatch & Kickbusch, 1983; Levin & Idler, 1983). The day-to-day worries associated with a chronic complaint not only affect patients and those who care for them but they also place heavy demands on doctors. Many medical professionals, in consequence, are now trying to help people cope more effectively with their illness through patient education (Gartner & Riessman, 1977; Green, 1984). This includes increased familiarity with various techniques of self-care to complement the specialist knowledge of medical professionals (Williamson & Danaher, 1978).

A study program on "self-care activating support"

Concern to find new ways of helping people develop their skills for self-care (termed "self-care activating support") gave rise in Holland, as early as 1969, to a program of research. In 1974, the program was based in the medical faculty of the University of Limburg (Bremer Schulte, 1973) and in 1986, transferred to the Institute for Self-Care Research in the same university. The role of the Institute is to investigate methods for supporting self-care and to promote their implementation through a health journal and group-oriented patient education. It teaches psychosocial skills and stress management techniques to patients and their partners, and helps them to assume more responsibility in the management of chronic illness. From its start, the research program on self-care covered both the care provided by individuals for themselves and the care provided through self-help groups. An "equilibrium model" was developed, suggesting that patients learn most effectively when they can draw simultaneously on the skills and knowledge of medical professionals and on the experiential insights of fellow patients (Bremer

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Schulte, 1984). To test this hypothesis (Bremer Schulte et al, 1985; Bremer Schulte et al, 1986), experimental groups were formed comprised of patients with various kinds of chronic complaints: skin and heart diseases, rheumatoid arthritis, and multiple sclerosis. The teaching methods derived from the approach used are known as the "duo-formula group training". They have been tested over fifteen years, refined and replicated in other countries (Bremer Schulte & Richardson, 1987).

These early studies made it clear that a new research area in health care had to be recognized, namely the area between conventional medical care provided by doctors, and the self-care provided by patients themselves. The potential role of medical professionals in helping people to learn how to look after their health was seen as requiring particular attention.

But there was a need, first, to answer two questions, namely: (a) the extent to which patients are interested in learning about self-care techniques, and (b) the extent to which doctors are willing to work with patients towards this end. The duo-formula group (DFG) program addresses these two issues.

Evaluation of the DFG program for the treatment of chronic diseases

The duo-formula group approach stimulates a balanced cooperation between professionals and patients in health care. A professional (called "co-worker") and a lay person (called "co-helper") are trained together for the purpose of conducting group sessions which follow a set protocol.

The intention is to equip individuals with the necessary skills and knowledge to promote health through changing lifestyles and increasing levels of self-efficacy. Currently, the impact of the DFG approach with heart patients and patients with psoriasis and other chronic skin diseases is being evaluated with a view to determining its potential for chronic illness in general.

The DFG approach is also under investigation for elderly people, chronically ill persons and handicapped persons. The chronic illness research is part of a broad project on "Health promotion and coping with chronic disease", which is a collaborative program of the WHO/EURO Health Promotion Unit, the Dutch Ministry of Welfare, Health and Culture and the Institute for Self-Care Research at the University of Limburg.

The results achieved so far indicate that the duo-formula group program has potential for preventing further manifestations of the disease. Furthermore, this program has important implications for improving the existing quality of life of patients. The results support the view that patients and their partners can achieve favorable outcomes, specifically by decreasing illness behavior and anxiety. These results are challenging and merit further study.

THE COMMONWEAL CANCER HELP PROGRAM

by Michael Lerner

The Commonweal Cancer Help Program is a stress reduction, health education and group support program for cancer patients and their families. It takes the form of one-week long retreats, held ten times a year. People come from all over the United States and Canada to these retreats, which take place at Commonweal, a health education and research institute located in the Point Reyes National Seashore, an hour's drive north from San Francisco.

The retreats are designed to help people reduce the stress of the cancer experience, to explore better health habits, to be with others facing the same difficult life passage and to critically review objective information on both established and complementary cancer therapies. The retreats are also open to spouses and close support people.

The Commonweal Cancer Help Program is *not* a cancer therapy. We do *not* advise participants on what therapies they should undertake, nor do we endorse claims made for any of the complementary therapies. We do seek to provide truthful and impartial information on health care options for participants to consider in pursuit of the health goals they have defined for themselves. Participants must be under the care of an oncologist or allopathic (conventional) physician, able to care for themselves in Commonweal's rural environment, and currently well enough to benefit from the program.

Spending a week at Commonweal

Participants in the Commonweal Cancer Help Program start the morning with a one hour and fifteen minutes yoga class including progressive deep relaxation, breathing practices and meditation. Then they have breakfast, followed at 10h30 by a morning session that may include sharing of experience with cancer or exploration of the use of imagery. After lunch – we serve vegetarian meals – there are a variety of individual activities: some participants have an hour-long massage session; others work with a sand tray, a Jungian technique for eliciting imagery which is a remarkable tool for self exploration; others yet may have individual conferences with me or with the program co-director. Then at five o'clock there is a second yoga class and a second session of progressive deep relaxation. Thus, participants have had extended deep relaxation twice during the day and discovered simple yoga practices that can be done by anyone at his or her own level of comfort. After dinner, which is at 6h30, there are evening programs. I may talk about my research on complementary cancer therapies or we may discuss diet and cancer, or write poetry together. This goes on for a week. We have worked with 35 groups of eight to ten participants each over the last four years.

We have found that the Commonweal Cancer Help Program retreats work best for the people who (a) have a real interest in making a sustained personal effort to engage with their illness, (b) have the personal maturity to work well in a small workshop setting, and (c) believe they would benefit from a week of yoga, relaxation, meditation, massage, and exploration of healing and of informed choice of conventional complementary cancer therapies.

An awakening

What happens to people who go through these retreats? One eminent pediatrician who came on a recent retreat wrote to a friend: "I learned how to rearrange my lifestyle, change diet patterns, and begin to focus on my inner self in new ways. The experience was more than educational. It was a deeply moving awakening. A new sense of kinship with other people developed, inspiring a realistic hope and faith."

Most participants in the Commonweal Cancer Help Program report a similarly positive experience. It is a very intensive experience that takes place at a time when participants feel very vulnerable. Many participants, whether their health improves or worsens, remember the experience as one

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of the most important things that happened to them since they were diagnosed with cancer. Our whole purpose is to give people an experience of total care and total support for a week and then to allow them to take home from that experience whatever they find of interest, whether it is imagery, nutrition, yoga, or a new sense of how to live.

We talk about informed choices in both established and complementary cancer therapies. We put as much emphasis on making wise choices in established therapies as in complementary therapies.

People come in panic and anxiety and they leave with a sense of real inner peace. They come feeling confused and disoriented and they leave with a sense of orientation and purpose. They come under severe physical stress and they leave looking relaxed and healthy. It is an extraordinary experience. It is so extraordinary that I have reached the point where my life outside the program seems less real to me than inside the program. The time I have the privilege of spending with these people who are fighting for their lives, who have chosen to come and to go through this experience with us, is the most valuable time in my life.

A very important distinction we make in the program is the distinction between healing and curing. As mentioned in my paper on *Emerging forces in cancer care* (cf. p. 83), curing is a medical intervention that reliably results in suppressing the symptoms of an illness, whereas healing is a process of becoming whole. Healing can take place at various levels: physical, mental, emotional or spiritual. I would say that the Commonweal Cancer Help Program helps people with the healing process. I believe there is often a kind of interaction between these three levels. For example, if you simply break a finger or break an arm, you may heal physically and it may have very little effect on your growth and your psychological and spiritual healing. But when you have cancer, heart disease or arthritis, and when you are an exceptional person who undertakes this form of intensive health promotion, the spiritual and psychological healing may collaborate with the process of physical healing, to whatever degree physical healing is possible. At a certain point, the resources for physical healing may no longer be there and physical healing may start to decline. But even though the physical healing is declining, the psychological and spiritual healing may continue to intensify. So we see the healing process as a comprehensive mind-body process which supports physical healing wherever possible but which may continue at a psychological and spiritual level whether or not physical healing is possible.

Towards a new approach to cancer care

The model that I use for what I hope is going to take place with cancer treatment, not only in the United States and Europe, but all over the world, is the model of birthing centers. Fifteen years ago in the United States the way in which children were born was profoundly different from the way in which birth now takes place in many hospitals. This change happened because people brought over from Europe the idea that it was possible to give birth in hospitals in a much more natural setting, with the father and the mother actively involved. This has really transformed hospitals in an extraordinarily short period of time. No-one would have predicted such a rapid evolution. Once people found out about these new practices, they voted with their feet and went to the hospitals that offered these birthing centers.

I think a similar evolution can also happen with cancer care. There is no scientific barrier to cancer care centers that would integrate the best of scientific medicine and the best of complementary approaches to intensive health promotion. In fact, such centers already exist. The Lukas Anthroposophical Klinik in Switzerland and the Bristol Cancer Clinic in England are among some really beautiful examples of places that are integrating the best of both worlds. In the United States so far there are no such centers. With the growing recognition of the role of intensive health promotion in chronic illness, it is my hope that we are going to create these kind of centers for the conditions we are concerned with, and that they are going to transform hospital practice, because this is what patients want to see.

THE PAIN THERAPY FORUM: AN INTERDISCIPLINARY APPROACH TO THE PROBLEM OF PAIN

by Thomas Flöter

The Pain Therapy Forum (STK) was established in 1984 in Frankfurt-am-Main as a registered, non-profit association. Its membership is open to all branches of medical practice concerned with the effective diagnosis and treatment of pain for the seriously and terminally ill. Aiming to achieve a clearer understanding and more effective management of chronic pain, it has set itself six objectives:

1) to establish in the minds of the medical and non-medical profession that a problem exists with regard to the diagnosis and treatment of chronic pain;

2) to actively promote algesiology – the science of pain;

3) to establish treatment facilities with specialized staff in every town and offer possibilities for treatment at the patient's doorstep;

4) to provide continued education for the medical profession in the science of pain;

5) to facilitate the cross-fertilization of ideas by the creation of interdisciplinary pain consultations – an open forum of specialists who meet in the presence of the patient;

6) to promote the "marketing" of the science of pain, i.e. convincing informed minds and opinion leaders of the need for a revolution with regard to current thinking about the problem of pain and its management.

Program of action

The open forum of specialists or interdisciplinary pain consultation is the *first* and most important *activity* of STK.
The forum meets on a regular basis, once or twice a month for two hours or more. It is open to all categories of specialists, and to chronic pain patients who are introduced by members of the panel. This approach results in collective, creative thinking from all types of specialists in an attempt to find new ways of treating a hitherto untractable problem. The pain forum should become the first resort of the patient, rather than the last one, i.e. the recognized authority on pain.
Are these interdisciplinary consultations a necessity or a luxury?
At present, chronic pain is like a puzzle: its pieces are scattered in the hands of various specialists. Therefore, it is only by bringing them together to pool their resources and knowledge that a complete picture of pain can be obtained. Chronic pain is unaware of the boundaries of the different medical disciplines. The pain specialist is one of the architects of a solution to the problem. He builds upon the foundations laid by the collective thinking of the open forum. The pain specialist "graduates" into his specialty from long-term involvement in pain consultations where he acts as initiator and coordinator.
An association of experienced people thinking along the same lines and willing to give time is necessary to deal with the complexities of chronic pain. No individual can deal with the problem singlehanded. Collective creative thinking is essential. An unstructured approach will only produce partial solutions.

STK's *second activity* aims to increase awareness about the science of pain through a positive educational program which includes:
- seminars;
- lectures;
- workshops;
- brainstorming sessions;
- discussion groups;
- practical training with specialists; and
- participation in pain consultations.

A newsletter is also regularly published by STK.

The *third activity* deals with the exploration of all possible links with relevant medical and non-medical bodies and indi-

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viduals – psychologists, physiotherapists, medical staff, pharmaceutical companies and government bodies – as well as with other organizations already tackling the problem of pain.
Is every medical practitioner able to say: "Pain is already one of my specialties"? If this were the case, chronic pain would be neutralized and fewer people would suffer from its effects. STK provides an opportunity for practitioners to develop their knowledge in this complex field.

STK's *fourth activity* concerns continued education. A committee of the German chapter of the International Association for the Study of Pain has formulated the aims and basic requirements of continued education for pain therapists. Seminars with well-known lecturers who discuss syndromes, methods of treatment and various scientific findings, are held regularly by STK in cooperation with national and international associations of specialists. These one-day and week-end seminars are arranged so as to facilitate continued education in algesiology. The educational effort is spread over various locations and is supported by all regional pain therapy forums which now have been established not only in Frankfurt, but also in eight other major cities.

PSYCHOLOGICAL TREATMENT OFFERED IN MEDICAL PRACTICES WITH PARTICULAR FOCUS ON CHRONIC PAIN

by Hans P. Rehfisch

For approximately seven years the Institute of Medical Psychology at the University of Marburg has been carrying out group treatment programs of patients in medical practices, together with the General Medical Department of the Hanover Medical School.
Among our most recent projects in this context is the psychological treatment of patients with chronic pain. Other projects include:

- weight reduction and health consultations for obese hypertensive patients (Basler et al, 1985; Basler, 1987);

- stress coping for hypertensive patients with normal weight (Basler, 1986; Jaekel & Basler, 1986);

- health consultation for diabetics;

- stress coping in the case of coronary heart and circulatory disease;

- pain treatment for chronic back pain patients (Kaluza & Basler, 1986);

- pain treatment for chronic pain patients with a syndrome of tenseness, stress and psychological strain (Rehfisch, 1987a).

These programs usually comprise 12 group sessions which take place according to standardized treatment programs at weekly intervals in the doctor's practice. In the initial phase, the group leaders are psychologists. Once the treatment has progressed sufficiently and its effectiveness has been checked, the groups are led by the doctor, and for certain parts, by the doctor's staff. At present, the pain groups are led only by psychologists. Some of these programs are applied all over the Federal Republic of Germany, in several hundred practices and with thousands of patients participating successfully. This approach is one of the few that enables the doctor to receive direct feedback about the effects of the intervention.

With high blood pressure groups, for example, the following results have been obtained:

- the patients are able to reduce their weight on a long-term basis;

- blood pressure is permanently reduced, and some patients require less medication or none at all;

- health behavior improves;

- patients consult the doctor less often;

- a better relationship with the doctor is established.

Psychological pain treatment

In the last 15 years there has been a considerable body of experimental and also clinical evidence on the effectiveness of psychological techniques for coping with various pain conditions such as migraine, tension headaches, cancer pain, burns, soft-tissue rheumatism and chronic polyarthritis, to name but a few (Turner & Chapman, 1982).
Three controlled studies carried out by our Institute in two settings, (a) self-help groups of the Rheuma-Liga and (b) medical practices, have proved the effectiveness of these intervention methods.
What, then, are the main elements of such programs? (Rehfisch, 1987b). They include:

1) informing patients about the effectiveness of psychological methods, the point at which these methods are used to intervene and where they can be applied;

2) relaxation of muscular tension, restoration of inner calm and reduction of reactions to stress by means of a relaxation method (a modified form of muscle relaxation patterned after Jacobson's method);

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3) introduction to methods of external distraction from pain;

4) use of imagery or of concentrative methods to distract attention from pain, including pain focusing methods;

5) easy physical relaxation exercises;

6) modification of negative cognition of pain;

7) modification of negative feelings such as anxiety, depression and helplessness;

8) exchange of experience with other patients;

9) dealing with external strains (stress coping strategies);

10) coping mechanisms for dealing with pain, handicaps and other consequences of illness.

Such programs usually result in long-term reduction of the pain; improved ability to deal with pain; reduction of anxiety, depression and helplessness; better spirits; new social contacts; better knowledge of the illness; improved coping strategies; modification of the model of the illness; improved general condition; greater sense of responsibility towards the illness; and reduction in the number of visits to the doctor.
Our controlled study with 62 patients suffering from chronic polyarthritis shows that this approach can also result in a lasting reduction of pain in the case of inflammatory rheumatic illnesses (Rehfisch, 1987a).

Some general and specific advantages

Our model has the following general advantages:

- treatment is locally based;

- it takes place under one roof;

- long-term care is provided following group treatment in the doctor's practice;

- costs are modest;

- treatment can also be carried out in regions with a low population density.

For the medical practitioner, this form of treatment has the following positive outcome: medical practices are more attractive for the patients; doctors learn a new way of dealing with patients and illness; contacts with patients are more intensive and open, even after the group treatment; doctors develop a more psychosomatically-oriented concept of illness based on direct experience; the recognition of the multi-factorial origin of illness is not merely theoretical but leads to practical applications.
The projects carried out do not only help patients to cope better with their chronic illness and reduce the suffering they experience, but they also change the views of doctors and patients on illness in a way that could not be achieved by providing training and information on a purely theoretical basis.

WHAT ARE THE VIEWS OF PATIENTS?

by Ina Alewell

What factors help patients to cope with their illness? What are some of the difficulties they come across and what aspects influence positive outcomes? What can be done to enhance treatment? These questions were discussed with groups of patients attending physical training sessions as part of the recovery process. Whether suffering from myocardial infarction, cancer or rheumatism, the patients expressed strikingly similar views.

- The best after-care is always experienced from one's immediate social environment, first of all from the family. Seldom does the doctor appear to play an important role.

- Diets have been changed by all patients, to make these as natural as possible. Emphasis is on full-value foods, with very little meat or sugar.

- All the patients express the same need for oxygen; there is a widespread belief that oxygen helps the body cells to recover. Hence, the interest in doing physical exercise in the open air and in jogging – not to win medals but simply for pleasure. People have learned that exercise in the fresh air always brings about a change in the autonomic nervous system. Everyone is convinced that one should have creative activities because it is good for the "soul".

- Information and education about a chronic illness should be given in a calm way, not causing anxiety, and should be properly prepared. This applies also to the information given to the family: "How do I treat my sick relative? What may he/she do or not do?" The majority of patients have, of their own initiative, obtained information about their illness which was not generally offered by their doctor.

- No less important is the line of communication between the various doctors responsible for treatment. It is not for the patient to "inform" his doctor because he is, after all, still facing an emergency and must try, first or all, to cope with this frightening situation.

- Most patients do not want to talk about their experience, but prefer to write about it. Afterwards, they feel better and are happy that they were able to express themselves. Irrespective whether patients suffer from cancer, heart infarction or rheumatism – all are of the opinion that "mental stress" or "aching hearts" have led to their organic breakdown.

- The cancer patients suggest "oncological lay helpers", similar to "Alcoholics Anonymous". The persons who are themselves affected are in a privileged position to help.

- The kind of relationship the patient has with his doctor and whether both are frank with each other plays a decisive role. Personal responsibility needs to be strengthened and the potential for good health encouraged. Simultaneously, a form of self-observation should be learned: what causes my anxiety, when do I have pain, which part of my body becomes tense? What are the negative effects of loneliness, of social and family isolation? Help is needed in connexion with exercise, relaxation, dietery changes, etc.

- Last but not least – many patients consider that they have too little faith; they feel that faith makes people stronger and pain easier to bear. This view is sustained by the argument that faith has been found to have supportive effects on the immune system.

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SOME PRIORITIES

1. The concept of medical care system needs to be broadened to a wider concept of *health* care system. This can be effected by emphasizing:

- the internal environment, physical and emotional, of care institutions;

- the organization of medical care;

- the involvement of different levels of care and linkages between institutions of care;

- the fact that institutions are not just bricks and mortar, but are essentially based on people.

2. Health care needs more concern with group care and the community; health promotion is to bring the macro levels in.

3. Self-esteem rewards should be given to health care providers and systems which incorporate health promoting ideals, e.g. the primary health care team approach or the concept of the health center with geographic responsibility for a community's health.

9.3 HEALTH RESEARCH

Documentation of the experience of living with chronic illness is unsatisfactory, and research must still determine the common problems, needs and preferences of people living with chronic illness. This knowledge must serve as a basis for action.

Systematic descriptions of current care alternatives are also lacking. It would be helpful, for example, to undertake an inventory of intensive health promotion programs in different countries for people with cancer and assess their effectiveness, investigating the outcome of therapies at the physical, mental and spiritual levels from the patient's viewpoint.

Altogether, research on coping and the experience of living with a chronic condition from the perspective of the patient and the family appears to be underdeveloped.

Following are three papers covering different areas of research and dealing each with aspects of importance in the perspective of health promotion.

SELF-HELP GROUPS: RESEARCHERS REVIEW THEIR IMPACT AND THEIR POTENTIAL

by Jan Branckaerts and Ann Richardson

Self-help and chronic disease was recently the subject of discussions among a group of researchers convened by the International Information Center on Self-Help and Health – on behalf of WHO's Regional Office for Europe – to a workshop held in Leuven, Belgium, 28-30 January 1987. The workshop was initiated on the assumption that the time was ripe for a review of existing evidence about self-help.

A wide range of disciplines were covered by the participants who came from nine countries of Europe and North America, including medical sociology, social medicine, clinical medicine, social psychology, political science, social administration and social work. The participants' research covered self-help in the context of many differing chronic diseases and handicaps, including diabetes, rheumatism, chronic skin disease, cancer, sarcoldosis, hypertension, blood diseases, Huntington's disease, mental handicap and others.

The following are extracts from the conclusions reached by the workshop.

What is the impact of self-help groups?

Self-help groups are essentially groups of people who feel they have a common problem and have come together in order to do something about it. On the one hand, the groups are concerned with the social and health needs of their members (called by some "defensive" functions), while on the other, they are concerned with the broader policies for, and provision of health care (termed "offensive" functions). These groups can be seen to be particularly appropriate in the context of chronic – as opposed to acute – diseases. Chronic disease, by its very nature, creates a new and permanent "stage of being". Sufferers must learn to cope not only with a new set of symptoms but also with a new sense of identity. They may also need to make substantial changes in their day-to-day lifestyles and living conditions.

In what ways and under what conditions are these groups helpful? They have in fact two separate kinds of impact: on their individual members and, more widely, on the political and social environment in which they work.

Impact on members – Research findings indicate that self-help groups can have a substantial and beneficial impact on people with chronic disease. Across many countries, and across many different conditions, they provide an important source of social and emotional support to those who belong. They help to raise members' sense of identity and to overcome loneliness and isolation through shared social activities.

Self-help groups provide patients an opportunity to meet and learn from one another over time, both about how to detect and control symptoms and about how to come to terms with their new situation. Patients who have had a disease for some time can provide a useful model for those who are new to it, offering a reassurance that it is possible to live with – and cope with – the condition. In short, self-help groups are an important source of information and advice, both about coping and various sources of help. They increase members' awareness of the quantity and quality of external help and therefore their ability to exercise informed choices.

But not all effects of self-help groups are positive. Some groups were found to have a negative impact on members, either because they isolate members from non-members or indeed the wider community, create a high level of expectation which cannot always be fulfilled and promote discussions that are not always realistic, so that suggestions are not followed up at home; or because they have too narrow an approach to particular problems.

As regards the physiological or psycho-

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logical impact of self-help groups on members, research evidence is limited and possibly conflicting. There has been little research on the effect of involvement in reducing personal stress.
What is certain is that one must be cautious not to generalize too freely about the impact of groups on members. This differs enormously according to the nature of the condition for which a group is formed. Benefits from involvement also differ according to the stage in the disease at which a member takes part. They also vary with the degree of stigma attached to the condition.

Impact on others — But many groups extend their focus beyond their immediate members and seek to engender greater public awareness about their condition in particular, and health needs in general. The "advocacy" role is an important one for many groups.
With regard to health *professionals*, the situation is somewhat complex. While some professionals view self-help groups inappropriately as a substitute for their care, others feel antagonistic. On the whole, however, there seems to be an increasing sympathy among professionals with respect to self-help. Experience shows that through involvement in a group, professionals often learn a great deal about patients' problems and views. They come to realize that self-help is a useful means of solving problems and is not a threat to themselves.
Self-help groups are making an impact in one specific area: they mobilize new resources into the provision of health care. A new kind of *volunteer* can be seen to emerge within groups, providing help to others with the particular disease or condition. Focusing clearly on one condition, strict professional and institutional boundaries tend to be ignored within the groups.
When it comes to the long-term impact of self-help groups on *society at large*, actual evidence is modest. It would be exceedingly difficult to trace, as a long time span is necessary and cultural changes are in any case highly subtle. Similarly, the impact of self-help groups on broader attitudes to health is interesting, but difficult to assess. Such impact undoubtedly varies notably from one country to another, affected both by particular health care arrangements and by local cultural norms.

Issues for research

On the agenda of the workshop were also such subjects as the operation of self-help groups; differential participation within groups; the incidence of self-help groups and differential memberships; the support provided to self-help groups by clearing houses; national organizations and professionals; and future issues for research. These include the need to ask questions with regard to such key issues as:

- the quality of services provided by self-help groups;

- which categories of chronically ill persons are served best by self-help groups and, conversely, those for whom groups may be inappropriate;

- the impact of self-help groups on medical professionals and the services they provide, as well as vice-versa;

- the numbers and nature of those who join and become active, those who become inactive members and those who never join at all;

- the economic impact and significance of self-help groups (viewed as one part of an economic evaluation of the lay health care sector);

- the extent to which differential outcomes are the result of political and social factors intrinsic to a particular environment;

- the circumstances which enable self-help groups to become successful pressure groups.

Some problems and limitations, but an important potential

Very broadly, the conclusions of the workshop were positive but cautious. Self-help groups have a great deal to offer their individual members and can also have a beneficial impact on the wider society in which they function. They represent an important contribution to the promotion of individual health care and bring to discussions a refreshing "lay" view of patient care. Self-help groups can also be described as "efficient" bodies, inasmuch as they carry out a number of different functions at the same time. They represent and encourage a wider view of health as a social idea.

But self-help groups do not function without problems and it would be inappropriate to place too high expectations upon them. They are not universally available, in terms either of every disease or of every country or local area. Not everyone, in any case, finds them an appropriate solution to his or her particular needs for care. They should be viewed as an important complement to existing systems of health and social care and in no way a substitute for them.

Their contribution needs to be recognized but not exaggerated. In particular, there remains a number of unanswered questions about the significance of self-help, both to those who belong and to those who do not.

There is a need to accept that self-help is not a universal solution and that many people, with full knowledge and competence, do not choose to become involved in groups.

One of the key elements of self-help is its holistic approach to individuals and their problems. A person is viewed not solely as someone with a particular disease, which needs treatment, but as an individual with a need for a wide range of kinds of care and attention. This approach is not unique to the self-help context, but it is well demonstrated through it. There are important lessons to be learned from such a perspective.

The development of self-help groups presents a kind of conundrum for those concerned with public policy. On the one hand, they can be viewed as solely "private" bodies: groups of people who find their mutual company congenial and derive a sense of benefit from taking part (as with a group of friends or a sporting club). On the other, they can be viewed as having an additional "public" function: a contribution to the health status of the population (as with programs for health education). To the extent that they are viewed as the former, they are a matter solely for the individuals involved. In contrast, to the extent that they are viewed as the latter, they are a matter for social policy. The growth of attention to these bodies, from national governments as well as from the WHO itself, suggests that the broader social interpretation is gaining currency.

The future of self-help: a shift towards health promotion?

In what ways will self-help groups seem different in ten years' time?

Crystal ball gazing is a notoriously hazardous activity; firm predictions are all too frequently knocked aside by subsequent unforeseen developments. In the self-help context, it is likely, however, that in many respects groups will be very much the same over the next decade or so. New groups will emerge and some existing groups strengthened. Some groups may also go into decline. This has always been so. With the growth of clearing houses and support from professionals, however, the self-help phenomenon is likely to become more secure.

But there are also new kinds of groups potentially on the horizon. These are *non-disease-specific groups for health promotion*. With growing interest everywhere in extending the role of lay people in health care, and growing concern to learn about health in its broadest sense, such groups are likely to flourish. A number already exist in various countries, focused on broad patient care or participation. They both reflect and foster an important holistic approach to health. Self-help groups themselves, as they begin to talk with one another and learn from each other, may help to spur this development. There are a number of general health issues likely to be born from coalitions, thriving on the search for a common cause. The effect of such new groups, combined with those of longer duration, will merit close attention. They too may have a positive impact on those who take part, liberating and extending their ability to promote their own health and that of others. They too may have an empowering function. Perhaps more significantly, they may affect broader service provision, reorienting health services in the direction of more general health promotion. They may serve to place health issues firmly in the lap of public policy, removing them from the more restricted domain of the medical profession.

In conclusion, the time is now right for a reiteration of basic principles. The role of the lay person in coping with a chronic disease, and the role of groups of lay people – self-help groups – in this regard, should be stressed and promoted.

EFFECTS OF CONTACTS BETWEEN CANCER PATIENTS ON THEIR PSYCHOSOCIAL PROBLEMS

by H.W. van den Borne, J.F.A. Pruyn and W.J.A. van den Heuvel

This paper presents a summary of the results of a study on the effects of patient-to-patient support on the psychosocial problems of cancer patients. Data were collected at two points in time from samples of lymphoma and breast cancer patients in accordance with a quasi-experimental, non-equivalent control group design.

Supporters of self-help claim that contacts between cancer patients will lead to a decrease in psychosocial problems. Opponents are convinced that such contacts increase uncertainty and anxiety and will lead to a decrease of self-esteem, for instance in the case when a fellow sufferer dies. In this study the effects of contacts between fellow sufferers are examined in a longitudinal and quasi-experimental, non-equivalent control group study. Hypothesis derived from social comparison theory are tested. These hypotheses refer to the influence of contacts between cancer patients on their psychosocial problems as *uncertainty, negative feelings, loss of control* and *self-esteem.*

During a period of three weeks on end 22 medical specialists in 15 medical centers across the Netherlands asked all breast cancer and lymphoma patients that came for treatment or for control to participate in the research. Also all the patients who were members of the national Contact Group for Hodgkin patients at the beginning of 1982 were asked to participate.

Eventually during the first measurement, which was carried out in February and March 1982, 216 patients with Hodgkin's disease and 282 breast cancer patients were interviewed. The interview was followed up by a written questionnaire that had to be filled in during that same week and by means of which a number of personality characteristics were measured.

Eighteen months later, in July 1983 and August 1983, the second measurement was carried out with 369 patients in total. The interviews (both in the 1st measurement and 2nd measurement) were of approximately two hours' duration and conducted in the patients' homes. The patients were interviewed by female interviewers, 40 ladies of middle age who were specially trained.

Results

In this study "contact with fellow sufferers" is defined as a form of personal contact that the patient has with one or more other patients or ex-patients with the same illness. In this context problems or experiences with respect to the illness are discussed. This contact can take place through face-to-face or in telephone conversations, through correspondence or it can take place in groups or at (national or regional) meetings.

We expected that social contacts with fellow sufferers in certain circumstances would (a) reduce uncertainty and negative feelings, (b) strengthen feelings of control and (c) increase self-esteem.

Contacts with fellow sufferers were expected to *reduce uncertainty* in patients who had obtained too little information from the doctor. The analyses show that contact with fellow sufferers is related in a complex way to the uncertainty of patients. If patients found their doctor's information relevant, contacts with fellow sufferers appeared to reduce uncertainty about the possibilities of help and good solutions.

For breast cancer patients who did not find information from their specialist relevant contacts with fellow sufferers contributed to a reduction of this uncertainty. For Hodgkin patients brief contacts, however, resulted in an increase of uncertainty in cases where information from the doctor was found to be too scarce. This difference in influence of contact with fellow sufferers on uncertainty between Hodgkin patients and breast cancer patients (when information received

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from the specialist was not found to be relevant) may come from the differences in type of cancer and from the possible function of contact with fellow sufferers as a validation of information received from certain sources (for example the medical specialist). In our study it was found that patients often use many sources of information to validate the facts (van den Borne & Pruyn, 1985).

When both lymphoma and breast cancer patients found the information they received from their specialists to be relevant, contact with fellow sufferers still contributed to reduce uncertainty, possibly as a result of this validation. The difference between breast cancer patients and Hodgkin's disease patients left without relevant information from their doctor, may be explained from the nature of the illness. Breast cancer can evoke a number of questions (uncertainties) to which fellow sufferers preeminently can easily give a concrete answer, for example to questions about breast prosthesis and about problems with the upper limb. The national organization of breast cancer patients in the Netherlands (LCBB) pays special attention to this kind of questions. Hodgkin's disease is less easily localized by the patient and seems to evoke more questions which cannot be answered by a fellow patient. Therefore it is not surprising that, when patients found the information they received from their specialist not to be relevant, in particular a restricted and brief confrontation with fellow sufferers evoked extra need for more information.

However, contact with fellow sufferers can as well help to reduce uncertainty in patients who do feel that they have received relevant information from their specialist. Finally, changes in uncertainty also appear to be determined by the fact whether or not the patient receives treatment. Uncertainty increases if the patient has to receive retreatment.

Regular contacts with fellow sufferers led to a reduction of *negative feelings*, but only in patients who were (still) under treatment. Reduction of negative feelings as a result of contact with fellow sufferers does not, as we expected, appear to be related to the extent to which problems caused by the disease can be discussed within the family. In patients who are being treated it appears that contact with fellow sufferers contributes of itself to reducing negative feelings and therefore it doesn't appear to compensate for lack of support or for insufficient support from the primary environment. Contact with fellow sufferers has no influence on negative feelings in patients who were not under treatment during the last 18 months. An explanation for the latter may be that contact with fellow sufferers is only effective when strong negative feelings are being experienced. This is especially the case with patients who are under retreatment. The findings considering the effect of contact with fellow sufferers on negative feelings partly agree with the findings of Spiegel et al (1983), who found that a self-help group (led by a volunteer/ex-patient and psychiatrist or a social worker) led to a reduction of anxiety, fatigue, confusion and phobias. These effects occurred only after approximately one year of contact with fellow sufferers. This also agrees with the results of this study.

Our analyses showed that contact with fellow sufferers was not related to changes in *feelings of control*.

Effect on *self-esteem* was only found in re-treated patients. In these patients regular contacts with fellow sufferers particularly led to an increase of feelings of self-esteem. These results form a confirmation of the "self-enhancement" function of social comparison (Hakmiller, 1966; Singer, 1966; Thornton & Arrowood, 1966; Gruder, 1977). However, they do not agree with the results of three other studies on the effects of self-help groups in cancer patients (Spiegel et al, 1983; Stecchi, 1979; Jacobs et al, 1983). In these studies no influence on self-esteem was found (van den Borne et al, 1986).

Recommendations for action

Based on the data of this study the following recommendations can be given to the medical team and to health education managers in the care and after-care of cancer patients:

1. Patients' contacts with fellow sufferers should be facilitated. This can, among other things, be done through:

- lowering contact thresholds (e.g. giving information to patients and their relatives about where they can contact fellow sufferers and about what this contact can possibly mean for them);

- organizational and material support of organizations of ex-patients/volunteers;

- dealing with the subject "contact with fellow-sufferers" as an important issue in the re-training of professional caregivers; and

- structural integration of the possibilities of help by (ex-)patients in the process of after-care (e.g. offering all patients the possibility of having contact with a fellow sufferer).

2. The most important source of information about the illness and treatment is the medical specialist. If information given by the doctor is evaluated positively, uncertainty is reduced. Contact with fellow sufferers appears, however, to reduce a number of negative feelings and to enhance self-esteem.

Our data plead in favor of a close cooperation betweeen ex-patients/volunteers and medical specialists in the after-care of cancer patients. This recommendation is strengthened by the fact that contact with fellow sufferers leads to an extra reduction of uncertainty in the case that patients feel that they have received important information from their specialist and by the fact that contact with fellow sufferers is especially effective (with regard to negative feelings and self-esteem) during the period of medical treatment.

The full text of this paper was published in *Patient Education and Counseling*, this extract is published with their kind permission.

A STUDY ON THE QUALITY OF LIFE OF CANCER PATIENTS

by Hanneke de Haes

In recent years the necessity of including quality of life in clinical research has been stressed. Especially in oncology, where the effects of treatment on survival are often uncertain and the side-effects considerable, quality of life has gained increased attention.

When studying the difference between the quality of life of cancer patients, patients of a general practitioner and a sample from the normal population, to our surprise, the differences we found were much smaller than we had expected. Similar findings were found in the literature.

From descriptive studies, it appears that the quality in certain domains of life is impaired by cancer treatment. However, results from studies in which two or more groups of cancer patients are being compared are not consistent. The expectation that the quality of life of patients is impaired more negatively by certain treatment modalities is confirmed in some studies but not in several others. Even the assumption that the quality of life of cancer patients is worse than the quality of life of the normal population is not substantiated (de Haes & van Knippenberg, 1985; de Haes & Welvaart, 1985; de Haes et al, 1986; 1987; 1987).

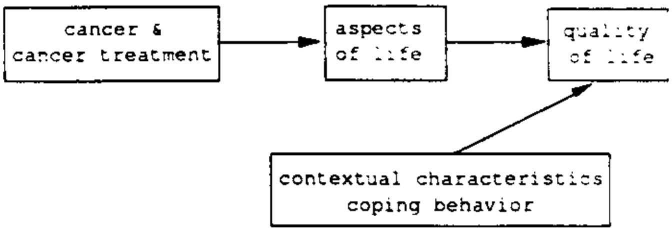
There are several explanations for these findings:

1) the definition and operationalization of the concept of "quality of life" differ enormously from one study to the other;

2) the measurement instruments used are not always valid, the sample sizes are often small and the effects of intervening variables has not always been taken into account;

3) psychological mechanisms, coping and adaptation processes may account for the absence of differences.

Based on these considerations, a further study into the factors explaining the quality of life of cancer patients was planned. Quality of life is seen as a subjective datum, covering the evaluation of the overall character of a person's life. Based on literature on the quality of life of the population at large, it is assumed that this evaluation is based on functioning with respect to different aspects of a person's life and the evaluation of this functioning. Moreover, quality of life is supposed to be related to contextual characteristics of the person (socio-demographics, the social situation and characteristics of the patient's personality) and coping behavior.



The diagnosis of cancer and intensive treatment (chemotherapy) are seen as a crisis in the patient's life. According to Caplan's crisis theory (1964), in times of crisis the usual homeostatis pattern is discontinued as the problem stimulus is larger and the normal problem solving mechanisms are unsuccessful within the usual time frame. Therefore we expect that in times of crisis the quality of life of cancer patients is lowered as a result of the impact of cancer on aspects of life and shortcomings of the contextual characteristics and coping behavior. After adaptation has taken place the usual level of life quality may be regained.

Based on the findings of our present study, we hope to get more insight (a) into the aspects of cancer and cancer treatment that are relevant to the patient's quality of life, and (b) into some of the mechanisms that explain the quality of life of cancer patients.

Note. The findings reported here will be up-dated at the time of final publication

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SOME PRIORITIES

Steps for improving treatment facilities and enhancing the lay potential of *chronic pain patients* should be grounded on reliable empirical data; hence, the necessity to:

a) undertake epidemiological studies (careful single case studies as well as group studies) on the cause and outcome of relevant disease processes with a view (a) to determine indicators of pain chronification, and (b) to increase our knowledge of the role of the patient, the family and the social support system in coping with chronic pain;

b) promote studies of cross-cultural and historical aspects of pain perception and attitudes towards pain;

c) collect information about the multiplicity of determinants of the pain experience in order to enhance our psychosocial-biological view of the problem.

The complex problems of health promotion in relation to *cancer patients* call for basic and applied research in many areas. Efforts should be made, in particular to:

- study ethical aspects of the information giving process and resistance to change in institutions with a view to developing models that would indicate (a) what a patient should know and (b) how a psychosocial cancer unit should be organized;

- draw up an inventory of health promotion programs in different countries, including an evaluation of their effectiveness;

- study and explore, clinically and in everyday practice, intensive health promotion programs at the local and international levels;

- carry out research, together with patients, on the experience of therapy and its outcome (mental, spiritual and physical) from the patient's point of view.

Health promotion among *coronary heart patients* requires that steps be taken to:

- promote innovative health promotion models for coronary patients together with controlled studies to evaluate and compare these models;

- explore ways to avoid the pitfalls of predominating medical practice, i.e. too great a focus on the illness at the expense of the patient; little emphasis on health promotion, and poor integration of psychological and sociological concepts in the medical care.

In all areas of chronic illness, a broader vision is needed in research. Interdisciplinary research into the contribution of different approaches to health promotion needs to be encouraged.

FOCUS ON THE FUTURE

Health services should be reoriented to:

- increase professional support to the public by initiating self-help and self-care activities, transferring professional knowledge and skills according to needs, and creating accessible and appropriate professional support systems for families and self-help groups;

- encourage patients to participate fully in making decisions about their care;

- promote greater involvement of the community and of employers in health care, to facilitate patients' rehabilitation and reintegration into society;

- explore new approaches such as health centers serving a defined geographic area, family-oriented group therapy at such centers, and outpatient care structured so as to make hospitalization unnecessary in many cases; and

- contribute to the creation of supportive environments and the strengthening of community action, to promote the health of people living with chronic illness.

The papers in this chapter clearly reflect the pressing need to take steps to reorient training, to stimulate and support innovative projects in health care, and to foster research.

PART III

A CALL FOR ACTION

A CALL TO ALL THOSE WITH RESPONSIBILITY

Statement adopted by the participants
at the Bad Honnef International Symposium

At the closing session of the International Symposium on Health Promotion and Chronic Illness organized 21 - 25 June 1987 in Bad Honnef, Federal Republic of Germany, by the Federal Center for Health Education, Cologne, in collaboration with the Regional Office for Europe of the World Health Organization, Copenhagen, the participants unanimously adopted the following statement:

- Health, as an essential element of the quality of life, both personal and social, can be promoted at every stage of life. This is equally true for those who are healthy and for those who are living with a chronic illness, specifically for people with illnesses and for those who support them.

- Health promotion underpins the lifelong development and growth of the whole person. The active participation of people in social life is just as important as physical and psychological well-being. Health promotion is directed against the stigmatization and social disadvantage experienced by those living with chronic illness. It addresses the conditions under which individuals live in the community in order to enable them to realize their personal needs and preferences.

- For people who live with chronic illness and their supporters, health promotion is a process of enabling and developing potentials for healing and health. By this means it affords new strategies and actions to strengthen hope among sufferers, to reduce their anxieties and to facilitate a meaningful life. Its goal is to increase the capacity of people to deal with the consequences of chronic illness and to ensure that this experience does not dictate their lifestyle.

- Health promotion through diverse modalities guides individuals in coping with chronic illness, contributes to the avoidance of such conditions, and improves the health of those living with chronic illness, pain and symptomatic illness. As formulated in the Ottawa Charter (1986), health promotion offers opportunities for new, broad based, health oriented action. The Charter urges the examination of current concepts and practices as well as the development and implementation of new approaches.

- Health promotion, with respect to chronic illness, requires the joint action of those living with illness and professionals engaged in different disciplines. The identification of successful strategies for dealing with chronic illness demands the constant exchange of experience and knowledge, which was begun in the Symposium at Bad Honnef. Joint action is urgently needed because of the growing number of people with chronic illness; this applies to all age groups, but is particularly salient with regard to the growing proportion of older people.

- Lessons from the practical application of current health promotion methods must be made available to those living with chronic illness, the experts who deal with chronic illness and the general public. New programs and policies must encompass coping with chronic illness as well as the promotion of health. The development of self-care and self-help approaches demands the provision of adequate resources.

- Interdisciplinary research into the contribution of different approaches to health promotion, including biomedical and holistic methods, is a priority. In this context, there is also a pressing need to establish the common problems, needs and preferences of those living with chronic illness; this knowledge must serve as a basis for action.

- The International Symposium in Bad Honnef was an encouraging first step towards interdisciplinary collaboration. Experts and people living with chronic illness were engaged in developing a mutual understanding and concerted action to promote the health of those living with chronic illness. It was evident that a large number of experiences, a body of knowledge and concrete strategies were already available.

- The participants in the Bad Honnef Symposium call upon all whose with responsibility for making policy, those professionally engaged in health care and health promotion as well as on those living with chronic illness, to respond to the main points in this statement, to further develop strategies and implement them in practice, and to make a clear commitment to the provision of necessary resources.

MOVING INTO THE FUTURE

Health is created and lived by people within the settings of their everyday life, where they learn, work, play and love.

Health is created by caring for oneself and others, by being able to take decisions and have control over one's life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all its members.

Caring, holism and ecology are essential issues in developing strategies for health promotion. Therefore, those involved should take as a guiding principle that,in each phase of planning, implementation and evaluation of health promotion activities, women and men should become equal partners.

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INDEX OF AUTHORS