

Clinical concepts and dilemmas between disease and averse life events

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A visual model of general practice as a field of medicine is presented. Definitions of terminology and concepts to be used are discussed. By the application of this terminology a model of health, including the concept of disability, is constructed. This model is used to define and describe dilemmas occurring in daily work. Such dilemmas are frequent and their nature needs to be explored. They present an area in which psychosomatic medicine could meet with general practice, and vice versa.

Key terms disability, general practice, health models, psychosomatic medicine.

This presentation is about everyday life in medicine. I am a general practitioner (GP) in Norway, currently working at the University of Trondheim. During the past 2 years, I have been conducting two studies of the doctor's role in relation to medicine in the field of social security, in parallel with my work as a GP in a rural community. This combination of clinical practice and academic work has proved to be highly inspiring, experience from general practice influences my scientific work—and the academic challenge of the university enables me to see my work as a GP in a brighter light.

Why listen to the experience of general practitioners? The answer has been formulated by the Englishman Peter Toon. He says: "There are more general practitioners than any other type of doctor, and many more individual contacts with general practitioners than with other clinicians. The cumulative impact of the many decisions made by general practitioners is enormous, even if the difference each of them makes, is small" (1).

I am using this opportunity to highlight some very basic concepts and dilemmas. They are not new and not at all advanced. They may actually be too basic, too evident to be seen as a problem. I want to show

how this situation repeatedly leads the GP, the practicing clinician at the front line, into trouble. The resulting frustrations cast long shadows on the rest of the health care system.

The concepts and models I use to describe my dilemmas are made for practical purposes. The description of the true nature and mysteries of health would require wider perspectives.

One might ask why we need a practical clarification of the basics. I can think of three main reasons: in order to communicate within the profession of medicine, in order to think about our knowledge base and about medical science, and in order to communicate with other professions, and with bureaucrats and politicians. We might even need the concepts to improve the dialogue with our patients!

The traditional model of general practice

The "cake" model of general practice is presented in figure 1. This is one of the traditional models illustrating how general practice corresponds to the classical medical specialities practiced in the hospital.

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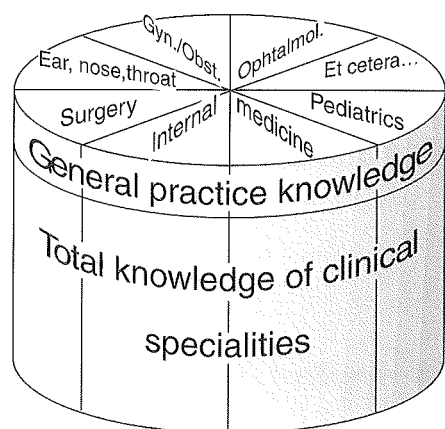


Figure 1. The traditional "cake" model of general practice.

General practice is thereby seen as the sum of internal medicine, pediatrics, obstetrics, and so on. When we look at such a model, it appears that the GP would know less than the corresponding specialist, no matter what the particular problem might be. However, I am convinced this model is wrong.

Figure 2 shows a modified model of the "cake" that I have made to express what I think general practice is all about. The sectors from the other medical disciplines are the same as in the first model, but note the emerging zone in the center. This zone is what makes general practice a particular area to specialize in, the very core of general practice. It is where biomedical medicine can best serve the individual human being, where qualitative knowledge about the individual can be integrated with knowledge developed in a strictly biomedical tradition. This is my frame of reference as a GP, and I will come back to this model at the end of this presentation.

Definition of concepts

I would first like to draw attention to a serious linguistic barrier involved in my topic. I start by defining three words that exist in everyday English, although not in this particular meaning. They represent nuances that have no counterpart in the Norwegian language.

Disease: a pathological process. Disease is an objective, naturally occurring entity that exists in the structure and function of organs. The individual "harbors" the disease. An example of serious disease is a brain tumor.

Illness: the bodily experience of suffering, a unique, subjective, individual feature. Nausea, headache and anxiety are examples of illness.

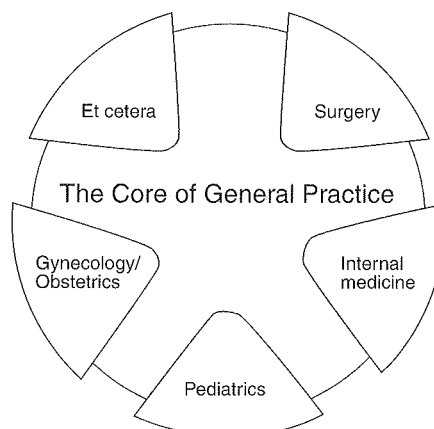


Figure 2. A revised model of general practice.

Sickness: the objective state of poor health, the person's behavior, limitations and reduction in functioning. An example is not going to work or refraining from social activities due to ill health.

Diagnosis: a recognizable entity, which might or might not correspond to a particular disease. Diseases occur naturally, whereas diagnoses are man-made.

Adverse life event: an unfavorable, contrary, hostile (*adverse*) happening, usually something important (*event*), according to the *Advanced Learner's Dictionary of English*.

Life change events

Now I will try to define an adverse life event as seen in relation to the neutral and more scientific term "life change event". Figure 3 shows a model of life change events, based upon my experience from general practice. Along the horizontal axis is the character of the event—more or less objectively characterized. To the right are the challenges, the entrances, the potential gains: A new job, a newborn child, moving to an interesting place are examples of gains. To the left are the losses. The death of a loved one, serious disease, destructive relationships, loss of job, and the like are examples of losses.

How will a particular event affect the individual? The vertical axis in figure 3 refers to a person's adaptation to the event. This response may vary from integration by personal growth and development to destruction. A recent personal report in the *British Medical Journal* pointed to the difference between survivors and victims.

The person's personal susceptibility and the social support from the environment are of major importance. In order to understand the effect of a life change event, three factors must be taken into account, the event itself,

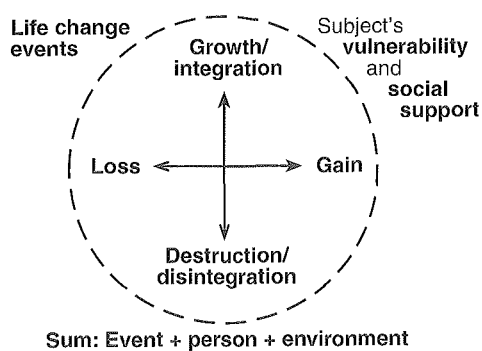


Figure 3. A model of life change events. Along the horizontal axis is the character of the event—more or less objectively characterized. To the right are the challenges, the entrances, the potential gains. The vertical axis refers to the individual's adaptation to the event.

the person undergoing the change, and the person's environment. Even though experiences can make some people grow, my clinical experience indicates that the sum or sequence of relatively minor events hitting the wrong person at the wrong time can lead to disintegration and ill health.

On the basis of this model, my working definition of an adverse life event is as follows. Caused by a constellation of the three factors—event, person and environment—an adverse life event leads to some degree of destruction or disintegration in the person experiencing it.

I am not focusing on how big the event must be or what events are adverse in themselves. "One man's meat is another man's poison". Rating scales for life change events have been constructed. I will not discuss them here. They are interesting as such, but add little to this picture.

What can be said about the evidence linking adverse life events to poor health? In my opinion, the evidence indicates a clear link. For example, take unemployment, an event that can be described as a loss to most people. Professor Steinar Westin at the Department of Community Medicine and General Practice in the University of Trondheim has summed up the literature, and I briefly report what he found regarding the health effects known to be causally related to unemployment (personal communication 1996).

Cardiovascular disease, mortality, psychological distress, and the "classical" psychosomatic disorders increase in the unemployed. Suicide rates rise. The use of alcohol and stimulants may or may not rise. Family conflicts become more frequent. As regards behavioral aspects—we see that the unemployed go more often to the doctor, they even end up in the hospital. They are at higher risk for sickness certification and disability pension.

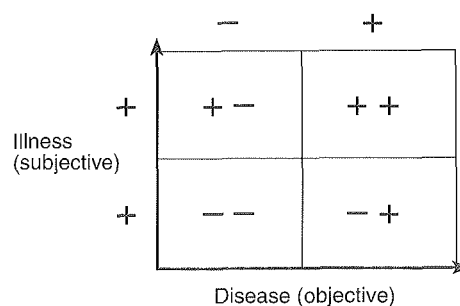


Figure 4. Intraindividual model of health. A sort of a two-by-two table to be read along two axes: disease—the pathological process—along the x-axis from zero to maximum; illness—the subjective discomfort—along the y-axis.

Models of normal and poor health

Let us turn to a typical situation in the doctor's office. Scene 1: I am in my office with a patient. Here is the start of our dialogue. D: "What can I do for you?" P: "You see, doctor, there must be something wrong with me, I want you to find out"

Without knowing it, I try to fit this patient into a mental map of the world of ill health. He is telling me that he has illness, his bodily experience is negative. My first question as a professional is—and is expected to be—does he have a disease? Cancer, for instance? This process is illustrated in figure 4, showing a basic two-dimensional model of poor health. Simplified, you either feel ill or you don't, you either have no disease or you have disease, and you may have any combination of the two.

What goes on in the clinician's head in this situation? I believe that adverse life events may present themselves through illness. Although this possibility was mentioned in my undergraduate training, the art of recognizing and diagnosing patients experiencing bodily responses to emotional strain was never taught. I do not know enough about the investigation and interpretation of illness in a psychosocial context to trust my own senses fully. Like most doctors, I therefore start by ruling out organic disease. Relying on intuition or belief that illness is not due to disease can be a risky business, because my actions will not be rooted in or supported by the medical tradition to which I belong.

It is not surprising to find that doctors end up with very different views and interpretations of their patients' bodily experiences. We are confronted with many enigmatic stories that have never been described in any textbook or medical journal. The GP has to learn to live with this situation. It can certainly be an interesting challenge, but it can also lead us to become too tolerant.

A British guru of general practice, John Howie, stated this opinion in the following manner: "The ability of general practitioners to tolerate uncertainty as a clinical skill seems somehow to have been carried too far" (2).

Here comes my first challenge to the experts: Help us to develop sound scientific knowledge about the patient experiencing illness but presenting little disease, when compared with his or her suffering. Can diagnostic strategies be developed? How can we learn to recognize life change events behind symptoms without exhausting our biomedical list of possible diagnoses?

My patient has not left my office yet. Here comes the ensuing clinical situation. Fifteen minutes have passed in this meeting between two experts—the doctor with her biomedical knowledge and the patient with knowledge about his own life and body. The doctor is rounding off her primary clinical investigation by saying: "We'll do some blood tests today. Come back in a week, and we'll carry on from there...." Then the patient says: "But anyway, I need a sickness certificate, and I want to apply for disability pension. I can't make it through the day at work anymore."

Situations like this give the doctor a sort of sinking feeling. Why? What has happened now? The patient's request has moved the whole situation out of the two-dimensional clinical model. The patient's statement is not about illness or disease alone. It is about a third dimension, that of sickness (figure 5).

The emerging model of ill health has three axes. Two dimensions are common to the previous model (figure 4) with disease, ischemic heart disease, as one example, and illness, "something feels wrong", be it chest pain or fatigue. These two axes define different but intraindividual entities, and they relate to the clinical situation.

A sickness certificate, however, is not a clinical issue. It is the result of politics, and it is governed by social security legislation. It regulates the person's right to refrain from job tasks given to him by society. Therefore, the third axis is not an individual dimension. It is relational, describing the interface between the patient and his surroundings.

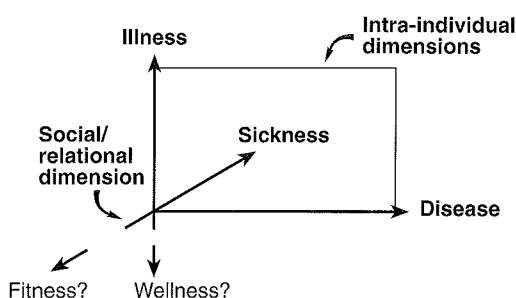


Figure 5. Dimensions of poor health—three-dimensional model.

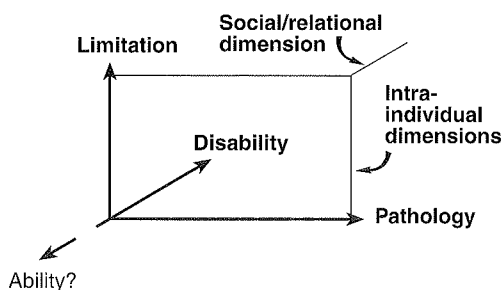


Figure 6. Dimensions of disability.

In this situation, the doctor is not a clinician, but rather a gate-keeper: "If you're healthy, you should go to work. If your health is sufficiently poor, you may enter the sick role, with its privileges and obligations". When we look at health in this three-dimensional model, the gate-keeper's role seems clear, even though difficult to practice. The patient not only asked for a sickness certificate, he wanted a disability pension. Let us therefore look at a model describing disability (figure 6). The terminology is to be found in an American paper in *Social Science and Medicine* from 1994 (3). Along the x-axis is the pathological process, corresponding to disease in figure 5. Along the second axis is the limitation experienced by the person, what he can or cannot do. Finally we come to disability that again is the relational feature, disability being defined as the gap between personal capability and environmental demand. The rationale behind the two theoretical models presented here is completely parallel.

Dimensions and models of disability

Now it is time to adjust to reality. I adjust to mine. You adjust to yours. In Norway one does not look upon or talk about health and disability in this way. This is

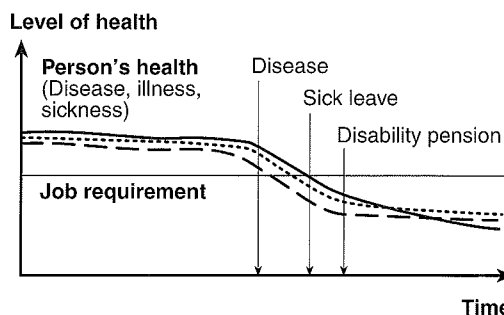


Figure 7. Medical model of disability (reference 4). The level of health required to perform the patient's job is represented by the thin straight unbroken line, disease by the broken line, illness by the dotted line, and sickness by the curved unbroken line.

where linguistics comes onto the scene: If someone is not well, we have one word to describe the situation: "Sykdom". We have no words to help us differentiate our thoughts in terms of disease, illness and sickness. Sykdom is still treated by many doctors and most bureaucrats as if it were an uncomplicated entity that can be quantified along one axis. In other words, the pathological process, the patient's experience and his functional disability are expected to vary together in a parallel manner as in the Norwegian model of disability presented in figure 7. Let us imagine a level of health sufficient for the patient to cope in daily life. As long as the three dimensions vary in harmony, the simple word "sykdom" will tell the tale. A man develops, for instance, severe rheumatoid arthritis. He experiences much pain, and after a while he is no longer able to work. He applies for disability pension. The three dimensions of health are affected in a parallel manner. The gate-keeper can relatively easily fit the occurrence into the medical model: "Sykdom"—objective pathology—is clearly the cause of disability.

But what actually happens in reality? Let us imagine the patient sitting in my office talking about disability pension. He is 60 years old, his back aches, he has constant headache, he feels worn out. But only minor defects can be found in him according to the biomedical model. However, he says he cannot work. The three dimensions of health are in disharmony (figure 8). Illness and sickness are major, but disease is minor. The doctor does not know how to handle the situation: the social security office demands pathology to be documented; the patient is sent from one clinical specialist to another. The GP has little choice but to listen to the patient and is left in the middle of the conflict.

This brings me to my second request, this time it is the gate-keeper's, not the clinician's. We need further theory and knowledge about the "disability gap". As a GP, both clinician and gate-keeper, I am confronted with this question so often that it has become of great interest to me. The welfare state that I live in adheres to

a model of health that does not want to see the depth and danger of this dilemma. This twilight zone between medicine and politics is loaded with preconceptions, but it seems to be a no-man's land from a scientific point of view. How can we explore and explain the disability gap? There is much evidence that the environmental syndrome is often associated with one or more psychiatric disorders, defined by criteria the *Diagnostic and Statistical Manual of Mental Disorders* (DSM). My question as a GP is then: Does this situation mean that the patient can be considered disabled?

In my presentation I have pointed out two common dilemmas occurring in the average GP's office. I have noted that our tools are inadequate and that there are severe limitations in our way of thinking and communicating about health and disability. I believe that this situation undermines the quality and fairness of care, and also the well-being of both the professional and the patient.

The GP is, as a result of patient turnover and his or her contact with people in the early phases of ill health, an important target if our wish is to implement change in the health care system. I therefore consider general practice to be among the most important targets when it comes to research in psychosomatic medicine. If the thinking and behavior of the GP can be changed, then health care as a whole can be changed.

An new model for general practice

I want to finish this presentation where I started, with my model of general practice (figure 9). In the center zone, the very core, lies the challenge for general practice, ie, to observe and understand the individual in his

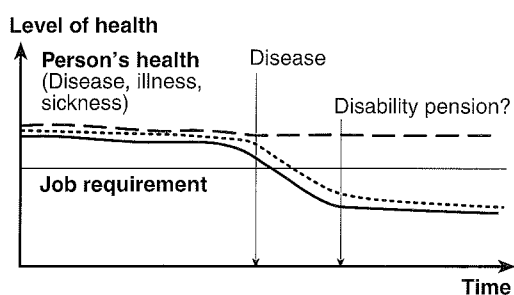


Figure 8. "Incongruent" model of disability (reference 4). The level of health required to perform the patient's job is represented by the thin straight unbroken line, disease by the broken line, illness by the dotted line, and sickness by the curved unbroken line.

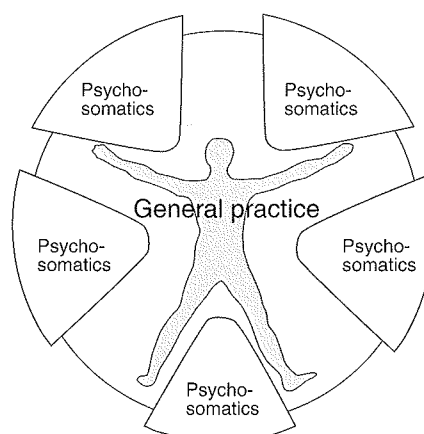


Figure 9. Model of general practice with the patient in the center.

or her context, in the jungle of life. This is also an area for genuine research in general practice.

Psychosomatic research does not have to be carried out in the middle of this jungle. One can select the phenomena one wants to study. I believe we have many interests in common and much experience to share. We should cooperate more. General practice can offer a contextual and relational perspective of health, which I believe is underdeveloped—in psychosomatic research, as in medical science as a whole. For instance, a general practitioner might be included in the reference group of a new research project.

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