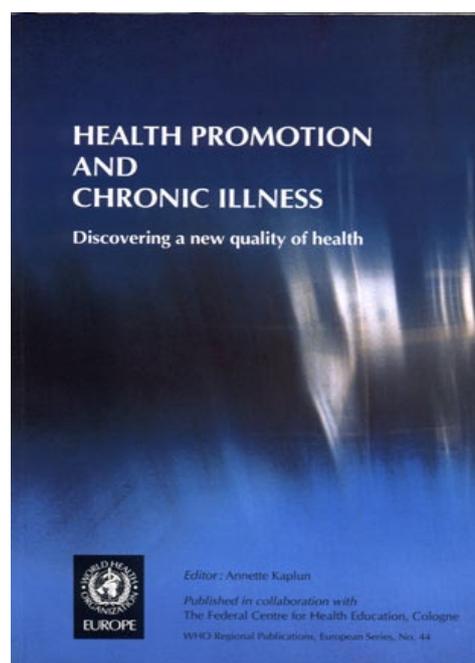


„HEALTHY ILL PEOPLE“: SOCIAL CYNICISM OR NEW PERSPECTIVES?

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

[Alan Watts]

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

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

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

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

All chronic illnesses can give rise to considerable conflicts with respect to one’s body image. While physiotherapy may be helpful, it is far from being sufficient. New ways of training, such as the improvement of sensory-motor body perception, seem to be vitally necessary for concrete health promotion with the chronically ill. In this respect, several exemplary teaching models have been developed in recent years. I will cite the Feldenkrais method (Feldenkrais. 1978), the Eutony method developed by Gerda Alexander (1976) and the work of Mathias Alexander (Barlow, 1981). In comparison to medical, social and psychological measures teaching possibilities of a body-related nature have been all too neglected in the past.

What is a „healthy ill person“?

Against what yardstick can such persons be measured ? What standards are we prepared to accept ? How are we to judge these persons and what entitles us to form such a judgment ?

After having overcome a serious illness Nietzsche (1886) wrote:

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

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

People who suffer from chronic illness often wonder to what extent they are the „perpetrators and victims „ of their present situation. Ways to cope with an illness can be very different, as Lazarus clearly demonstrates (see article p. 11). Which is the „right“ - or „correct“ way to become a „healthy ill“?

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

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

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

Components of effective support

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

All these studies may very well provide us with important knowledge and help in decision-making. Could they not show us the „right“ way of providing the kind of support needed to promote the health of sick people? In a critical summary of epidemiological studies available, Kasl (1983) reaches the conclusion that, up to the present, there have hardly been any systematic or comprehensive research attempts to investigate the influence of psychosocial factors on the progress of specific illnesses. With a few other studies available, the one presented by Badura and his colleagues on myocardial infarction has set the standard for the future (Badura et al, 1987; see also article, p. 73).

If we want to help support and widen health-promoting lifestyles as well as existing potentialities in a person, we must try to investigate the complex real-life situation of that person, including social and ecological interrelationships. Only then might it be possible to offer a useful mediation to help solve the frequent conflicts resulting from the divergent inner logic of organic, mental and social processes and show that „healthy ways of living „ are mainly the result of personally coming to terms with the contradictions of daily life. On this last point, Horn (1983) has remarked: „Where decisions about one's life are, by and large, geared to the relatively short-term safeguarding of one's existence, for reasons of lesser job security, for instance, or less years spent in education, it is not reasonable to expect that, in the health sphere behaviour oriented towards the future will be developed.“

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

- the physical and physiochemical level (disease);

- the psychological, subjectively perceived level (illness);
- the psychosociocultural level (illness as a socially defined role, with leg and insurance dimensions).

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

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

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

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

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

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

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

Starting from where the person stands

As Gibson (1982) points out, an ecological observation of perception processes shows that perception always aims to comprehend action-related differences. Bateson (1980) similarly underlines the fact that information arises from the perception of differences which receive their significance only in their respective and specific context. Information about differences alters the form and manner of our perception structure, and leads to new forms of enquiry into one's own physical and psychological existence and, consequently, to a modified pattern of selection and reception of new information (Neisser, 1979).

Memory, experience, emotion and mood control perceptive processes within an ordered framework. Thereby, depending on the situation, they influence our understanding of action-related information. What can such findings, and other findings from perception research, teach us with regard to joint efforts to support the health of persons with a chronic illness ?

McGuire (1983) has investigated possible key elements of self-healing processes and comes to the conclusion that the form of information we provide must be oriented towards the „language“ of the persons concerned in order to help them develop their

self-healing potential. If we include not only words but also the behaviour and actions of a person under the term „language“, then our efforts to support the chronically ill must begin in the respective environment and take into consideration the fact that: the ability of „language“ to promote an altered perception of the arrangement of an event depends on the degree of congruence between the „language“ used in providing the information and the context of the „language“ of the persons concerned; the understanding of one’s own potential of influence is decisive for improvement (from external dependence to inner participation and personal action).

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

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

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

Towards new forms of self-realization

All the papers in this book illustrate common approaches in the search for new quality of individual health, independent of the specific form of illness. Often, these approaches focus on the training of body awareness, relaxation and new possibilities for physical exercise. They also stress ways of developing inner awareness with the aid of various therapeutic techniques leading to a new appreciation of individual experience and of the socio-ecological environment. They indicate that parallel to a „willingness to accept“ and an „ability to accept“ a specific illness, the „willingness to change“ and the „ability to change“ in terms of the whole person stand in the forefront.

For the „healthy ill person“, these approaches appear to me as striving towards new forms of self-realization via new self-awareness.

Can we now answer the question: What is a „healthy ill person“? Is it the person who follows all the well-intentioned advice to promote health which is given at all levels by the „experts“? Will he thereby be caused to suffer new stresses or harm on prescription? Or, is it someone who, as a result of illness, makes „health“ his sole life objective? To what extent will he perhaps become incapable of consciously taking risks and dealing with risk situations ?

Are „experts“ able to show those affected reliable ways of becoming a „healthy ill person“ ? To what extent are we, the „experts“, programming and introducing new dependencies and how many spontaneous learning processes do we thereby prevent?

Or is, perhaps, a „healthy ill person“ the one who accepts all medical and therapeutic treatments without questioning their merit and complies with them to the full? How many opportunities for personal initiatives are thereby lost and to what degree is the mobilization of the existing self-healing potential reduced?

This paper has to be understood in terms of stimulation for debate, as a contribution to a necessary discussion over possible ways towards joint support. The term “healthy ill person“ may even awaken in the minds of some people an association with a hypochondriac (is illness only a matter of the “mind”; of the psyche and of individual attitudes?).

Health promotion: an integrated concept leading towards new health

Health promotion, within the terms of the WHO Ottawa Charter, sees its central tasks in enabling, mediating and advocating the health of the individual and his social community. Furthermore, health should neither be standardized nor prescribed. The term „healthy ill person“ can stand for a new life perspective for those affected, but it can also be misused in a chauvinistic and paternalistic manner. Some may decide they do not want to be healthy again - for reasons related to their individual life situation or due to perceived environmental threats which may be either personal or collective in origin. Such a decision can represent a legitimate, personally satisfying response and therefore a „healthy“ approach to one’s illness.

Health promotion, if it is to become a humane strategy beyond any social cynicism, must recognize and respect such decisions and accept that the shadow“ may be „ the embodiment of the un-lived and a full part of life” (Dürkheim, 1984).

For his part, the individual stands solitary, face to face with the task of finding a lifestyle compatible with his illness, in his particular world. For him, there is no general guideline and the process he will follow can never be identically repeated.

„Healthy ill people“ are those seeking a new way of living. Health promotion, as it is conceived in the Ottawa Charter, represents a social, ecological and holistic concept. „Taking care“ of each other is an essential constituent of this concept. Health promotion is no new form of medical treatment. It is rather an outline for a combined approach to health that aims to enable all persons, whether ill or not, to have greater control over their health and its enhancement.

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

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

The healing process is the development of new relationships at a variety of levels. It presupposes the recognition of the sickness and/or the illness by those who suffer. Health promotion is to be understood as a process contributing, at all social levels, to the opening-up of new health opportunities and supporting people in their efforts.

„Healthy ill people „... Is it Utopia? Or is it, in view of the millions who suffer from a chronic illness, an imperative, humanitarian necessity to which we must contribute with all available means at our disposal?

Finally, do we not find in the term „healthy ill person“ yet another indication that we are not ready to leave the arbitrary and dualistic view of health versus illness? Yet, the way is shown both by healers of many traditions and cultures, in accordance with their empirical experience, and by modern researchers such as Menninger, Mitscherlich, Dubos and Antonowsky as a consequence of their scientific work.

Perhaps then, the healthy-healthy, the ill-healthy, the healthy-ill and the ill-ill can come to a new alliance for a personal, social and ecological health expressing a continuous process of learning and gradual change, as well as of development and growth.