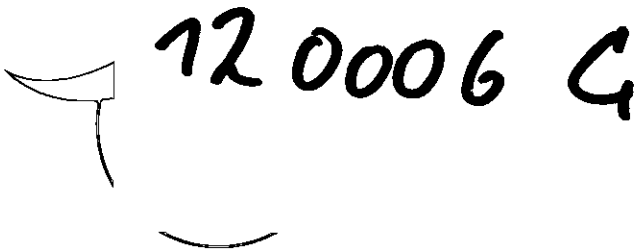


HEALTH PROMOTION AND CHRONIC ILLNESS

- Chronic pain conditions
- Cancers
- Recovery from heart attack
- Challenges facing individuals and groups



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Health promotion and chronic illness

Report on an International Symposium
organized by
the Federal Centre for Health Education
in collaboration with
the Regional Office for Europe
of the World Health Organization

Bad Honnef, Federal Republic of Germany

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Annex : The Bazaar - a focal point for the exchange of experience

Much can be done to promote the well-being of people suffering from a chronic illness. A body of knowledge exists, based on a large number of experiences, and concrete strategies are being applied to improve the personal and social health of people with a chronic illness and those who support them. This statement is documented in the report covering the first international meeting organized in Europe to discuss chronic illness from the viewpoint of health promotion.

Sections 1, 2 and 3 give the background of the Symposium, its scope and purpose and the methods of work that were used, including the very stimulating Bazaar approach.

Section 4 introduces the health promotion concept, its areas of focus, and its strategies concerned with advocacy for health, enabling actions and mediating actions. At the heart of health promotion is the notion of health potential, which exists in each individual and can be developed at whatever stage of life. Health promotion is concerned with enabling people to maximize this health potential, to move ahead from whatever point they start and to develop, *despite* or *because* of chronic illness, a new quality of health and life.

Section 5 deals with chronic pain conditions. Our understanding about the causation, processing and sensation of pain has considerably advanced in recent years. Research in the physiology and biochemistry of pain and in the fields of psycho-neuro-immunology and psychology has shown that the distinction between acute and chronic pain is of central importance, not only for diagnosis and treatment but also for enabling patients to understand their affection and alter lifestyles conducive to pain. Pain itself does not make life unbearable. It is our attitude to pain and the manner of perceiving the pain experience which makes pain unbearable. Hence, the importance of social support and of making people aware of the possibility to activate their health potential.

Section 6 highlights innovative health promotion approaches with regard to cancer. Increasing recognition of the limits of conventional therapies and the need to be cautiously hopeful about new biological therapies, have prompted lay groups of former patients and a number of oncological centres around the world to explore the potential of "complementary therapies". These therapies can often be considered as systems of intensive health promotion, aiming to change the psycho-biological milieu that was favourable to the growth of cancer through some combination of diet, exercise, relaxation, meditation, imagery, improved family and work environments, and new perspectives on what is meaningful in life. Their goal is to strengthen the general immune function, morale, vitality and other host resilience factors.

The value of health promotion has not yet been demonstrated conclusively but the intelligent integration of complementary therapies with established therapies appears to benefit many cancer patients. Apart from possibly influencing the course of the disease, health promotion facilitates effective coping and helps to improve the quality of life.

Section 7 provides evidence of the essential role played by self-reliance, self-help, and self-determination in the process of recovery from a heart attack. In light of these findings, many questions are raised regarding the best possible ways to promote a holistic approach and avoid neglect of the psychological factors during the three phases of rehabilitation, namely : the acute phase, convalescence and late rehabilitation. Several projects indicate possibilities for change within the relatively rigid system of medical and health care. These models, based on the concept of health promotion, emphasize the independence of patients undergoing rehabilitative treatment and give them a partnership role in the process of rehabilitation. They also focus on social support to enhance coping, and give due consideration to the work status of the patient, with its major social and psychological consequences.

Challenges facing individuals and groups are dealt with in *Section 8*. This section analyzes the process of coping and the many factors that influence the capacity of people to cope effectively. It gives the views of the three working groups which discussed the family and self-help groups, the workplace and the community, and medical care. The groups identified problem issues and indicated priority areas for action. Finally, the section discusses the notion of a "healthy ill person" and new perspectives for living with a chronic disease. This notion is an outcome of the health promotion concept and its focus on developing the health potential that exists in each individual.

Section 9 lists the recommendations of the Symposium for health promotion planning and action, followed by concluding remarks in *Section 10*.

The annex provides an overview of the 24 innovative projects presented at the Bazaar.

1.

Background

The Federal Centre for Health Education, Cologne, organized, in collaboration with the Regional Office for Europe of the World Health Organization, the International Symposium on Health Promotion and Chronic Illness in Bad Honnef, Federal Republic of Germany, from 21 to 25 June 1987, with 84 participants from 12 European countries, Canada and the USA. Participants represented 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 representatives of governmental and non-governmental organizations and self-help groups.

The Symposium represented a major step in the new area of health development inaugurated in the European Region in 1980 when representatives of Member States adopted the European Strategy for Attaining Health for All as their common health policy.

The strategy urges that a much higher priority be given to health promotion, seen as "a mediating strategy between people and their environment, synthesizing personal choice and social responsibility in health to create a healthier future". Hence, the emphasis placed on the need for all sectors with an impact on health — and not merely the health services — to take positive steps to maintain and improve health, and the focus on the role that individuals, families and communities can play in health development. The adoption by the Regional Committee, in 1984, of 38 targets in support of the regional strategy provided the necessary framework for action.

The Bad Honnef meeting was part of the continuing process of programme development in health promotion in the European Region. It was the result of a long series of international seminars and workshops and of research dealing with lifestyles, self-help and health promotion, many of which had been organized in collaboration with the Federal Centre for Health Education. The meeting was the first one in Europe to tackle, from the viewpoint of health promotion, the major problem of chronic illness which affects 10 per cent of the population in industrialized countries.

2.

Scope and purpose

The working document on the scope and purpose of the Symposium quoted below clearly sets out the problem and the challenge that chronic illness poses when placed in the context of a holistic view of health and the perspective of health promotion :

In the context of health promotion, "chronic" means life-determining. Thus, "chronic illness" represents a decisive turning-point in the life situation of the persons concerned, affecting not only those who have contracted the illness but also members of their immediate social environment. This concept of chronic illness goes beyond the strict biomedical definition. Persons suffering from a chronic illness are more than just "chronically ill people". Their daily life now has a different starting point from which they not only perceive themselves and their environment but are in turn perceived by this environment.

The number of people living with a chronic illness is growing constantly in all industrialized countries. This applies not only to the rapidly rising number of elderly people, but also increasingly to the younger age group. According to the medical definition of chronic illness, there is no real successful cure available, but only an alleviation of an otherwise constantly deteriorating condition. This definition is essentially negative and leaves little scope for action by the persons concerned.

Chronic illness represents a special challenge for : (a) the persons themselves; (b) their families and social reference groups; and (c) various institutions, namely the community, the workplace, the medical and social services. In all these areas there is an urgent need to critically assess the experience and knowledge available, in order to meet the rapidly growing needs of people suffering from chronic illness. The types of practical help and measures that will become necessary largely depend upon : the nature of the onset of the disease and its expected course; the nature and extent of the disability caused by the disease; and the changes in physical integrity and individual bodily functions.

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 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 heart attack;
- make a broad assessment of the personal and social implications of these diseases, as well as of the various options for action in health promotion;
- identify corresponding needs for action from health and other institutions exercising social responsibility in the community.

3.

The process of the Symposium

With these objectives in mind, the Federal Centre prepared a four-day programme offering experiences on four levels.

First, the *plenary sessions* - Starting with statements on the programme perspectives of WHO in the field of health promotion and reflections on health promotion and chronic illness, they went on to provide an overview of 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. These presentations drew upon more extensive papers prepared for participants prior to the Symposium as well as overviews of current practice in Europe regarding the management of chronic pain, cancer and myocardial infarction. Specific examples of innovative projects illustrating health promotion in action were presented at one of the plenary sessions.

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", the Bazaar 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 programming, obviously enjoying the experience and learning very much from each other.

Projects and activities presented at the Bazaar are listed in the annex.

On the previous evening an open session entitled "Practice and Idea Exchange" had served as an "ice-breaker" and enabled participants to meet informally and to discuss their work and personal experiences.

The venue of the Symposium, a specifically designed hotel, was itself conducive to interaction, due to its excellent facilities for meeting, food and exercise.

4.

A conceptual framework : the Ottawa Charter

The First International Conference on Health Promotion held in Ottawa, 17-21 November 1986, 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.

At the end of the week-long meeting, participants adopted a *Charter on Health Promotion* which extended the notion of primary health care and stressed the need to mobilize all resources towards the goal of health for all. As stated in the Charter, this goal cannot be achieved by the health sector alone. Health promotion demands therefore 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.

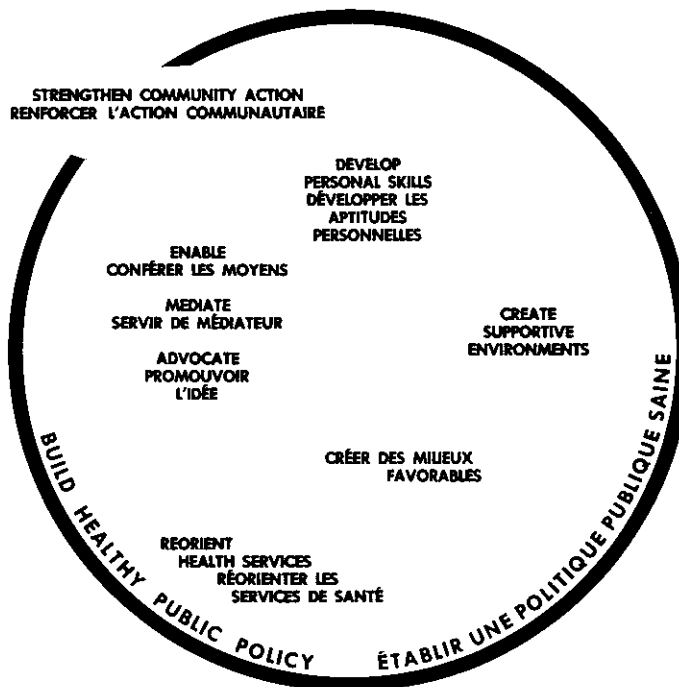
With its focus on personal participation, social and cultural factors and environmental conditions, the health promotion concept represents a definite departure from the medical model. It puts health on the agenda of policy makers in all sectors and at all levels, stating that health aspects should always be taken into account in *shaping public policy* and that those who shape it should be 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*. It 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, health promotion requires a *reorientation of health services*, which need to become part of the community responsibility again and to

embrace an extended mandate which is sensitive to the total needs of the individual as a whole person.

Health promotion thus focuses on "the process of enabling people to increase control over, and to improve, their health" and on 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". 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.



The Ottawa Charter

Doctor Ilona Kickbusch, Director of Lifestyles and Health at WHO/EURO, stressed at the opening session of the Symposium that the five major elements of health promotion are based on a definition of health "which highlights the notion of *health potential*, i.e. the fact that there are aspects of health and well-being that can, or could, be developed from whatever point one starts in life, whether as a wonderfully healthy baby or as somebody who has already gone through a lot of life crises ; health promotion is concerned with enabling people to maximize their health potential and move ahead."

Health promotion strategies include :

- enabling actions;
- 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.

Yet, 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. This is the real challenge facing the persons themselves, their families and social network, the caregivers — both professional and lay — and the various institutions concerned : in the community, at the workplace, in the medical and social services.

There is an urgent need therefore to critically assess the experience and knowledge available, in line with the Ottawa Charter urging the examination of current concepts and practices and the development and implementation of new approaches.

The three following sections highlight key points presented in the plenary session papers and the background documents on the three chronic illness groups selected for study by the conference.

5.

Chronic pain conditions : a new understanding

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. A more differentiated approach to pain conditions has led to a clearer division between two phenomena : acute and chronic pain. This awareness, unfortunately, has remained limited to a small group of experts.

The term "chronic pain patient" applies to people for whom the experience of pain — chronic headaches, low back pain, rheumatic pain, reflex disturbances, neuralgias, etc. — has become a central focus of their lives. 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 social learning process. Others yet see in chronic pain the incapacity of the individual to confront change and to grow.

The most common error made by clinicians is to treat only the physical aspect of the problem — as if they were dealing with acute pain.

The objective should be to treat "the person" and to understand the ultimate message of the pain which is a signal that "something is wrong". In this perspective, several approaches to treatment have been developed, based on psycho-behavioural therapeutic strategies, alternative approaches to break "the pain career" of the patient, and, last but not least, to promote new attitudes to pain and adequate social support.

Experience shows that chronic pain patients are often able to activate their potential for a better quality of life, provided they receive adequate professional and environmental support.

5.1 What is chronic pain ?

The distinction between acute and chronic pain is of central importance not only for diagnosis and therapy, both medical and psychological, but also for the attitudes and expectations of all those concerned¹.

Long lasting pain is very often accompanied by depressive symptoms such as sleep disorders, lack of appetite, loss of libido, irritability, diminishing interests, loss of contact with friends and relatives and an increasing preoccupation with the pain symptoms. The experience of pain frequently becomes detached from the initial or continuously underlying physical cause and results in the "rupture of the most natural of all unities, the unity of our personal and our physical being".

Clinically, pain is regarded as chronic when lasting half a year or longer. The process of chronification of pain varies greatly. It may be caused by inadequate treatment, as in the case of acute herpes zoster leading to therapy resistance; or it may be perpetuated by the treatment itself, as in the case of iatrogenous headaches (caused, for instance, by the use of a combination of drugs); these headaches may disappear entirely or largely after drug withdrawal. On the other hand, tension headaches continue to be chronic until their individual etiology has been found and a preventive strategy can be applied, e.g. through conflict and stress management.

Pain requiring permanent treatment, such as tumour pain, is also called chronic, even if it can be relieved successfully. Pain may also chronify because of mental and social conditions, for instance if tensions exist or if the patient avoids exercise following an accident. When attention is focused on pain, it tends to worsen and to suppress healthy activities; pain may continue even after recovery from a lesion if the patient is rewarded by secondary gains from illness; it may as well persist for a long time as a conversion syndrome in the sense of hysteric pain or as an exhaustion syndrome following permanent overtaxation.

The heterogeneity of pain states with respect to their etiology, their phenomenology and their resulting stress makes it difficult to arrive at a standardized definition of chronic pain, especially with a view to its impact on the quality of life of the patient.

¹ Seemann, Hanne (1987). *Health promotion and chronic illness: chronic pain. On the situation of pain patients in the health care system — deficits and proposals for change.* Summary of the background document for the International Symposium on Health Promotion and Chronic Illness. Federal Centre for Health Education, Cologne.

5.2 Incidence of pain and role of lifestyle factors

The first representative study on the incidence of pain was carried out in the USA and is reported in the Nuprin Pain Report¹. The report identifies pain as a major health problem: 10 to 12 per cent of all patients of general practitioners, internal specialists and neurologists suffer from chronic pain, the figure being roughly 30 per cent for orthopedists. *The Nuprin Pain Report* reveals some obvious correlations between pain and lifestyle factors, such as sports, smoking, alcohol consumption, TV watching, etc.; however, linking cause and effect proves difficult.

Concerning the impact of pain on work activities, it appears that women, patients with poor education or low income and those experiencing a lot of "daily life stress" feel most restricted. On the other hand, individuals with an "internal health locus of control" are less disrupted in their daily life and their work activities. Back pain, joint pain, headaches and muscle pain are the major cause for absenteeism. There is an obvious and linear-related connection between pain intensity and the amount of stress factors; this applies to all types of pain. When patients are asked to identify causes on a subjective basis, stress stands out as the main cause.

5.3 Treatment of chronic pain : from traditional to innovative methods

The Nuprin Pain Report states that all patients reporting severe pain and 88 per cent of those occasionally suffering from pain call on the facilities provided by the health care system. Proceeding on the assumption that chronic pain should be treated by a doctor, it may be assumed that reliance on medical care is comparably extensive in other countries.

Generally, the primary port of call for chronic pain patients is the general practitioner who is seldom in a position to deal with those 10 per cent of his chronic pain patients with advanced chronification and whose pain has become therapy resistant. Chronic pain very often transgresses the boundaries of a single medical speciality. Interdisciplinary diagnosis by a pain council or a pain conference has proved to be much more adequate; in this approach, different specialists try to reach a comprehensive understanding of the particular pain problem, in cooperation with the patient who provides a subjective view of his ailments.

¹ Tailor, H. and Curran, N. M. (1985), *The Nuprin Report*. Study NS 851017. Louis Harris & Associates Inc., New York.

A large number of pain patients are problem cases, needing treatment in special pain units ; most of these patients can receive treatment as outpatients. "Classical" somatic pain therapy techniques (drugs, local and conduction anesthesia, peridural opiate application, neuroleptic nerve blocks, physical therapy) still predominate although some "alternative" procedures start to be applied, mainly transcutaneous electrical nerve stimulation (TENS) and acupuncture.

In the field of psycho-behavioural therapy, the trend is towards a multidimensional approach, intervening at different levels of the pain experience. Thus, relaxation methods (primarily progressive muscle relaxation according to Jacobson) are increasingly combined with guided imagery techniques, bio-feedback, diversion of attention by (hypnotic) focusing and defocusing methods, alteration of pain and stress related cognitions, alteration of the pain behaviour and of the emotional state of the patient.

There is a growing consensus on the value of a holistic approach in pain therapy based on Lerner's model for integral cancer therapy¹. The focus is on treating the person suffering from pain and not just the pain syndrome. It stresses the patient's autonomy in selecting and carrying out diagnostic and therapeutic steps. Holistic therapy is centred on the individual : it respects his belief system and his personality and takes into consideration the characteristics of the patient's personal world and lifestyle.

An integral pain therapy may start at different levels, i.e. at the physical, mental, cognitive, motivational, religious or spiritual level, and considers as well the social and ecological environments. Since its methodological range should be as broad as possible, the spectrum of therapy must perforce cover several levels.

It has been found useful to start at the point where the patient stands, i.e. to make use of what the patient thinks about the pain and its cause, how he expects to be helped and what he is willing to accept. The level where healing takes place often differs from the level at which therapy has initially been directed.

Rehabilitation of chronic pain patients should not focus only on regaining fitness to work ; it should recognize that other aspects such as relationships, recreational activities and enjoyment are important for the quality of life and beneficial to health.

¹ Lerner, Michael, and Remen, R.N. (1985). Varieties of integral cancer therapies; *Advances* 2 (3): 14-33.

5.4 The role of the therapist

A certain amount of fatalism is not uncommon among therapists facing severe states of pain: "I cannot do more for you, you just have to live with it !" Such an attitude provokes resignation and helplessness and results in a deterioration of the patient's condition. Every therapist should be able to show the patient how to live with incurable pain, using psycho-behavioural techniques which have proven effective in pain therapy and can help the patient to control the pain himself. Often the patient is resigned and passive, sometimes aggressive. If the therapist succeeds in meeting him in a warmhearted, hopeful and encouraging manner, he may stimulate those parts of his personality that are still positive and strengthen them.

A key question that must be asked by the therapist is : Why does this person have this pain at this time ? No healing is possible unless the therapist comes to understand what the illness represents in the external and inner world of the patient. Is it a transition ? Is it a link between two periods of life or a crisis ? Is it the sum total of conscious experiences ? The perception and processing of pain can only be understood on the basis of the individual history of the patient. Pain has a specific significance in relation to patterns of life.

No less important is the perception that therapists have of their role. They should no longer see themselves solely in a curative role but rather as companions and advisers to their patients in helping them cope with difficult life circumstances. This will require additional training in advisory functions for doctors and psychologists as well as for nurses in the medical or caring sectors and for social workers confronted with the practical problems of pain patients¹.

5.5 The role of the patient

It is most important that the patient comes to understand that pain is influenced in many cases by psychic factors. He/she then becomes aware of the possibility to reduce pain without medical means, by learning to analyze the pain condition and to interpret its meaning and its function as a warmer and internal advisor. Furthermore, the patient should realize that whether or not a sensation is painful depends upon the way it is interpreted. It is possible to have significant pain and yet not suffer. "It hurts but it doesn't bother me": such attitude represents a state of enhanced tolerance. The critical difference is

¹ Alten, Rieke and Lafaille, Robert (1987). *Pain and chronic pain in medical training programmes*. Background paper for the International Symposium on Health Promotion and Chronic Illness. Federal Centre for Health Education, Cologne.

in the manner of perceiving the pain experience: "How you view the world determines how you experience it."¹

Since pain basically conveys the message that "something is wrong" the patient must be aware that his best long-term interests are not served when the major goal of the treatment is to artificially mask or suppress his pain without attempting to understand its ultimate message. The patient must therefore closely collaborate with the therapist in determining why the pain arises. Only then can the self-healing power available in each person be mobilized and the patient participate in the healing process. Support and understanding from the social environment greatly facilitates such an alteration.

Chronically ill patients need more than symptomatic help. They require overlapping concepts to understand their affection and give them the courage to alter many areas of their life. Often such alterations involve a shift to positive lifestyles rather than risk-avoidance behaviour. Bresler expresses this convincingly: "In practising 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."

5.6 Health promotion oriented projects

Experiments cited by Seeman in the background document as well as those presented in plenary sessions, in the working groups and at the Bazaar (see annex 1) highlighted innovative efforts based on the health promotion concept. These efforts have three main goals in common, namely:

- raising the competence of the individual and his social environment in developing coping strategies and improving his/her quality of life;
- using a holistic approach in tackling pain conditions and broadening the views of the medical, health and social work professions;
- providing social and environmental conditions conducive to healthy lifestyles and involving all the sectors concerned.

¹ Bresler, David E. (1987). *Health promotion and chronic pain: challenges and choices*. Background paper for the International Symposium on Health Promotion and Chronic Illness. Federal Centre for Health Education, Cologne.

These attempts represent an encouraging step forward. But much remains to be done (and on many fronts) to enable people suffering from chronic pain to maximize their health potential.

5.7 Areas for action and research

Participants in the Expert Preparatory Meeting held in Berlin on chronic pain conditions¹ indicated a need for action on three levels:

- a) enlighten the public on recent advances in our understanding of pain, including the role of mental or emotional processes, of lifestyles and of the self-potential for change; promote a different attitude to chronic pain and illness;
- b) modify the outlook of the medical, health and social work professions: inform medical and other health and social workers, as well as students, of recent findings regarding the physiology and bio-chemistry of pain, the role of the immunologic system, and the influence of psychological factors and of the social environment; training programmes should aim to reorient professional thinking on chronic disease and pain and change attitudes;
- c) develop adequate models based on the health promotion concept and 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.

For their part, members of the working group which discussed at Bad Honnef the problem of health promotion for chronic pain patients felt that adequate steps for improving treatment facilities and enhancing the lay potential should be grounded on reliable empirical data. Hence, they emphasized the need for research and specifically recommended:

- a) to 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) to promote studies of cross-cultural and historical aspects of pain perception and attitudes towards pain;
- c) to collect information about the multiplicity of determinants of the pain experience in order to enhance a psycho-social-biological view of the problem;

¹ *Report on an expert preparatory meeting on chronic pain conditions*, 3-5 December 1986, Berlin (West). Federal Centre for Health Education, Cologne.

- d) to provide information to help patients find the treatment facilities they need;
- e) to enhance self-help activities making use of experiences carried among already existing groups (e.g. for patients with rheumatic diseases);
- f) to provide encouragement and financial support for complementary pain therapies and thus help reduce the patients' dependence on the biomedical system.

5.8 Concluding remarks

The Berlin and Bad Honnef meetings have served to highlight a number of key points:

- 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 all have a decisive influence on chronic pain conditions.
- Above all, it is important to encourage the persons concerned to make full use of their health potential and of their capacity for active participation, and also to help them become familiar with existing possibilities for action leading to effective change.
- Some factors, however, lie beyond the ability of the individual to promote change; such is the case for the quality of foodstuff, their composition and processing, and their availability and affordability which can have considerable influence on chronic pain conditions; migraine or rheumatic pain, for instance, may be indications of foodstuff and/or chemical environmental incompatibilities: such observations reinforce the need for health promotion which involves many sectors.

Recent findings and experiences clearly show that pain is part of life. It has a meaning. A life without pain would be a bad utopia. Pain itself does not make life unbearable. It is our lifestyle which makes the pain unbearable, and also our attitude to pain. Chronic pain conditions are essentially a subjective phenomenon. This knowledge, together with recent findings regarding the physiology and biochemistry of pain, as well as discoveries in the field of psycho-neuro-immunology, open up wide avenues for hope. This message must be widely shared with professional circles and the lay public.

6.

Cancers : towards innovative health promotion approaches

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 patients¹. 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 per cent among those patients achieve exceptional results, another 10 per cent fail, and 80 per cent 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 behavioural 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 "healing". Healing is defined as a process that overlaps with being cured, yet is distinct¹. A cure is generally understood as an external medical intervention that eliminates the disease process in the patient. Healing by contrast is a process emerging from the inner resources of the individual. It refers to a psycho-biological process of becoming whole, which can take place at physical, mental, emotional and spiritual levels. There is a growing consensus that psychological healing may sometimes stimulate physical healing.

¹ Lerner, Michael (1987). *Exceptional cancer patients as an emerging force in cancer therapy and care; their use of complementary cancer therapies and the search for personal strategies of intensive health promotion*. Background paper for the International Symposium on Health Promotion and Chronic Illness. Federal Centre for Health Education, Cologne.

6.1 A complex subject and a tenuous knowledge base

Health promotion among cancer patients is extremely difficult due, first of all, to the complexity of the subject and, secondly, to the current state of the art regarding effective programmes of medical and behavioural intervention. In addition, health promotion involves not only the cancer patient but also his medical, professional and lay caregivers, i.e. his/her family and natural social support system. The latter frequently experience the "burned-out" syndrome and are also be in need of supportive interventions if they are to be effective providers of socio-emotional support.

Over the last few years, health promotion has been at the heart of discussions in international and European forums of professionals and lay people working in the emerging field of psychosocial oncology. The aim of these groups is to promote physical, psychological and social well-being among tumour patients, in particular in the major target groups of individuals surviving cancer due to curative therapies and having to adjust to a "life with cancer". These forums have focused on two goals of health promotion: one is concerned with effective coping and the quality of life, and the other with possibilities of influencing the clinical course of disease by innovative, holistic approaches in behavioural intervention¹.

Complexity of the subject — Cancer is a complex subject due to the fact that 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. Some cancers have a good prospect of being "cured", whereas for others only palliative modes of therapy are currently available and diagnosis entails a massive threat to physical existence. Some neoplastic diseases are most prevalent in a particular age group, either in childhood or early adulthood, at middle age, or among the elderly. The problems and concerns, as well as the need for psychosocial supportive programmes, may therefore vary considerably from one target age group to the next. Sociodemographic characteristics, sex, and the psychosocial situation of the particular patient define requirements within the various target groups. For this reason, the needs of tumour patients for health promotion intervention strategies can be described in a multidimensional scheme along the following axes:

- the curative/palliative therapy dimension ;
- the childhood to old age dimension ; and
- the dimension of changing needs during the "cancer patient career" from diagnosis to long-term adjustment.

¹ Waltz, Millard (1987). *Health promotion following cancer*. Background document for the International Symposium on Health Promotion and Chronic Illness. Federal Centre for Health Education, Cologne.

State of the art — The needs of cancer patients and their lay/professional caregivers are gradually being recognized, but relatively little is known about the kind of behavioural interventions which might be effective in achieving the twofold goal of health promotion.

Psychosocial oncology is still in an exploratory phase of development but cancer-specific models of support are slowly evolving as our relevant knowledge base becomes broader. Hunches, speculative thinking, and a paucity of hard data constitute currently the tenuous knowledge base available for guiding the development of behavioural interventions. The emerging field of psycho-neuro-immunology and allied disciplines may provide a more adequate body of bio-psycho-social knowledge in the near future.

There is, for example, a behavioural research literature demonstrating that acute stress causes immunosuppression and facilitates rapid tumour growth in animals. The accumulated data for humans, although not so extensively documented, are similar and suggest that acute stressors result in immunosuppression or tumour facilitation in humans. 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.

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 may directly influence the mobilization of the organism's anti-tumour resources, e.g. elements of the immune system such as NK cells. Clinical experience, as well as empirical research guided by the bio-psycho-social paradigm, are supportive of this type of speculative thinking and corresponding intervention. One innovative research design with mammary carcinoma 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.

Similarly, characteristics of the Type-C behaviour pattern — which includes repression of negative cognitions and affect, a lack of emotional outlet, disturbed interpersonal relations and feelings of low personal worth and self-efficacy — have been shown to predict differences in survival in studies of patients with malignant melanoma and mammary carcinoma. Just as in cardiac rehabilitation, programmes geared to altering a pathological style of coping with stress, i. e. the Type-C pattern, could constitute an important aspect of health promotion with regard to the quality of life and physical health. It is speculated at present that the Type-C pattern is a psycho-physiological pattern of response to environmental conditions or demands, possibly linked to adverse patterns of neuro-immuno-modulation. Solomon has termed it an *immunosuppressive* personality pattern. At the physiological level, it may be

related to *hyperadaptosis* to chronic stress and increased risk of developing neoplasia, as well as an unfavourable clinical course of disease.

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 tumour growth in humans in clinical practice. Other studies indicate that relaxation, imagery, and hypnosis can diminish nausea, vomiting, fatigue, insomnia, and eating problems related to cancer and cancer treatment. Behavioural techniques have also been reported to diminish anxiety and pain, reduce recovery time after surgery, and greatly improve quality of life and the experience of death. The striking fact is that these accessible mind-body techniques, which offer such great potential to improve the human experience of cancer, are still undervalued and underused in cancer treatment and cancer care.

6.2 New approaches to cancer care focused on health promotion

Although we know too little about the causes of cancer or about the influence of behavioural factors in the clinical course of the different malignant tumours, many oncological centres and lay groups of former patients in the USA and various European countries are developing innovative programmes for coming to terms with the manifold problems triggered off by a diagnosis of cancer and its medical treatment.

There are literally hundreds of self-help groups, support organizations and health centres for 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 centres with an orientation towards self-help and towards the kind of care many cancer patients seek out.

Psychosocial intervention projects are being tried out at numerous cancer centres in Europe, aimed both at the general needs of patients and at specific problems, such as psychosexual functioning or social reintegration on the job. The following projects were cited by Waltz in the background document as examples of health promotion models which appear promising for future developments of the field:

- the Berlin (West) model, a comprehensive programme of short- and long-term psychosocial supports, both stationary and ambulatory, using a variety of psychotherapeutic approaches, involving therapists and cancer mutual help groups;

- mutual help groups for the parents of childhood cancer patients in Bonn, Federal Republic of Germany ;
- psychotherapy for the psychosexual problems of gynecological patients at the Leiden University Clinic in the Netherlands ;
- return to work after cancer: findings from a pilot study in the Weser-Ems Tumour Centre in the Federal Republic of Germany, and the intervention programme which the Regional Tumour Centre in Besançon, France, has developed ;
- lay visitor programmes: effectiveness and problems ; the example of the ILCO mutual help groups ;
- initiation and promotion of mutual help groups in a rural area of the north-western region of the Federal Republic of Germany with deficits in after-care ;
- supervision and development of effective intervention programmes for oncological social workers in the Netherlands.

During the Symposium, other examples of innovative efforts based on the health promotion concept were cited. Special mention should be made of:

- the Bristol Cancer Help Centre in England, an adjunctive cancer therapy centre that vigorously utilizes nutritional, psychological, and spiritual support for cancer patients in an integrated programme ;
- the Lukas Klinik in Switzerland, an anthroposophical hospital which makes use of all established medical therapies for cancer together with a wide range of remedies from the European naturopathic tradition ; art, movement and other approaches to creative expression are given a key role in the treatment ;
- the Cancer Patients Foundation in Australia, a thriving self-help group for exceptional cancer patients that is by no means hostile to conventional therapies, but places strong emphasis on psychological, nutritional, spiritual and alternative immunotherapies ;
- the Wellness Community in Santa Monica, California, one of the largest and most successful of the autonomous cancer self-help centres, which offers a wide range of classes and activities for people who are suffering from cancer ;
- the Commonweal, a small institute in California which conducts cancer help programmes focusing on stress reduction, health education and group support for cancer patients and their families ; these programmes take the form of retreats and provide an intense inner experience that enhances the self-healing potential of patients.

Finally, the development in the USA of a National Coalition for Cancer Survivorship is significant. The group focuses primarily on psychological and social issues but seeks also to identify cancer survivors as a group with common interests and perspectives, and reflects the growing power of the cancer self-help movement.

6.3 Emergence of a social movement among cancer patients

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 emerged. In many parts of the world, what can be described as a social movement among "exceptional cancer patients" who engage actively in the fight for recovery and a better quality of life, has been growing larger with every passing year. 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 — integration of the best of conventional and complementary therapies — in the coming years.

Lerner¹, who has extensively studied complementary cancer therapies, found no "cure" for cancer among these therapies and little scientific evidence on which to evaluate them; 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 immunomodulating approaches to supporting the general health of the cancer patient.

It is important to distinguish among the various components of complementary cancer therapies. These include:

- use of psychological approaches such as counselling, imagery, relaxation and meditation to improve quality of life, help control pain, diminish side-effects of conventional therapies, or lower resistance to medical treatment;
 - use of psychological approaches with the objective of affecting the course of the illness and extending life;
 - use of improved general health practices — diet, exercise, recreation, positive thinking — both for quality of life and, some would argue, for possible life extension;
 - application of special programmes proposed by schools of intensive health promotion that make claims for life extension with cancer, e.g. the macrobiotic diet, the life change programme, the Gerson therapy and the wheat-grass and raw food diet;
- use of approaches that derive from well established "traditional medicine", i.e. acupuncture, naturopathic medicine and homeopathy;

¹ Lerner, Michael (1987). *Exceptional cancer patients as an emerging force in cancer therapy and care; their use of complementary cancer therapies and the search for personal strategies of intensive health promotion*. Background paper for the International Symposium on Health Promotion and Chronic Illness. Federal Centre for Health Education, Cologne.

- use of some secret or indecipherably complex or esoteric component that results in the therapy being partially closed to the possibility of ready scientific evaluation.

An analysis of complementary cancer therapies shows that many of them are, in part or in whole, systems of intensive health promotion, i.e. they represent a multimodal approach to enhancing physical, mental, emotional and spiritual well-being tailored to the specific needs, beliefs, goals, preferences and psycho-physiological responses of the individual.

The dictum that "it is more important to know what kind of patient has the disease than what kind of disease has the patient" is most relevant with regard to cancer.

The complementary therapies that can be considered systems of health promotion aim to change the psycho-biological milieu that was favourable to the growth of cancer through 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. Their goal is to strengthen the general immune function, morale, vitality and other host resilience factors.

Many cancer researchers and clinicians now believe that specific cancers may develop in different patients by different pathways. If this is the case, it may be that a specific type of intensive health promotion may have markedly different effects for similar cancers with different etiologies. 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 also creates great difficulties.

In summary, 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.

6.4 Target groups, goals and priorities of health promotion

Health promotion in the field of cancer is concerned with three target groups:

- a) patients with a favourable physical prognosis ;
- b) patients in the terminal stage ; and
- c) caregivers, i.e. on the one hand, medical oncologists and cancer nurses, social workers and therapists, and on the other hand, the family and the natural support network of the patient.

With regard to the first two groups, the major goal of health promotion is to enhance the quality of life, defined as social and psychological well-being. In addition, and most important for patients with a favourable prognosis, health promotion aims to mobilize their biological resources in order to enhance physical health and possibilities of survival.

The most pressing problems facing health promotion in cancer are the need :

- a) to explore the use of holistic approaches in attempting to find cures for malignant diseases for which only palliative modes of treatment are available;
- b) to develop medical and behavioural interventions for tackling the problem of metastasizing tumours at the time of surgery.

Reports from various European countries highlight unmet needs as well as areas in which behavioural intervention programmes are most promising. Among patient target groups, important deficits are found at the time of diagnosis; prior to surgical treatment; and in relation to long-term needs of ambulatory patients (ca. 2-10 years after diagnosis). Innovative programmes appear at present to be best geared to meeting patient needs in the hospital setting at the time of surgery and adjuvant treatment, and at the terminal stage.

As regards caregivers, major deficits concern the lack of psychosocial programmes for medical and psychosocial professionals, e.g. supervision, Balint groups, etc. In addition, supportive programmes for the parents, spouses, and elder children of cancer patients in various age groups seem necessary in respect to the provision of information, support and the maintenance of the mental and physical health of the lay caregiver.

Table I lists the current needs for behavioural intervention measures among various target groups and provides a starting point for health promotion.

TABLE I. A MULTIDIMENSIONAL SCHEME OF TARGET GROUPS FOR HEALTH PROMOTION IN COMPREHENSIVE CANCER REHABILITATION

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 tumours	XX	X	X

6.5 Areas for action and research

A large number of areas for action and research were identified by members of the working group which discussed problems related to cancer. They stressed in particular the need 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 programmes in different countries including an evaluation of their effectiveness;
- study and explore, clinically and in everyday practice, intensive health programmes 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;
- develop people's coping and communication skills, according to cultural differences and needs; this is especially important for key persons in the patients' network and community, and also for children, in order to make them less vulnerable;
- promote the involvement of the patient in the decision-making process;
- introduce psychosocial and behavioural oncology in the medical curriculum.

These recommendations are in addition to those proposed by Waltz as a conclusion to his background study. These call for:

- allocating sufficient human and financial resources for developing comprehensive short-, medium-, and long-range systems of professional and self-help strategies for supporting tumour patients from the point of diagnosis onwards;
- creating awareness of the central role of the workplace and of social reintegration in cancer rehabilitation;
- developing strategies for an effective transfer of knowledge — i.e. clinical experience from promising projects and the latest research findings from bio-behavioural cancer research — to the many target groups of users for whom this knowledge is essential;
- increasing funding to basic and applied research on (a) the links between behavioural factors and tumor-related biological processes (e.g. psychoneuro-immunology) and (b) the effectiveness of behavioural interventions (quality of life, impact on the effectiveness of medical therapies, risk of metastasizing, survival as outcomes);
- promoting further extension of the patient-to-patient and self-help movements;
- using a wide variety of media to disseminate knowledge about the needs of cancer patients and how to meet these needs;

- providing adequate support to health care providers through group sessions (e.g. Balint groups) and self-help groups, and programmes focused on supervision and emotional support, etc.;
- developing measures to decrease pressure on the family as principal caregivers of cancer patients at home, especially terminal cases, through the provision of tangible supports including housework services, community nurses, the opportunity for leisure and vacation for tanking up psychologically, as well as information and emotional support programmes.

6.6 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 centres" have transformed hospital birth practices over the past decade, powerful consumer interest in humane cancer care might result in the integration of innovative strategies of health promotion and promising complementary cancer therapies with the best of efficacious conventional cancer treatment.

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

7.

Recovery from heart attack : focus on self-reliance, self-help and self-determination

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 programmes 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.

7.1 Rehabilitation : the quality of life comes first

Rehabilitation of patients with cardiovascular diseases covers, according to WHO "the sum of activities required to ensure the best possible physical, mental and social conditions for patients, so that they may, by their own efforts, resume as normal a place as possible in the life of the community"¹. This concept emphasizes the importance of aiming not only towards the

¹ WHO Regional Office for Europe (1969). *The rehabilitation of patients with cardiovascular diseases*. Report on a Seminar. WHO, Copenhagen.

reduction of risk factors, morbidity, mortality and the reintegration into the working process, but of focusing on the quality of life of the affected person, considered as the all-important factor in the rehabilitation process¹.

The ideas on the concept of health promotion for the chronically ill are still in their infancy and are not, as yet, integrated in medical practice. Two questions arise here: (a) in what areas is it possible to achieve qualitative changes within the existing structures and (b) should new approaches replace or supplement old ones.

Causation and development of myocardial infarction — As somatic risk factors could explain only a small proportion of the variance of coronary heart diseases, the concept has been enlarged to psychological and social variables, including social mobility, social incongruence, work stress, psychological stress and fear, depression, sleep difficulties, and Type A behaviour. There seems to be a correlation between work overload, chronic conflict situations and socio-structural variables such as social mobility, migration, level of education and number of life events, and the risk of developing an illness.

There are still very controversial ideas, however, to be found in literature on the causation and development of coronary diseases and both areas require further clarification.

7.2 Coping with the illness

Coping has been defined as the way people deal with stress, that is with situations or events that they perceive as threat or loss². The concept of coping relates the social to the psychological process, and it relates the psychological process to physiology and behaviour. *Social support* is supposed to either reduce the level of stress or to enable people to better cope with it. Its main functions are :

1. to prevent cognitive disintegration or enable people to regain a "sense of coherence"³ ;
2. to help overcome negative emotions and to promote positive ones ;
3. to keep or to regain a self-concept that is realistic, stable and positive.

¹ Döhner, Hanneli, and Gorres, Stephen (1987). *Health promotion and chronic illness: the situation following myocardial infarction*. Background document for the International Symposium on Health Promotion and Chronic Illness. Federal Centre for Health Education, Cologne.

² Lazarus, R.S. (1987). *Coping with the stresses of illness*. Background paper for the International Symposium on Health Promotion and Chronic Illness. Federal Centre for Health Education, Cologne.

³ Antonovsky, A. (1979). *Health, stress, and coping*. San Francisco, Jossey-Bass.

Sources of social support may be found in social networks and interpersonal processes, religion, socially defined and culturally accepted roles which structure our daily activities.

There are several factors which justify attention being directed not only to causation and development but also to coping with illness: (a) the number of myocardial infarction survivors has steeply increased; (b) patients are confronted with mental and social consequences which entail even more difficult problems than the infarction; (c) there is widespread uncertainty in how to handle these problems on the part of all concerned: patients and family, medical care institutions, the competent social insurance institutions and health policy makers.

The stress experienced by the patient, such as fears, ignorance, uncertainty, adjusting to change, disturbances in family and working life and problems with the institutionalized care, etc. all have a bearing on the recovery process. In fact Badura¹ identifies three key factors as having a major effect on recovery:

- *self-reliance*, which is influenced by (a) early mobilization as clearly proven by experience, and (b) the counselling behaviour of the physician (provision of accurate information, open discussion, etc.);
- *self-help*, which is influenced by the involvement of the social network of the patient and participation in outpatient heart groups (physical exercise and interaction);
- *self-determination*, i.e. opportunity for the patients to decide on the course of their convalescence as well as on their resuming their work activity; experience shows that the work status of the patient has a tremendous effect on his/her life.

The effectiveness of the treatment does not, therefore, just depend on the quality of medical measures, but also on the provision of emotional support, of adequate information and advice and on how successfully the patient's psychic strength and social support potential is promoted. Alongside institutional support, a major role evolves to the social environment of the patient (mutual help and promotion of self-help) in facilitating the coping process.

The following section reviews current procedures used in the rehabilitation of heart patients as presented in the background study prepared by Döhner and Gorres² for the Symposium.

¹ Badura, Bernard (1987). *Effecting institutional change in health promotion of heart patients*. Background paper for the International Symposium on Health Promotion and Chronic Illness. Federal Centre for Health Education, Cologne.

² See reference N° 1, page 34.

7.3 Rehabilitation following a myocardial infarction

The approach used in the Federal Republic of Germany will be discussed and compared with the situation in other countries.

In the Federal Republic of Germany, the rehabilitation system is organized along the lines of a "therapy chain". The programme of treatment is oriented towards the WHO phases I to III — acute phase, convalescence phase, and late rehabilitation phase — and is available, in principle, to all patients. The therapy chain provides for initial treatment in the acute care hospital, followed by treatment in a rehabilitation clinic and further treatment from the general practitioner. The patient is then urged to join an outpatient heart group near his home.

While the claim to "comprehensive rehabilitation" has been formulated in terms of a concept, in practice the medical aspect often strongly dominates in all three phases. Psychosocial aspects are no doubt taken into consideration to an increasing extent in the care of a patient but these are rather considered as an appendage to the current practice. Instead, they should be treated as an integral part of the process in the sense of a holistic approach characterized by flexibility and orientation towards the particular situation and requirements of the individual patient.

WHO phase I : the acute phase

In the Federal Republic of Germany this phase involves a stay in an acute care hospital which usually begins with treatment in the intensive care unit. Patients spend a very long time there in comparison to other countries and, also in contrast to most other countries, the treatment is followed by continued hospitalization in a rehabilitation clinic.

It has not been proven that the extension of the acute phase is useful for recovery nor that it reduces the mortality or the risk of repeated infarction. On the contrary, the Oldenburg Longitudinal Study¹ gives evidence of possible iatrogenic damage.

Different approaches are currently the object of controversial discussion. Views differ as to which of the following solutions would be best:

- to keep the stay in the acute care hospital as short as possible in order to be able to refer the patient to a rehabilitation clinic at an early date;

¹ Badura, Bernard, Kaufhold, G., Lehmann, H., Pfaff, H., Schott, T., and Waltz, M. (1987). *Living with a myocardial infarction*. A social epidemiological study, Berlin, Heidelberg, New York, London, Paris, Tokyo.

- to equip the acute care hospital in such a way that the rehabilitation can be carried out there, thus rendering a specialized rehabilitation clinic unnecessary, at least for some of the patients (example : Israel);
- to structure the outpatient care in such a way that the stay in hospital can be completely avoided for many patients; a point in favour of this solution is that the emotional support of the patient and an adequate supply of information and advice including members of the family or friends could be better realized through treatment and rehabilitation near home.

The provision of adequate care in the acute phase poses several questions :

1. Is the stay in the acute care hospital, and in particular in the intensive care unit, necessary and appropriate for all patients suffering from a myocardial infarction ?
2. For whom and under which conditions can, or should, the hospital stay be shortened ?
3. How can emotional support, adequate information and advice be guaranteed in the acute care hospital ?
4. How can the convalescence phase, or rather the final treatment, be planned and prepared as early as possible in the acute phase in order to take into account individual needs and requirements ?

WHO phase II : convalescence

A variety of approaches are used in different countries. In the Federal Republic of Germany, this phase is characterized by a wide offer of specialized rehabilitation facilities for inpatients. Current practice tends, however, to provide solutions which do not involve a stay in hospital and are near to home. Innovative aspects include:

- family-oriented group therapy for patients and members of the family at the acute care hospital (example: Israel);
- outpatient rehabilitation with group therapy at the local cardiologist (example: Berlin (West));
- cooperation between local doctor and rehabilitation adviser or social worker (example: practice in the rural district near Ulm, Federal Republic of Germany);
- outpatient rehabilitation within the framework of the medical and social services already existing in the community (example: Finland).

The following questions arise with regard to the convalescence phase:

1. In which cases is hospitalized rehabilitation indicated and when can it be replaced by outpatient care and by which forms of such care ? Which role would the local doctor assume in this case ?
2. To what extent and in what form should the mental and psychosocial aspects of coping be covered in addition to the somatic aspect of treatment ?

3. How can the patient himself and his social environment (family, friends etc.) be included to a greater extent in decisions relating to the process of rehabilitation ?

WHO phase III : late rehabilitation

The concept of the "therapy chain" in the Federal Republic of Germany provides for further care by the general practitioner and participation in outpatient heart groups. There are now approximately 1200 such groups throughout the country. The main criticism of these outpatient groups is their strong performance orientation and their neglect of the psychosocial problems which are very important for the affected person.

Of particular interest are the following projects which provide supplementary or alternative forms of support :

- company heart groups for current or former employees of a company (example: Texaco) ;
- discussion groups within outpatient heart groups (example : heart group in Hamburg, Federal Republic of Germany) ;
- self-help groups (examples: three different initiatives in the Federal Republic of Germany and "Take Heart" in England) ;
- support for self-help provided to CVD patients by a team including a former heart patient and a professional person (example: reintegration through "duos" in the Netherlands).

These models raise a number of questions :

1. To what extent does the former heart patient need the medical system and when is it more appropriate to encourage independent solutions of health promotion ?
2. Which solutions best support the gradual move away from the hospital ?
3. Is it appropriate and possible to change outpatient heart groups so that psychosocial aspects be given greater emphasis ?
4. Should the offer of heart groups be integrated into everyday life ?
5. Why are self-help groups better established in certain countries, like the USA and Great Britain, than in the Federal Republic of Germany for instance ?
6. Should more efforts be made to promote self-help initiatives and if so how and by whom ?

7.4 A model of health promotion : the Munich Health Park

A model which is not related to a specific illness but is concerned with the promotion of health at all stages of life (including the post myocardial infarction stage) deserves special mention. It is the Health Park in Munich.

The principle behind this model is the integration of the healthy and the sick in activities to maintain health or promote rehabilitation.

The many possibilities offered by the Health Park make it easier for patients suffering from a myocardial infarction to participate in a broad range of activities which focus on self-expression, body movement and creative, pleasurable experiences. The specific group activities developed for heart patients include movement, relaxation and discussion. Simultaneously, members of the family can take part in other programmes.

The success of the model is due to the high quality of the staff, good interdisciplinary cooperation, and the significance attached to the individual competence of participants, their individual requirements and the importance of providing differentiated advice. The Health Park reflects an approach which enhances possibilities for chronically ill persons to maximize their health potential. An illness-specific path is pursued only as far as necessary and the person is integrated into the overall programme of health promotion in good time.

7.5 Areas for action and research

The working group which discussed the question "How can health be promoted among coronary heart patients?" broadened the subject to include patients with angina pectoris and those recovering from a bypass operation or a dilatation. Participants recommended that steps be taken to:

- promote innovative health promotion models for coronary patients as well as controlled studies to evaluate and compare these models and determine to what extent they 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; poor integration of psychological and sociological concepts in the medical care;
- avoid long stays of heart infarction patients in the acute care hospital as experience show such stays to have iatrogenous effects;
- promote an effective exchange of information between the various institutions in the health system in order to minimize feelings of insecurity and superfluous diagnostic procedures;
- take steps towards the systematic involvement of the family and other social resources of the patient;
- ensure that professional competence (bio-psycho-social) is available in self-help groups;
- promote greater involvement of the health care system with the community and with employers to improve knowledge of pathological and protective factors in the community and at the workplace (ample socio-epidemiological evidence exists but with little practical consequences for patients);

- give more weight to the anamnesis, in view of the significance of social and psychological factors in heart diseases;
- create awareness of the major impact of lifestyle changes on the progress and prognosis of coronary heart diseases;
- start health promotion activities before people become ill and focus on factors which favour the slow development of coronary heart disease, including social pressure in "meritocratic" societies and inequity in the distribution of resources (being socially underprivileged increases the risk of illness);
- strongly encourage various social groups, the community and industry to become more involved in health promotion, and families to assume more responsibility for their members; individuals and groups will then reach a stage where they can develop their own ideas about dealing with health and illness and thereby become less dependent on the medical system.

7.6 Concluding remarks

Existing institutions and models must be analyzed in the perspective of health promotion to determine to what extent they (a) emphasize the independence of the persons undergoing rehabilitative treatment, (b) strengthen their self-reliance, and (c) give patients a partnership role in the process of rehabilitation.

Are these institutions able to consider patients otherwise than as cases with somatic symptoms and instead develop ways to motivate them, to activate their social environment and to integrate family members, friends, work colleagues and self-help groups into the process of rehabilitation ?

The models and projects reviewed in the background document indicate *possibilities for change within the relatively rigid system of medical and health care*. This is an important finding. Efforts must therefore continue in order that structures may become more permeable and supportive services may be developed on a wide and flexible basis to ensure effective participation at all levels. The quality of life of a patient should be the guiding principle of rehabilitation measures.

8.

Challenges facing individuals and groups

The challenges concern the chronically ill persons themselves, their families, self-help groups, the work milieu and the community. They also concern the medical care system and the sectors whose responsibility it is to develop training programmes for the medical, health and social work professions.

Point 1 in this section examines the process of coping from the viewpoint of the individual while points 2, 3 and 4 present the views of the three working groups which discussed the family and self-help groups, the workplace and the community, and medical care. These reports are followed by reflections on training, research needs, and the concept of the "healthy ill person".

8.1 The chronically ill persons

Enhancing people's capacity to cope effectively with chronic conditions represents a major challenge, both for those with disabilities and for health care providers.

Lazarus and Folkman¹ define coping as constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. Each illness has its own unique source of psychological stress (harm, threat, challenge), and shares some with other illnesses.

There are great differences between individuals in the appraisal of the meaning of the illness: e.g. challenge, fate, punishment, self-blame, etc. These lead to different coping processes. 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.

¹ Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal and coping*. Springer, New York.

Eight ways of coping may be distinguished : *confrontive coping* (e.g. stood my ground and fought for what I wanted), *distancing* (e.g. went on as if nothing had happened); *self-control* (e.g. 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); *escape-avoidance* (e.g. wished the situation would go away or somehow be over with); *planful problem-solving* (e.g. I knew what had to be done, so I doubled my efforts to make things work); and *positive reappraisal* (e.g. found new faith).

These ways of coping comprise variations of the two basic functions of coping: (a) *problem-focused coping* which consists of efforts to change the actual circumstances of an adaptational encounter, for example, by changing the environment or oneself; and (b) *emotion-focused coping* which involves purely cognitive activities that do not directly alter the actual relationship with the environment but do alter how this relationship is cognized. Most people use nearly all eight forms of coping in every stressful encounter. Although some forms of coping might be generally functional or dysfunctional, any given coping process may have favourable or unfavourable results depending on who uses it, when it is used, under which circumstances, and with respect to which adaptational outcome. Coping becomes inappropriate when the approach used is disconnected with reality, for example, persisting in problem-focused coping when there is nothing to be done.

The motto of Alcoholics Anonymous, which states: "God grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference" provides a very clear distinction between problem- and emotion-focused coping, the principle of secondary appraisal, and reality-testing.

Interventions to help a person with chronic illness develop effective coping strategies require careful assessment of the appraisal and coping variables for each patient, taking into account personal agendas, illness and prognosis, life stage, and other personal circumstances.

8.2 Families and self-help groups

The Ottawa Charter clearly indicates the core role of families and self-help groups in health promotion of the chronically ill. The Canadian framework for health promotion identifies three key mechanisms to address the challenges of coping with disabilities. These are: self-care, mutual aid, and healthy environments.

Terminological discussions about the definition of the family, self-help groups and other helping networks seem unnecessary at this point. The terms should

be flexible enough to refer to people who do care, in their everyday lives, for the chronically ill. These groups 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 (SHGs) and the like. However, in most contacts there is no systematically organized or coordinated effort to support people with chronic illness or their families.

The potential contribution of professionals is exemplified by several experiences. Clinical work with cancer patients in Berlin (West) shows the crucial role of health professionals in encouraging people to have an active involvement with alternative sources of information and support, symbolized in the advice: "Stay away from hospital as long as you do not really need it". Another example, the Sonnenberg Clinics, Federal Republic of Germany, highlights various strategies of interface between lay and professional involvement in the after-care of cancer patients. In this model, there is a two-way interaction between the clinical staff and the lay public: on the one hand, congresses are organized for and by patients and their families, joined by their helping professionals; on the other hand, training programmes have been provided for patients to enable them to start their own SHGs in the community settings where they live. Still another model from Maastricht, Netherlands, explores the perspectives of teaching self-care and self-help techniques within clinical settings using the principle of a balanced process of mutual teaching and learning between lay people and professionals.

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. SHGs 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 per cent of expressed needs in the total population as opposed to 2-3 per cent 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 SHGs 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 reinforce 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 people afflicted by chronic diseases. SHGs 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 SHGs and/or other forms of community support.

Priority areas for action

1. At the *public policy* level, there is a strong need for a more equitable distribution of financial, technological and other social resources between the professional and the lay sectors concerned with health promotion for

people with chronic disease and their families. There is an urgent need to complement policies for community living with chronic disease by policies to support the carers.

2. Regarding *reorientation of health services*, there is a need to increase systematic professional support to families and SHGs in health promotion using the following main strategies :
 - initiating self-help and self-care activities by transferring professional knowledge and skills according to needs ;
 - creating accessible and appropriate professional support systems for families and SHGs actively involved in health promotion ;
 - educating the professional helpers concerned (nurses, social workers, etc.) in maintaining continuous support for families and SHGs in their health promoting activities without endangering the self-reliance and independence of patients.
3. At the level of *community action*, there is a strong need to facilitate social learning processes in health promotion for chronically ill and disabled people by using the following complementary strategies :
 - making people aware of the accessibility of alternative forms of health promotion in their immediate settings ;
 - setting up accessible and effective networks of information by using contemporary technologies of mass communication and making available existing materials ;
 - fostering the capacities of community services in helping families and SHGs in health promotion.
4. At the level of *personal skill development*, there is a need to provide families and members of SHGs with accessible and effective technologies for learning and applying techniques and skills of health promotion according (a) to their needs and preferences and (b) to the changing body of scientific knowledge on the treatment and care of persons with specific chronic diseases. This approach to skill development must be holistic while reflecting the specific problems associated with different conditions.
5. At the level of *environmental changes* conducive to health promotion, there remains a need to integrate disabled persons, their families and support systems with the rest of the society by supporting them in creating healthy environments both for themselves and the communities to which they belong. Changing social attitudes towards people with chronic illness and their families is a priority area. Any kind of strategy for creating separate environments which would isolate the chronically ill (such as building special houses) would be counter productive to the basic aims of health promotion as a common social goal.

8.3 The workplace and the community

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 multifaceted 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, counselling, 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.

Health promotion in the company — In addition to occupational health services, companies should set up special health promotion groups to facilitate both occupational rehabilitation of the chronically ill and general health 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 programmes 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.

Models for financial support — Regulations and mechanisms for financing health promotion at the workplace are needed. These should involve all the groups concerned in sharing expenses. Cost estimates for a comprehensive system of health promotion, health care and rehabilitation are needed. If the social cost of chronic illness and disability is taken into account, such a model is likely to be cost-effective.

Health policy — Implementation requires a coherent health policy directed at health promotion and health care. In addition, an appropriate social policy is necessary, including laws and regulations, to help create employment for the chronically ill and the disabled.

Priority areas for action

1. Work is highly important for the chronically ill person who should have the option of being part of the working community.
2. Because of the growing population with chronic illnesses, there is a serious need to develop special programmes for the less skilled and low-income groups of society.
3. New modes of financing health support for the chronically ill and health promotion in general should include several parties, e.g. employers as well as health insurance, the community and trade unions.
4. Public health policy and appropriate social policy together with suitable health laws and regulations should be conducive to the introduction of programmes and measures that integrate rehabilitation and health promotion.
5. Companies need encouragement and support to consider and adopt health promotion programmes at the workplace which would integrate help and services for the chronically ill.
6. Such programmes should include opportunities for counselling, education and training for self-help and mutual aid, and for assessing the impact of working conditions on health.
7. Ideally, health promotion programmes at the workplace should be integral elements of health promotion programmes in the community.

8.4 The medical care system

The issue of reorienting health services, in particular for the chronically ill, cannot be examined in isolation: creating supportive environments and strengthening community action are just as vital for dealing with chronic illness.

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 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 centre 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.

Priority areas for action

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 health centre concept.

8.5 Reorienting the training of medical, health and social work professions

Throughout the plenary sessions and working groups as well as in discussions at the Bazaar, the all-important problem of adequately trained personnel, able to bring in a new focus on health promotion, was constantly brought up.

Many questions were raised : What knowledge and skills need to be transferred ? At which point of the training process should these skills be taught ? Do we need short or long training programmes or both ? How can the life experience of students receive adequate attention in the curriculum ? What coverage should be sought in terms both of professional disciplines and of numbers ?

Training needs cut across the three groups of chronic illnesses on the agenda of the Symposium. These needs are on two levels: (a) adequate knowledge of latest 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.

To be meaningful, the health promotion approach 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", 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.¹

Effective interventions demand careful listening to the patient to discover 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 patient's emotional life.

8.6 Focusing research on factors of health promotion

In previous sections of the report, specific needs for studies and research in the field of chronic pain, cancer and myocardial infarction were discussed. Some of the research needs common to the three groups of illnesses are summarized below:

A broader vision is needed in research; the participants favoured the encouragement of interdisciplinary research into the contribution of different approaches to health promotion, including the biomedical and the holistic. The documentation of the experience of living with chronic illness is unsatisfactory, however, and research must still determine the common

¹ Rijke, Rudy, P.C. and Rijke-deVries, Pohanna (1987). *Health promotion for health care professionals*. International Symposium on Health Promotion and Chronic Illness, Federal Centre for Health Education, Cologne.

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 programmes 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.

8.7 Maximizing the health potential : the "healthy ill person"

The notion of a "healthy ill person" is an outcome of the health promotion concept which focuses on developing the health potential that exists in each individual at whatever stage of life.¹

Who are the healthy ill persons ? Those who accept all medical and therapeutic advice without question? Those who make health their sole life objective ? Those who carefully avoid risk situations ? Rather, it would seem that the main characteristic of the healthy ill is the search for new qualities of individual health, independent of the specific form of illness. This search is oriented towards the training of physical perception, relaxation and new kinetic possibilities, diet alterations and psychotherapeutic aids leading to a new understanding of the individual experience and the socio-ecological environment. The person moves from the "acceptance willingness" and "acceptance ability" of a specific illness to the "alteration willingness" and "alteration ability" stage, leading to a new self-perception and new forms of self-realization.

Adapting successfully to chronic illness means finding 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.

It must be recognized, however, that the degree to which a patient can become a "healthy ill person" is definitely influenced by his/her socio-economic situation and by the degree of social and political support that the "healthy", as

¹ Miltz, Helmut (1987). *Healthy ill persons : social cynicism or new perspectives for living with a chronic disease ?* Background paper for the International Symposium on Health Promotion and Chronic Illness. Federal Centre for Health Education, Cologne.

a society, allow that person to receive. Here, the five key elements of health promotion take on their full meaning. The extent to which a person *with, despite or because* of a chronic illness can develop a new quality of health is determined by action at all five levels of health promotion: building a healthy public policy, creating supportive environments, strengthening community action, developing personal skills, and re-orienting health services.

The healing process requires the development of new relationships on a variety of levels. At each level, health promotion opens new health opportunities for the chronically ill, helping them to develop their health potential and to become "healthy ill persons".

9.

Recommendations

Implications for health promotion planning and action of the facts and trends discussed during the Symposium, including the working groups' recommendations, resulted in specific goals being identified in each of the five areas of health promotion:

- First, *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 programmes 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.

- Second, *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 programmes for less skilled workers;
 - encourage and support businesses in developing health promotion programmes in the workplace for people living with chronic illness; and
 - promote support for caregivers, both professional and lay, through programmes 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).

- Third, *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 (such as the "duo approach", in which professionals and ex-patients team up) 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 programme of leisure and creative activities, which promote the health of healthy people as well as of those living with chronic illness).

- Fourth, *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 the needs and preferences of people with chronic illness, the changing body of scientific knowledge on treating and caring for people with specific chronic diseases and 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.

- Fifth, *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 centres serving a defined geographic area, family-oriented group therapy at such centres, 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.

In addition, participants stressed the need for action at the international level and urged that concerted efforts be undertaken, with the advice and/or support of WHO/EURO, with regard to :

- a) the constant exchange of experience and knowledge begun at the Bad Honnef Symposium and which is indispensable to identify successful strategies for dealing with chronic illness;
- b) the creation of a centre of holistic medicine, a sort of "think bank" where studies could be carried out and stimulated;
- c) the development, by a group of experienced psychologists, psychotherapists and ex-patients, of a course for doctors, nurses and other professionals on the psychosocial processes relating to chronic conditions;
- d) the broadening of the cancer programme in European countries to include psychosocial aspects;
- e) the establishment of an international network of pain researchers working within the holistic paradigm.

Thus, participants put on the agenda for action a number of important issues that now need to be taken forward.

10.

Conclusion

The Symposium took place in a context of growing clinical and scientific awareness of the value of health promotion in the approach to chronic illness. The following extracts from the statement adopted by participants at the closing session clearly reflects this :

"Health promotion, as formulated in the Ottawa Charter, offers opportunities for new, broad based, health oriented actions. With respect to chronic illness, it is directed against the stigmatization and social disadvantage experienced by the people affected...

"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 and of their support networks...

"The symposium brought evidence of the fact that a large number of experiences, a body of knowledge and concerted strategies are already available. Lessons from the practical applications of current health promotion methods must be made available to people with a chronic illness, the experts concerned and the general public...

"For people who live with a chronic condition and for those who support them, 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, reduce their anxieties and facilitate a meaningful life."

Indeed, the Bad Honnef meeting ended with a message of hope. In simple words it said this :

Yes, people who suffered a heart attack have the capacity to become fully reintegrated into normal life.

Yes, many people with a cancer have the potential for becoming "healthy" cancer patients.

Yes, people may have pain, yet not suffer and enjoy a full life.

By stressing the potential of each individual to grow throughout life, to move ahead, health promotion opens new perspectives for living with a chronic condition and being a "healthy ill person".

For health care providers as well, the Symposium opened new perspectives in showing clearly the important roles they have :

- in *enabling* people to cope effectively with chronic illness ;
- in *mediating* between them and all the sectors of society concerned: the governments, the industry, the voluntary organizations, the media, to name a few ; and
- in *advocating* effective health and social measures to improve the quality of life of people living with a chronic condition and of those who support them.

"Policy makers and professionals engaged in health promotion must further develop strategies together with people living with chronic illness and clearly commit the necessary resources to implement these strategies in practice." Such was the closing appeal of the Bad Honnef International Symposium on Health Promotion and Chronic Illness which stands as a privileged event in the continuum of planned efforts undertaken by the WHO Regional Office for Europe and its member countries to develop effective strategies for health promotion, based on caring, holism and ecology.

"Health", says the Ottawa Charter, "is created and lived by people within the settings of their everyday life : where they *learn, work, play and love*". This is no less real for people with a chronic illness. The challenge is to respond to their needs and to enhance their capacity to achieve their health potential to the fullest.

The Bazaar - a focal point for the exchange of experience

A special feature of the International Symposium on Health Promotion and Chronic Illness was the Bazaar, an oriental market place where 24 innovative projects were presented by participants and invited groups.

The Bazaar was also the stage of informal presentations followed by discussions on such topics as : what is pain; coping with the shock of cancer diagnosis; coping with cancer illness; a rheumatic patient's career; long-term follow-up care of patients with rheumatic illnesses and dysfunction of the auto-immune system; and the programme of activities of the Munich Health Park to restore and maintain physical health, develop social relationships, and gain a broad understanding of health.

1. Some of the projects dealt with creating a supportive environment, as for instance :

Returning to work after cancer - This important determinant of the quality of life represents a neglected problem area. Results of a pilot study at the Weser-Ems Tumour Centre (Federal Republic of Germany) and of a rehabilitation programme at Besançon (France).

2. Other projects focused on strengthening community action :

"Take heart" - This support group offers opportunities for heart patients and their partners to meet and share doubts, anxieties, successes and recovery. Members gain confidence, feel less isolated and are able to face the future more positively (Chesterfield, Great Britain).

The Altona heart model - This is one of the very few self-help groups established specifically for people following a myocardial infarction. The group provides emotional and social care for myocardial infarction patients and their families (Hamburg, Federal Republic of Germany).

Mutual help groups for the parents of children with cancer - Members of a parents' self-help initiative report on their experiences (Hamburg, Federal Republic of Germany).

Cancer self-help in rural areas - An advice centre promotes cancer self-help groups for patients and their families in rural areas with deficits in after-care (Northern region of the Federal Republic of Germany).

Layman's help for cancer cases - The German ILCO programme : visiting service in hospitals, mutual help and advice, cooperation with physicians and nurses (Cologne, Federal Republic of Germany).

3. Many presentations in the stands concerned the development of personal skills :

Awareness, expression and art experience - Art therapy and related methods provide useful tools for self-exploration. They allow deeper understanding of the symptoms and support processes of integration. The exhibition included paintings on increased breathing (rebirthing) ; symptom paintings and clay-modelling (case studies) ; and masks : the hidden side outside. The demonstrations enabled participants to practise two approaches to self-discovery : clay exploring and clay modelling (Hamburg, Federal Republic of Germany).

Gynaecological cancers : the quality of life of survivors - Does survival mean that the emotional problems disappear ? To what extent might the physical loss of female functions influence the survivors' lives ? Do partner relationships and sexual behaviour change ? Reports of the experience of a psychotherapist (Leiden, Netherlands).

Psychotherapeutic pain treatment through neuro-linguistic programming (NLP) methods - When creating tailor-made relaxation methods and individual pain processing strategies the intervention patterns of NLP can be developed on the basis of existing "fakir strategies" so that the patient suffering from pain can selectively use the system (Hamburg, Federal Republic of Germany).

Helping migraine sufferers with a psycho-physiological therapy programme - A multi-dimensional approach to interrupt the conditional structure of migraine pain at various levels. The patient's competence for self-treatment is promoted with three treatment elements : stress coping, relaxation and vaso constriction training (Bochum, Federal Republic of Germany).

Enabling chronic polyarthritis patients to cope with pain - Concept and first results of courses to help rheumatic sufferers to cope with pain (the Schleswig-Holstein League against Rheumatism).

Cancerlink - This nation-wide organization provides in Great Britain an information service for cancer patients and their families as well as for medical

personnel. It coordinates and supports self-help groups, offers training courses for group members and leaders, and helps in the foundation of new groups (A service throughout Great Britain).

4. Most of the projects focused, however, on the problem of reorienting health services, including training, and presented innovative approaches :

A new role for public health services - A "Healthy City" Health Department sets the trend. Programmes are reported in the "Bremen health guide", "Help for cancer patients", and "Promotion catalogue - the unemployed" (Federal Republic of Germany).

Maintaining the identity and freedom of the patient in everyday hospital life - A different organizational and social structure in hospital care. New approaches in handling the chronically ill (The Herdecke Charitable Hospital, Federal Republic of Germany).

Psychological treatment in medical practice - Successful cooperation with family physicians in training patients to cope with pain through a standardized treatment programme involving Jacobson relaxation and imagery techniques.

Interdisciplinary approach to pain - Problematic, therapy-resistant patients suffering from pain are examined in open groups of clinical specialists. An internationally successful approach to help people suffering from chronic pain (Frankfurt, Federal Republic of Germany).

Reintegration with "duos" : a self-care programme following myocardial infarction - A model of cooperation between patients, ex-patients and professionals to help myocardial patients reduce feelings of anxiety, stress and isolation and to facilitate integration (Maastricht, Netherlands).

Reducing the risk of coronary heart disease - A new course at the Open University for primary health care workers to promote planned, coordinated action (Great Britain).

Holistic pain medicine - A holistically-oriented concept of diagnosis and therapy including complementary therapies based on the maxim : "Including subjective awareness may reduce and avoid additional symptoms." (Bad Nauheim, FRG)

"Burnout" : health promotion for health professionals - Many health care providers, in particular those working with the chronically ill,

experience the "burnout" syndrome : they complain that there is no sense to their work and that they are overworked. An interdisciplinary training programme helps professionals to cope with their problems and those of their patients along "healthier" lines (Rotterdam, Netherlands).

"Support for the supporters" - Training and supervision for social workers in oncological care. A support programme that provides information and emotional support (Eindhoven, Netherlands).

Health care : architecture focusing on people - Building with a holistic health concept in mind : the Habichtswald clinic model. (Kassel, Federal Republic of Germany).

5. Finally, some presentations covered broad, general subjects :

Maharashi Ayurveda - Ayurveda, the "science of life", claims to be the oldest complete science of human health. It is based on a dynamic concept of man and the unity between spirit, soul, body and environment. Ayurveda encompasses recommendations on lifestyles, spiritual exercises, basic prophylaxis and therapeutic applications to restore the psychological balance.

Health promotion and chronic illness - what is happening in Canada? - A national programme, with examples of projects structured according to the principles of health promotion and dealing with subjects along the lines of the Ottawa Charter.

Note : On request, the Federal Centre for Health Education will be pleased to provide the names and addresses of persons to contact for further information on the above projects.

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