



Notes for Experience-Based Medicine: The Disease Origins Permanent Biopsychosocial Changes in the Person

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Abstract

The experience of the disease has a complex structure where there is a biological and a psychosocial moment form a plot. A biological moment, partly conscious (post-infectious immunity and allergy) that marks the whole experience of life, and also partly subconscious: The individual temperament, education, etc., that direct our behaviors. And a psychosocial moment of intra-psychic elaboration of the feeling of illness, where general or basic components intervene (the psychic consequences of the biological or somatic alterations), and the personal ones as the constitution of the individual, the type of illness (acute, where predominate feelings of affliction and threat; or chronic, where the feelings are more biographical), the social-historical situation, sex, race, etc., which are both conscious (changes in the feeling of one's life: Distress, threat, solitude, and resource), and subconscious (phenomenon of transference), and interpretative (punishment, chance, challenge, test). The fact of contracting a disease is not always pure incomprehensible chance; it influences a conscious and subconscious disposition of a human person in front of his own biography; "The patient does not have a disease, but he does his illness". Consequently, the disease, both acute and chronic, gives rise to lasting biopsychosocial functional experiences or mutations (immunity and allergy, pathobiographical modification, changes in the feeling of own life and in the way of living). Studies are recommended to evaluate how patients experience a long-term illness to begin to build an experience-based and patient-centered medicine.

Keywords

Attitude to health, Sick role, Adaptation, Psychological, Illness behavior, Concepts of illness; Doctor-patient communication, Social interpretation, Health related quality of life, General practice

"Pain is a landscape ... I am only a body. Everything I have to do, everything that I can do, I can only do it within this body..." Gustafsson L. The Death of a Beekeeper (1981).

Introduction

An adult, in 25 years of life, suffers on average 1 very serious disease, 20 serious, and about 200 less serious [1]. Illness and health are singular concepts, inasmuch as they refer to a state of the human being, and not so much to organs and parts of the human body. If one of its functions is disturbed, the harmony of the whole is broken and then we talk about illness.

The term "Illness concept" commits all assumptions, interpretations, explanations, and predictions in regard to one's health status. Doctors and patients have concepts of illness that can differ from each other. The concepts of illness can be described under formal, phenomenological and psychological-functional aspects. The concepts of disease influence the perception of the disease, cooperation and satisfaction with the treatment by the patient [2].

The concept of illness behavior was introduced to indicate the ways in which given symptoms may be perceived, evaluated and acted upon at an individual level. Illness

behavior may vary greatly according to illness-related, patient-related and doctor-related variables and their complex interactions. In the past decades, important lines of research have been concerned with illness perception, frequent attendance at medical facilities, health care-seeking behavior, treatment-seeking behavior, delay in seeking treatment, and treatment adherence [3].

But what is the experience of the disease? The patient

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has an experience: fever, pain, anxiety, disability, isolation, etc.; these situations really feel; these situations are “experienced” [4].

When a symptom manifests itself in the body of a person, it draws attention interrupting the continuity of daily life. The symptoms of diseases produce experiences and have consequences for the sick. Almost all symptoms require changes in behavior, and can be classified into 2 groups:

1) Experience of symptoms that prevent us from doing the things we would like to do; and, 2) Experience of symptoms that force us to do what we do not want to do.

Thus, flu prevents us from accepting an invitation and forces us to stay at home; the change of forced behavior is a forced rectification. But also, the hyperactive is forced to rest; the communicative is silenced, etc. Thus, it can be thought, at least in part, that the knowledge of what prevents the symptom and what the symptom requires from the patient, can reveal the central theme of his disease [5].

The symptom is an indicator of a process that is not always visible in its entirety. The loss of internal balance manifests itself in the body as a symptom. However, the symptom and the disease itself are not necessarily enemies whose destruction should be the main objective, but can be allies for healing, or more broadly, to live life [5].

The uncertainty of the disease is present for both acute and chronic diseases and has been described in the literature as a factor of cognitive stress, a sense of loss of control and a perceptive state of doubt that changes over time [6].

The wide range of expressions of illness behavior is likely to affect the presentation of any disease and its identification, course and treatment [3]. The concept of abnormal behavior of the disease includes several clinical conditions characterized by a non-adaptive way of experiencing, perceiving, evaluating and responding to one's state of health [7].

The most negative perceptions about the disease are associated with higher ratings of unmet needs on the part of patients. Negative perceptions are also related to poorer attitudes toward medication and lower functioning. On the contrary, perceptions about the personal capacity to control the disease are constantly associated with better results. The causal attributions of the patients could be classified as social, psychological, biological and behavioral. The most frequent visits to the general practitioner are associated with the perception of more serious symptoms, greater concern and greater emotional responses to the disease and psychosocial causal attributions [8].

Usually, the professional communicates that “he is a true expert” in the disease. However, the knowledge of the symptoms and the disease has different forms and is not only the health professional's possession: He only contributes a perspective to the problem. Because, who will know better the difficulties of handling after a stroke, for example, that the patient (and partly also their caregivers)? Who will know better the difficulties of a problem than the people who do you

experience it? The real experience (of illness, of symptoms) provokes knowledge that cannot be acquired through intellectual understanding alone. The doctor or nurse, as examples of healthy, cannot cure: “Only the wounded can heal”. The expert can practice medicine effectively only at the technical level. Only in what the doctor is affected, he acts therapeutically [9].

The experiences and perceptions of those involved, both carers and patients represent a resource of great value for others. This helps the individual to be equipped in the most relevant context, with knowledge, skills and confidence, which is a therapeutic experience in itself. Illness concepts influence perception of illness, the cooperation and satisfaction with treatment by the patient. To respect the illness concepts of patients means to respect the patient himself. Communication between healthcare professionals and patients is limited by many contextual factors, but it is often possible for physicians to detect shared implicit concepts of the meaning of symptoms and disease [10]. The patient's perspectives are valuable completions of the therapist's perspectives and should, therefore, be integrated in the planning of therapy [2]. Assessing illness behavior and devising appropriate responses by health care providers may contribute to the improvement of final outcomes [3].

In the literature, there are several qualitative studies that address the issue of living with a chronic disease from the perspective of the adult patient. However, the lack of clarity and consensus among the existing studies makes this concept ambiguous when analyzed in depth [11].

In this scenario, this article aims to reflect, from general medicine, on the experience of the disease, both acute and chronic, and on the bio psychosocial changes it gives rise, to start building an experience-based medicine and centered on the patient.

Discussion

Interpretations of the disease in history

Diseases have their own rhythms that are modified over the centuries; each society builds its way of thinking and feeling diseases. The interdependence between the biological and social conditions of civilized life has caused that each historical moment the patient lives in a different way the disease [12].

There are 4 interpretations of the disease in the story [4]: Punishment (feeling responsible and being at fault), chance, challenge, and test. At the beginning of the 21st century, post-modern man transfers the crisis of current thinking to the field of health; this poses tensions that are evident in the way of living and dealing with the disease.

Quality of life and experience of illness

It can be considered that the quality of life is an opinion that the person builds from his/her own state of health in comparison with certain constructed standards about which he/she expects that he/she should be able to achieve. And in this assessment there is a personal stamp that each person

prints to the perception of their quality of life. So, quality of Life related to health is the result of the complex interaction between objective and subjective factors of the disease [13].

Even though quality of life is a commonly used phrase but there is no universal definition. Five perspectives of quality of life have been proposed: Sociological, economic, psychological, philosophical and ethical. However, health has emerged as an important but distinct perspective [14].

Quality of life is a concept dependent on the experience of the disease. Patients with chronic diseases can recognize different processes that influence their experience of illness, emotional well-being and coping behavior, such as: (1) Recognizing themselves as sick and healthy, (2) Recognizing their own emotions, (3) Having awareness of their own needs, (4) Being part of a community and (5) Being recognized as a credible patient [15].

The unconscious experience of the disease

But, such experiences of the disease happen when the disease passes or subsists? Does the experience of the disease become a habitual modification of the bio-psychosomatic reality of the person who fell ill? Does it become a lasting change in way of being and acting? It can be thought that, in acute diseases, the impact on the quality of life as a consequence of the experience of the disease is a specific or momentary situation that occurs during the episode of illness; that the experience of the illness is temporary; an anecdote. However, the biological event of the acute disease usually leaves behind a more or less lasting somatic experience, consisting of a change in the capacity of the organism to react to the causal agent of the disease suffered and to others close to it: immunity and allergy. Therefore, they constitute a "functional mutation" of the affected organism [4].

But neither the immune nor the allergic are aware of being so. The experience of immunity or allergy becomes personal when patient hear about it. Although it is also personal in a subconscious way: The individual temperament, education, etc., mark or subconsciously direct our tastes and behaviors. This subconscious experience of immunity or allergy occurs through mechanisms not well known or explored; For example, post-infectious states inform our experience of life in some way. The fact of contracting an infectious disease is not always pure incomprehensible chance; influences a conscious and subconscious disposition of a human person in front of his own biography [4].

The patient does not have a disease but he does his illness

Generalizing, one could say that the disease is "sought" by the patient's biography. Richard Siebeck (1883-1965), along with Ludolf von Krehl, and Viktor von Waizsacker that were the pillars of the Anthropological School of Heidelberg, gave special importance to the patient's biography, its pathographic evolution and its historicity. "The patient does not have a disease but he does his illness". In this disease, it is important to know the social (relational), the ethical (its renunciations, duties, values and principles) and, above all,

the spiritual-religious (the meaning that for the patient has life, death, God) [16,17].

In the healthy/sick dichotomy, the disease develops as a time of life. The "healthy" (which is not a quantitative and biological concept, but related to the personality, with its position and situation, environment and community) feels good and strong. The healthier we feel, the less attention we pay and the less we know about the Health. The patient feels the disease; the doctor discovers it or at least accepts it. The patient feels discomfort, feels handicapped, bothered and threatened, whether it came suddenly to his conscience the change from healthy to sick by an event, whether the transformation occurred gradually and was discovered only casually, either by pain or for some difficulty in life.

You should know the multiple relationships and links in human life, if you want to understand the sick, if you want to delimit between sick and healthy. Not all discomfort, or any deviation in structure and function, or all "bad mood", or any wrong posture or poor performance are "pathological". Where should we set the limit? Health and illness make sense; they have a meaning for life, existence, position and performance within the community. The disease develops as a time of life, changes or progresses, and always leaves its lasting traces. Illness is the destiny that man carries within him, that reaches him from the outside. The doctor has to decide between healthy or sick, not for this or another concept, but as offered by life.

It must be borne in mind that the more frequent and serious the functional disturbances are, the more an organic defect can be counted on. Clinical disease is the history of a lifetime (problems, desires, failures, successes, efforts, etc.) and marks exacerbations or improvements. The disease demonstrates clear diaphanous dependence of its course and prognosis of personality and it also points out the importance of context. And also, disease demonstrates dependence of the treatment established in time and with logic (before deep or irreversible structural anomalies are produced). So, the workers with heavy work, both in factories and in the countryside, the people in precarious economic situations, the restless characters, etc., are in worse situation in front of a disease [16,17].

Course, prognosis, evolution and context of the experience of the disease

In addition to recognizing the importance of the personality and the constitutional peculiarity in the disease and in the experience of the disease, the position or position of the patient before the world, as well as the external conditions of his life in the disease, must also be taken into account. The disease always develops in the course of a life replete with history; it always has multiple roots, both internal and external, the same in the somatic as in the psychic sphere and in the personal and social ligaments.

Health and disease should not be interpreted solely because of their biological references, but also because of their personal references. The transformation from healthy to sick, either unforeseen or very slow, is linked to a general

commotion, derived from the more or less conscious experience of suffering, knowledge of the diagnosis and interpretation of its meaning [16,17].

Therefore, how the illness proceeds, what the illness means for the patient, the experience of the illness, does not depend only on the "illness", but also essentially on the patient himself, on his position and his situation in life. Each patient does not "have" only "his illness"; he himself and his destiny "form" it. The disease is at the same time a story of a lifetime [16,17].

A frequently cited example is the connection of biographical stress with diseases. Victorious soldiers are more resistant to infection than defeated soldiers. Moreover, the peculiarity of the post-infectious state (immunity or allergy) depends to a certain extent on the patient's conscious and subconscious attitude towards his illness. Biological experience when becoming personal makes the experience of the disease personal [4].

In this sense, the characteristics of the patient's disease allow a correct classification of more than 50 percent of the cases that will require hospitalization. However, coping (the way in which patients face the current crisis) is a comparable predictor - it allows a correct classification in 50 percent of cases - that will require hospitalization [18].

When the patient heals, something has changed in him

It is traditional to call "restitutio ad integrum" to a complete healing. As if the patient, once past the convalescence, did not have any change; as if the patient after the disease was the same as before presenting the disease. However, this is not correct: When the patient heals something has changed in him; There is a "new health" that is not the same as before the illness. There are functional sequelae: Various modifications in relation to the previous state. There are different biological abilities (immunity and allergy). But not only this, there are also changes in the feeling of one's life; in the way of life [4].

How does the sick person feel his experience of disease?

The patient may feel pain, fever, tension, anxiety, thirst, disability, vertigo, etc. Physicians attentive to "objective" exploration have not been sufficiently applied to the task of describing, understanding and ordering the different ways of subjectively feeling the disease.

The disease is an interpretation system. The psychosocial aspects of diseases are the factors that intervene in the patient's ways of reacting to the disease: Their thoughts, emotions, behaviors and habitual bodily sensations when people face a medical diagnosis, and play a role in the expression of the symptoms and diseases. The patient's experience opens during the clinical consultation. The disease has symbolic and sociocultural meanings for the patient and the doctor. The patient's response to the psychological stress evoked by the medical illness and the extent of the regression that occurs as

a consequence of the diseases modify the quality of the doctor-patient relationship. Then, the doctor-patient relationship may be different, for example, in the cardiovascular patient, the hypertensive patient, the asthmatic patient, the digestive patient, the patient in psychiatric diseases, in digestive, endocrinological problems, with an incurable disease, with hematologic diseases, with cancer or with AIDS, etc [19,20].

Thus, physicians may be well equipped for the biological aspects of the disease, but not for their psychosocial dimensions, and this issue has been absent in general medicine. The psychosocial aspects of diseases are the factors that intervene in the patient's ways of reacting to the disease, and have a role in the expression of symptoms and illnesses, and in the implications they produce in people's lives. In addition, the biological (specific) and psychosocial (non-specific) effects are not simply additives, but interact [21].

The general practitioner, after living the experience of accompanying patients in their usual task of continuous care, can confirm their previous biological conception of the chronic disease, but also discover the ways in which some patients and their families overcome their limitations. Thus, the physician's understanding of the meaning of the disease for the patient and the family is a type of knowledge that changes the doctor-patient relationship [22-24].

Ways to feel subjectively the disease

Living with a chronic illness is a complex, dynamic, cyclical and multidimensional process. In the process or development of living with a disease, the implication of five different attributes has been described: Acceptance, coping, self-management, integration and adjustment. Depending on how these attributes operate, there are four different ways of living that can result from the process of living with a chronic illness: 1) Disapproval, 2) False rule, 3) The new normal and 4) Interruption [11]. Other authors order and synthesize these different ways of subjectively feeling the disease, which can be reduced to 4 cardinal feelings: 1. Affliction; 2. Threat; 3. Loneliness; and 4. Resource [4].

Affliction: All that in the complex feeling of the disease is painful. The uneasiness incomprehensibly comes to our life. The affliction produced by the disease, is at first, discomfort: Positive discomfort such as pain, anxiety and vertigo. And also negative discomforts: Not being able to do certain behaviors such as exercise or activities proper to life in health: You have to rest, etc.

Threat: Feeling sick is feeling threatened; There is a risk of dying. The patient feels radically threatened his impossibility of life projects before the illness. A "biographical death" occurs. And if the health problem is serious, the possibility of the same "biological death" also appears.

Loneliness: The patient feels lonely; You cannot communicate the vital feelings of our body. The disease isolates to patient not only by preventing a normal way of relating to others, but also by fixing attention on feelings that only the patient can feel. Hence the ambivalent disposition of the sick towards the company: They need it and ask for it, but sometimes it irritates them.

Resource: Illness is also a resource; It serves for something. Sometimes, the disease serves to evade us (sick leave, cessation of responsibilities, etc.). Also the forced immobility of pathological origin allows expanding and perfecting a work of life, as can be seen in the artists.

The arts express or symbolize the emotional response to the disease, and could be used to understand this paradigm of experience-based medicine [25]. We have an example in Paul Klee. This brilliant artist lived the last few years of his life in Bern, but they were years which were overshadowed by a dark star. In 1935 Klee suffered a variety of setbacks and became seriously ill. Although he never recovered from this illness, he always maintained his love of life, facing his suffering with a trenchant “so what?” Paul Klee died in 1940 at the age of 60. He died of a mysterious disease that at that time remained undiagnosed; Symptoms include changes in the skin and problems with the internal organs. Along with these symptoms, the artist suffered isolation and solitary internalization. The last works of Paul Klee are clearly distinguishable from those of his previous period. However, he wanted to use and develop to the maximum each gram of his creative abilities. This desire for perfection can be a clue to understanding why Klee was able to run to finish his life’s work despite his severe illness and predictably short lifespan. Viewed in this way, his involuntary isolation and his intuition that he suffered from a terminal illness were perhaps a prerequisite for him to achieve the ambitious goals he set for his life. His work in this last period, not only was influenced by his illness, but was made in defiance of that disease, but it is surely one of the most brilliant demonstrations of how suffering and sadness can be overcome through art. And that despite everything, irony can still shine in his pictures [1,26,27].

Many novels or poems can also be the source of exam-

ples, such as Lars Gustaffson’s *The Death of a Beekeeper*: Lars Westin, a retired primary school teacher and an occasional beekeeper who has terminal cancer, with metastasis in the surrounding tissue. For a long time he has allowed himself to believe that he has a kidney stone. But when the pain became too unbearable, he saw a doctor and had a lot of exploratory tests. He has been waiting a few months for the doctor’s letter to arrive. When it arrives, then he has to decide whether to open it or not. Eventually he decides to destroy the unopened letter. Lars Westin makes us participants of his moods and his reflections, in a range of voices from poetic to everyday, while trying to understand what it is that gives meaning to life. From pain can also arise knowledge, learning, connection with our own nature [28].

General or basic components and personal components intervene in the intrapsychic elaboration of the feeling of illness:

1. The generals: The psychic consequences of biological or somatic alterations
2. The personal components which intervene in the constitution of the individual, the type of disease, acute (where feelings of distress and threat predominate) or chronic (where the feelings are more biographical), the socio-historical situation, sex, race, age, etc.

Thus, for example, it has been reported that women live longer with more illnesses. There are also gender differences in life with respect to risk behaviors for health. For example, men spend more years of their lives overweight and have fewer years during which they consult a doctor [29]. It has also been reported that children with insulin-dependent diabetes mellitus have a more developed and sophisticated understanding of the concepts associated with the manage-

Table 1: The plot of the experience of the disease.

Moments	Concepts		
1. A biological moment (immunity and allergy)	1.1. It becomes personal when they give us news of disease. 1.2. It is also personal in a subconscious way: the individual temperament, education, etc., mark or subconsciously direct our tastes and behaviors. This subconscious experience of immunity or allergy occurs through mechanisms not well known or explored; For example, post-infectious states inform our experience of life in some way. The fact of contracting an infectious disease is not always pure incomprehensible chance; it influences a conscious and subconscious disposition of a human person in front of his own biography.		
2. A sentimental or emotional or psychosocial moment. This intra-psychic elaboration of the feeling of illness	2.1. General or basic components (the psychic consequences of biological or somatic alterations)		
	2.2. Personal components	2.2.1. Individual constitution	
		2.2.2. Type of illness, as acute (where feelings of affliction and threat predominate), or chronic (where the feelings are more biographical)	
		2.2.3. Socio-historical situation, sex, race, etc.	2.2.3.1. Conscious (changes in the feeling of one’s own life, in the way of life, the different ways of subjectively feeling the disease: affliction, threat, loneliness, and resource)
2.2.3.2. Subconscious (this subconscious mode of the feeling of illness has not been satisfactorily studied or elaborated, except perhaps in part on the phenomenon of transference)			
		2.2.3.3. Interpretive (punishment, chance, challenge, or test)	

ment of the disease than siblings of children with diabetes or normal healthy children (no experience of insulin-dependent diabetes mellitus); In addition, experience with the disease is associated with more complex conceptions of social relationships [30]. And likewise, for example, it has been reported that young people living with chronic illnesses generally see themselves and their lives in the same way as their healthy partners. But, their aspirations are often limited by disease and treatment. So, the relationship between disease and life cannot be seen in isolation from development [14].

Conclusion

The experience of the disease has a complex structure where they form a plot between a biological moment (immunity and allergy), and a sentimental or emotional or psychosocial moment, with intra-psychic elaboration of the feeling of illness (Table 1). As a result, both acute and chronic illnesses give rise to lasting bio-psychosocial functional experiences or mutations (immunity and allergy, pathobiographical modification, changes in the feeling of one's life and way of life). These elements imply a critique of the existing concept analysis of quality of life and suggest hypotheses applicable to patients with acute and chronic diseases. The findings in this analysis should be evaluated with caution and more research is needed on this subject to confirm them. In addition, more studies are recommended to assess how patients experience a long-term condition to begin to build an experience-based and patient-centered medicine.

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