CHRONIC CONDITION AND NORMALITY: TOWARDS THE MOVEMENT THAT BROADENS THE POWER OF ACTING AND BEING HAPPY\(^1\)

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Souza SPS, Lima RAG. Chronic condition and normality: towards the movement that broadens the power of acting and being happy. Rev Latino-am Enfermagem 2007 janeiro-fevereiro; 15(1):156-64.

This article is an epistemological-theoretical study of the health-disease process, whose central discussion is the frontier between health-disease and between the normal-abnormal of the person in chronic condition. It emphasizes the importance of the subjective dimension, without denying the objective dimension of this process. It shows that, when considering the objective aspect of the health-disease process, the definition of normality is based on the biological indicators grounded on statistic parameters, which are applied as a reference for all individuals. When considering the subjective aspect of the health-disease process, different normalities appear, as people with chronic conditions deal with daily demands in different ways, since the way they lead their life oscillates between expansion and introspection. Thus, having a chronic condition and being able, active and powerful in life means to be awake, open and always moving, creating new ways of being happy.

DESCRIPTORS: health-disease process; chronic disease

CONDICIÓN CRÓNICA Y NORMALIDAD: HACIA EL MOVIMIENTO QUE AMPLÍA LA POTENCIA DE ACTUAR Y DE SER FELIZ

Este artículo es un estudio teórico-epistemológico del proceso de salud-enfermedad, cuya discusión central es la frontera entre la salud-enfermedad y la normalidad de la persona en condición crónica. Destaca la importancia de la dimensión subjetiva sin negar la dimensión objetiva de este proceso. Muestra que, al considerar el aspecto objetivo del proceso salud-enfermedad, la definición de la normalidad se basa en indicadores biológicos calculados en parámetros estadísticos, que se aplican como referencia a todos los individuos. Cuando se considera el aspecto subjetivo del proceso salud-enfermedad, aparecen diversos normalidades, pues la persona con condición crónica lidiá con los requisitos diarios de formas diferentes, puesto que su manera de llevar la vida oscila entre los movimientos de expansión e introspección. Así, tener una condición crónica y ser capaz, activa y potente en la vida significa estar despertó, abierto y siempre en movimiento, creando siempre nuevas normas para ser feliz.

DESCRIPTORES: proceso salud-enfermedad; enfermedad crónica

CONDIÇÃO CRÔNICA E NORMALIDADE: RUMO AO MOVIMENTO QUE AMPLIA A POTÊNCIA DE AGIR E SER FELIZ

Esse artigo é um estudo teórico-epistemológico do processo saúde-doença cuja discussão central é a fronteira entre a saúde-doença e entre o normal-anormal da pessoa em condição crônica. Destaca a importância da dimensão subjetiva sem negar a dimensão objetiva desse processo. Mostra que, ao considerar o aspecto objetivo do processo saúde-doença, a definição de normalidade baseia-se em indicadores biológicos calculados em parâmetros estatísticos, que são aplicados como referência para todos os indivíduos. Ao considerar o aspecto subjetivo do processo saúde-doença, surgem diferentes normalidades, pois a pessoa com condição crônica lida de formas diferentes com as exigências cotidianas, visto que seu modo de andar a vida oscila entre o movimento de expansão e o movimento de introspecção. Assim, ter uma condição crônica e ser capaz, ativo e potente na vida significa estar desperto, aberto e sempre em movimento, criando novas normas para ser feliz.

DESCRITORES: processo saúde-doença; doença crônica

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INTRODUCTION

The basic concepts guiding scientific knowledge production in health were founded on positive science. The scientific discourse, specialty and institutional organization of health practices were delimited on the basis of objective disease instead of health concepts (1). Merely using the scientific rationality reference framework to understand health entails difficulties, which are managed within the limits inherent to the reduction process characteristic of the scientific construction (1-7).

Through depth, reduction and narrowing of thinking, modern scientific rationality attempts to explain reality objectively and precisely. This requires translating phenomena into abstract, calculable and demonstrable schemes, so as to find explanations that corresponded to unquestionable truths, because they expressed universal laws. The basic characteristic of modern science is to transform concrete objects into a general law, with the help of mathematic language (1,6).

Modern science explains human body experiences through its objectivation method and the results of these scientific studies cannot be ignored by praxis, although this does not hide the limits of general objectivation (6). In modern scientific development, representations of reality were constructed which started to be considered as the truth and to exert power on other types of knowledge. However, scientific rationality ignored a fundamental aspect: the limit of concepts in relation to the real, particularly in questions inherent to health, mainly with respect to the concrete experience of feeling healthy and getting ill (1).

In the 17th century, Descartes concluded the philosophical formulation that sustained the birth of modern science. Through his ideas, the organic view made room for the rationalist, mechanistic and reductionist conception of the world, in which the human body starts to be considered in a way similar to a machine (3,8).

Descartes’ philosophic construction proposed that clear and distinct ideas should not be mixed with the senses emanated from the body. He established the dualistic rationalism that separates the thinking subject (res cogitans) from the object/nature (res extensa) "as two ontologically distinct types of phenomena, constituting intransitive epistemological fields - that of philosophy and reflexive knowledge on the one hand, and science and objective research on the other"(9). Thus, Descartes and Kant provided the base for the theoretical framework that sustains scientific rationality and understands the reason above and beyond nature and hence, separated from the world it observes and manipulates (3,7-8).

Hence, modern scientific rationality was born together with natural sciences and aimed to dominate the phenomena through the naturalization of explanations about all objects it applies to. Therefore, through its method, it attempted to classify the phenomena, get to know the causes and regularities, with a view to discovering universal laws to be able to forecast, dominate and interfere. In the 19th century, this rationality model was extended to the then emerging social sciences (10) and was consolidated in medicine, mainly through the experimental method defined by Claude Bernard (2).

With a view to theoretical reflections about the theme, this article discusses the normality concept present in the health-disease process of people in chronic conditions. The central theoretical discussion is based on George Canguilhem’s epistemology and on Baruc Spinosa’s philosophy, and allows for reflections about the frontier between health and disease and between normal and abnormal. To reach the objective, the text was organized as follows: first, normality is discussed as a quantitative variation between health and disease; next, normality as a qualitative difference between health and disease and, finally, the different normalities present in the life of people in chronic conditions.

NORMALITY: QUANTITATIVE VARIATION BETWEEN HEALTH AND ILLNESS

August Comte and Claude Bernard exerted a strong influence on 19th century philosophy, science and literature, as both of them “semivoluntarily played the role of flag bearers” (2) of the scientific dogma endorsed by biology and medicine, which identified normal and pathologic vital signs as being of the same kind, that is, pathologic phenomena as quantitative variations of normal phenomena (2).

Comte’s positivism aimed to determine the laws of normality that were capable of supporting a scientifically-based political doctrine. According to him, all societies have an essential and permanent structure that is considered normal, and any social crisis starts...
to be considered as a disease which politics should deal with, with a view to returning to the previous state idealized as normal, in the same way as a treatment. Claude Bernard believed that the study of live material phenomena through the experimental method allowed for the explanation of the relation between physiological and pathological phenomena, reducing them to a common measure and making them homogeneous, just like gross matter. In 1877, Claude Bernard published the result of his experimental studies and concluded that disease results from a dysfunction, that is, from a variation, whether upward or downward, in the organism’s normal functioning. In addition to research by other experts at that time, his study considered that disease is not something external entering the body, but an alteration in physiological life itself, that is, "it is nothing more than the organism’s own reaction and, more precisely, the growth in tissue irritation, which will be judged during a certain period as responsible for a majority or all of the pathological problems."

In a study from 1878, Pasteur showed the existence of microorganisms and their implication in the transmission of infectious diseases. Disease started to be conceived as a result of the organism’s invasion by external agents (microorganisms) that provoke organ and tissue damage. From then onwards, each infectious disease started to have a specific cause and the different responsible germs were progressively isolated and catalogued.

Microbial theory contains an ontological representation of the disease, in which it is considered as something entering the organism. However, this “something” starts to have a natural and no longer a magical cause, like what happened in the primitive conception. Respecting the appropriate differences, this ontological representation was similar to the primitive disease conception and left little leeway for imaginary popular interpretations. This was responsible for a considerable part of microbial theory’s success. However, it is when we feel the need to tranquilize ourselves that anguish puts a constant weight on our thoughts and, when we delegate to the magical or positive technique the task of restoring the organism affected by the disease to the norm, it is because we do not expect anything good from nature in itself.

In this context, nature did not directly interfere in the health reestablishment process. This was substantially different from the Greek conception, in which nature, both outside and inside the human being, was seen in balance and harmony. If disrupted, this created disease, seen as nature’s effort to achieve a new balance. The cure process acknowledged the existence of curative natural forces inherent in live organisms. Treatment involved creating favorable conditions to allow these forces to act in the cure process. Therefore, the Greek conception was not ontological and localizing, like in the case of microbial theory, but dynamic and totalizing. "Nobody can contest the optimistic character of infection theories in terms of their therapeutic extension. The discovery of toxins and the acknowledgement of the specific and individual grounds’ pathogenic role destroyed the admirable simplicity of a doctrine, whose scientific clothing dissimulated the persistence of a reaction towards evil, which is as old as man himself."

Although they explain different situations, scientific advances cannot handle the entire complexity involved in the health-disease process. In this perspective, it is observed that, by itself, the presence of bacteria in an organism is not enough to characterize their bearer as ill. It is concluded that, for people to be considered ill, the number of invading microorganisms has to exceed a rate that is considered normal, above which the organic reaction is no longer physiologic but becomes pathologic, that is, a disease.

Thus, the normality concept was strengthened as a fundamental scientific parameter to define health. From this point onwards, disease started to be understood in terms of deviations from this normality, that is, people moving away from normal levels in any direction are considered ill. Thus, scientific studies started to look at health when it is reduced to standards that should be restored. However, disease became a privileged scientific object, because it attended to the methodology inherent in modern science. This was the case because it generated alterations in the
physical-biological body that can be measured and, therefore, scientifically studied, based on a fragmentation of this body, which was considered on the basis of morphological and functional constants (1).

In this context, in the development of scientific rationality in health, the focus centered on disease as a deviation from normal. Then, this normal became a synonym of health and the sick person was relegated to the background. This person was then considered as passive, as someone who awaits help from someone who, in the name of knowledge, attempts to reestablish the lost normality, whether through treatments or normative prescriptions to be followed.

Originally, the term norm comes from Latin and means squadron, while the term normal means perpendicular. A norm is a rule that serves to rectify, implement, straighten (2). Thus, a norm is what is adopted as a base or measure to carry out or assess something; it is a principle; rule; model; standard (13). Hence, a norm is something that exists to be followed. Normal is what or who follows the norm. In this same context, standardization is the act of effect of creating and establishing norms. Normalization, in turn, is the return to the normal state, to normality. Abnormal, on the counterpart, is what is outside the norm; what is against the rules; what is irregular (13), that is, what or who does not follow the established norm is considered abnormal.

The norm can be seen as means used to an end, hence taking the form of guidelines, regulations or prescriptions (12) that are set by someone (e.g. health staff) and oriented to an addressee (e.g. the sick person). Customs are norms, as they determine certain standards of conduct that, in a way, put pressure on individuals with a view to their adjustment to these standards. The custom controlled by a society is a social norm, because it is a type of behavior this society requires, under penalty of punishing anyone who does not behave as desired (12).

The concepts originated from the word normal are used in a wide range of contexts, although their meaning is not always precisely delimited or suggested. This is where difficulties to define a situation as normal come up, as it is not always clear who or what determines a norm and on what parameters these norms are based. In this context, the judgment that defines a norm will always be subordinated to the person who established it (2). "An investigation of studies from many areas leads to the belief that the use of the term normality is guided by consensus. An analysis of possible meanings leads to different conclusions, whose compatibilization sometimes requires considerable effort" (12). In clinical practice, disease is considered abnormal, while health is considered normal. Norms for countless clinical variables, such as weight, height, pulse and breathing are statistically based and considered in terms of average, and these are associated with "certain tolerance intervals, which in turn characterize a normal variation" (12).

Statistical normality does not satisfactorily attend to all cases in which healthy persons need to be distinguished from the ill. One of the reasons for this difficulty is the fact that clinical and medical practice mix metric and non-metric elements. Hence, the application of statistical normality in medicine is limited (12).

This limitation is due to the static and punctual character of clinical statistical variables, which lose the perception of movement, reducing the human being to the "body, to the visible and measurable, ignoring the mental, the dynamic, experience, that is, the actual condition of that body with respect to life and its activities and projects. The body is not only what one can see, and the visible does not always allow for measuring (14).

In view of this discussion about statistical normality and the norm as a rule, "normal is the person who adjusts to the norms. Whoever attempts to reach a goal and follows instructions, obeys the rules of a game and does not make any forbidden moves, who accompanies the regulations is normal. On the other hand, abnormal means not following guidelines, making illegal moves, ignoring rules, fleeing from customs, turning one's back on moral principles (12). Thus, normalization emerges from the need to quantitatively differentiate between health and disease. There is considered to be a continuity between health and disease, in which different qualities are no longer seen but understood as graduations from one to another, that is, as physiological variations (12). There is a need to establish norms in order to define what is normal and, hence, healthy and desirable, in contrast with what flees from this normal and enters the space of the pathologic, ill, abnormal and, therefore, not desirable.

Within this focus, health and disease are similar to life and death. Therefore, normalization is needed to be able to control the disease, that is, in a
In this perspective, health and disease are located in the field of normality, as both of them imply a certain life norm. Consequently, disease is no longer the opposite of normal and becomes the opposite of health. Abnormal is no longer seen as the absence of normality, because there is no life without life norms, as even the morbid state is a way of life. The point disease and health have in common is the presence of a logic, of a characteristic organization, of a norm that will always be present, even under abnormal conditions. Thus, abnormality does not indicate the absence of norms, but the presence of a different norm than what is expected\(^2\).

Disease entails a certain degree of incapacity to create new norms. However, in general, this incapacity is temporary, as new norms are created, different from earlier ones, on the basis of the new situation installed by the disease. And this, independently of the type of disease, becomes healthy. Due to the irreversibility of biologic normativity, cure becomes the capacity to create new life norms, sometimes superior to previous ones. “Lucid awareness of the fact that curing does not mean returning [to the previous state] helps the patient in his search for a state marked by a minimum level of renouncement, releasing him from being fixed in the previous state”\(^2\).

The irreversibility of biologic normativity, defended by Canguilhem, can be understood in a wider sense, considering social, mental and environmental issues\(^7\). Not being a machine, the human being is always transforming himself, maturing, advancing. Hence, this normative irreversibility results from the complexity of each being’s experiences\(^16\).

Thus, while health is characterized by opening to modifications and by the establishment of new norms, disease corresponds to the temporary or definitive impossibility of changes and unrestricted compliance with norms. Moreover, health implies the possibility of getting ill, the temporary state of disease and the capacity to leave the pathological state\(^2\).

This entire theoretical construction by Canguilhem leads to the proposal to reformulate health practice, in which treatment and diagnosis should privilege observation and the sick person’s perspective. Disease establishes a new way of life which treatment needs to respect, and the primary goal should not be the return to a previously established ‘normal’ state\(^4,7\).
The understanding of health and disease should not remain restricted to biological and statistical criteria only, but expanded by a perspective in which the norms that define health and illness are in accordance with the ways life is led, which each human being is immersed in, with greater or lesser transformative capacity. If, on the one hand, the health concept is related to organic functions, on the other, it should also relate to the subjective body\(^3\).

Thus, life does not know indifference, it is a dynamic polarity in which movement and transformation are closely related, among others, to health-disease, to individual-environment, to the normal-abnormal, and in which normative capacity is sometimes manifested more open and dynamically and sometimes more restrictively\(^2\).

The dynamic polarity with the environment is what defines a living being. In the case of human beings, the environment is not only physical, but also social, cultural, among others. Hence, this is about a polarized activity, whose extremes are health and illness; and at the same time a normative activity, which indicates one of the poles as wanted and the other as unwanted. This dynamic polarity is different in each human being and this difference becomes fundamental according to each being’s set of capacities or powers to cope with the aggressions he is exposed to\(^3\).

Polarity – health-disease, normal-abnormal, inspiration-expiration, sleep-alert, life-death, is not an absolute experience that belongs to different categories. Instead, it composes one and the same reality, that is, parts of a whole, in constant interaction, highly interdependent, in which one pole cannot exist without the other. This unity, constituted by opposite poles, does not emerge from a static identity, but as a dynamic interaction between two extremes. Denying the existence and fighting against one of the poles means fighting against the Whole\(^17\).

In the Greek view, being integrally means being healthy, being complete. Disturbing the whole arouses the presence of our corporality in our conscience. This went by unnoticed before the disturbance. Once his well-being is disturbed, the human being turns towards himself and it is only then that he perceives that, before being disturbed, he was awake, open and receptive\(^6\).

Disease creates an introspection movement that leads us back to our interior world and makes us perceive, feel and see ourselves. Consequently, to a certain extent, this introspection movement distances us from the external world. When looking at the state of well-being before the disease appeared, the following doubt emerges: ‘what is it that revolts against this state, this disturbance that, when we feel bad, leads to distancing from everything that happens on the outside?’\(^6\).

This question was reinforced by the German poet Rainer Maria Rilke who, when confronted with an incurable disease that caused strong pain, complained that the pain obliged him to remain locked up inside himself, inside the pain, without managing to participate in the place he was in\(^6\). In other words, the pain entailed the introspection movement by isolating him from the external world and closing him inside his interior world.

Current medical science has an almost virtuous capacity to eliminate pain, turning many pains and diseases transitory. The ability to suppress pain has removed it from its place in the human value scale, as pain tends to transform when there is no hope of disappearing or when its suppression is certain\(^6\). If people are able to question their disease, it will always have something to communicate that can help them.

"There are ways of being ill, according to the ways of the illness. Some diseases are visits: they arrive without warning, disturb the peace of the home and go away. That is the case of a broken leg, appendicitis, a cold, measles. Once the right time has passed, the disease picks up its bag and leaves. And everything returns to how it always was. Other diseases have come to stay. And it is no use complainting. If they have come to stay, we need to do with them what we would do if anyone permanently moved into our house: arrange things in the best possible way so as to avoid joint life from being painful. Who knows one may even get some benefit out of the situation? [...] Hence, if you make friends with your disease, it will give you free lessons about how to live wiser\(^18\).

**CHRONIC CONDITION: PRESENCE OF DIFFERENT NORMALITIES**

People with chronic conditions start to live with them and it is expected that they will attempt to accept them. And that is not easy, as the disease, in one way or the other, represents a threat to life and
well-being. Learning to accept the disease often means accepting what is given, what is limited and painful, but our human side consists in always keeping the future open and allowing for new possibilities. In this perspective, normalization is perceived as the possibility of change, of transformation, of creating norms deriving from new health levels established on the basis of the disease.

“Sometimes, I think about whether we do not need to redefine the concepts of health and illness, so as to see them in terms of the organism’s capacity to create a new organization and order, adequate to its special and modified disposition and to its need, more than in terms of a rigidly defined ‘norm’. The disease implies a contraction of life, but these contractions do not need to occur. It seems to me that almost all of my patients seek life – and not only in spite of their conditions, but because of them and even with their help.”

In this context, health and disease have a rhythm that characterizes them as poles that are complementary and belong to life. Thus, disease is no longer just related to what is limited, to death, to pain, to suffering, to the absence of movements, as it starts to be understood as a part of the movements of life. Health as a process implies activities and changes that even include temporary disease phases.

Chronic conditions are characterized by the fact that they are not temporary, as they become part, whether for a long or indeterminate time, of people’s lives. However, this does not mean that these persons always feel ill, since another characteristic of chronic conditions refers to exacerbation and remission phases. In an exacerbation period, the family needs to get closer to the sick persons, characterizing a centripetal process, that is, a movement of family introspection; in a remission period, on the other hand, greater autonomy needs to be promoted for the patient, characterizing a centrifugal or expansion movement.

During these expansion and introspection movements, that is, dealing sometimes more intensely with the internal world and at other times more intensely with the external world, people in chronic conditions feel more at ease or more restricted in their own norms and in those ruling their peers.

Health has a normative plasticity that is not restricted to an average or to an ideal, imposing standards of conduct from the top downwards, from the outside to the inside or from the universal to the singular. Being healthy means being able to incorporate norms that differ from those ruling until then, and even pathological norms, without losing the ability to act. Thus, people can be ill – etymologically speaking not firm – and continue able and healthy in several other aspects of life. People can lie outside the average of cultural ideals of health, but may still be able, active and happy.

Being able, active and potent in life, despite being obliged to live with a chronic condition, means being awake, open and always moving. It also means being able to deal with challenges by overcoming adverse conditions, in the attempt not to restrict the way of leading one’s life to the limitations of chronic conditions. Therefore, there is a need to seek ways of maximizing coping abilities, that is, each person’s potency.

Authors in the health area have looked at Baruc Spinosa, a philosopher contemporary with Descartes who opposed the Cartesian view and presented a conception of the human being as a somatopsychic unit composed of multiplicities and, therefore, without dissociation between body and soul.

Spinosa proposed a concept of health related to each person’s power to think and act. Thus, affections, that is, the impressions human beings feel when they have contact with the world, create affects that influence their way of seeing and being in the world, of thinking, knowing and valuing things. According to this author, knowledge, in the sense of wisdom, increases human beings’ power to think and act, making them more active and creative and, therefore, healthier.

“Not knowing our internal causes distances us from our spontaneous impulse to persist in our existence, from the intrinsic movement towards us (conatus), and puts us in a vulnerable position, submitted to external causes, decreasing our power to act and making us passive. Activity is related to potency. Passivity, then, leads us to servitude when, without knowledge about ourselves, we do not perceive that internal causes were replaced by external ones. Failing to recognize our dominator in the external power turns us refugees of another person, slaves without knowing it. This way, we would be reacting alienated from ourselves, passive, without using our active and creative ability, which decreases our power and induces us to a vicious circle of dependence, often dependence on who or what is dominating us.”
In this sense, the chronic condition affects our *conatus*, that is, our desire, our effort to persist in being and our power to act and think, and start to exert effects on our own duration, on pleasure and pain, on joy and sadness. These effects take the form of augmentative powers (expansion, joy, opening, freedom) or diminutive servitudes (introspection, sadness, closure, imprisonment)(21).

A liberating process is created in the interior of the passions that increases the force of *conatus* to the extent that sadness moves away and joy gets closer. The joy and desire this gives rise to prepare the human being for activity, decreasing their passivity(21).

There is no contradiction between Spinoza's philosophy and norms, except when they are imposed, whether as values or as averages. However, these norms are not contradictory when they are established by men and women in their own interest, because they consider that complying with these norms guarantees, or even expands their powers (their possibilities) of realizing happiness. It should be asked for every norm whether it increases or decreases the appetite for life. All human beings have conditions that strengthen their own health (increase the force of their power). Health professionals are responsible for helping these people to take hold of their powers and acting as facilitators of the search for what is really necessary to be happy(21).

It is not enough just to know the reasons why a certain norm exists. First, there is a need to seek self-knowledge, and then choose to accept these norms and aggregate them to one's existence, without creating requirements that cannot be experienced in a potent and healthy way(14). Thus, the more knowledge human beings have about the causes that affect them, the greater their possibilities of being active and free towards their own life. The less knowledge they have, on the other hand, the more they will be subject to coincidence, without perceiving the true dimension of their servitude.

**FINAL CONSIDERATIONS**

This article discussed the normality present in the health-disease process of people with chronic diseases. Health professionals need to expand the research and discussions about what is considered as normality. If it is understood as static and unique, this can impair people who do not fit into established standards. Without denying the importance of scientific knowledge and health practice, ill people should maintain their autonomy, and this will only be possible if they are granted the conditions to choose and be creative. Only people who understand what is going on in their own body can make truly free choices, people who follow standards not because they were imposed, but because they understand them and know that they expand their possibilities of being happy.

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