Chronic Illness and Self-Care Management. A Perspective of Diabetic Patients

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Abstract: Increasing the quality of life and life expectancy of patients at acceptable levels requires the study of the ethical dimension of medical care. The research aims at understanding the social construction of chronic illness from the patient’s perspective, taking into account the perspective of patients - chronic diabetic - on the significance of the chronic illness they suffer from, and the dimensions of self-care management. The research is based on a secondary analysis of data, focus groups and interviews with insulin-dependent diabetes mellitus patients. The condition of chronic illness requires the patient to have a certain awareness - the disease as a life situation, the limitations that arise due to the chronic disease status, the lifestyle and the quality of the illness that arise from the disease. The chronic patient experiences the chronic condition, as the normality of his life, as what defines him or will define him his whole life.

Keywords: Chronic disease; self-care; chronic condition; patient’s perspective.

Introduction

Increasing the quality of life and life expectancy of patients at acceptable levels requires the study of the ethical dimension of medical care. This allows knowledge and understanding of the mechanisms by which individuals are subjectively integrating the medical act, transforming it into an element of increasing the quality of life (Vlădescu, Astărăstoae, & Scîntee, 2010). The integration of the medical act is a form of describing the way to "resign" the current experience of being assisted in the medical services of the patient (and family members); the ethical posture invoked can be used by the right of everyone involved in the act of assisting the person in distress, of having their "Voice" recognized and taken into account.

Literature Review

The concern for studying the construction of autonomy and responsibility in chronic illness requires a series of contextualizations related to the specific features of each chronic disease (disabling conditions, marginalization and social vulnerability, etc.) (Oprea, Cojocaru, Sandu, 2013; Sandu, 2016; Sandu, Necula, Frunza, Unguru, & Damian, 2017; Sandu, Neculau, & Damian, 2018). Because chronic illness requires ongoing medical care (Damian, Oltean, & Damian, 2018; Gemene, Unguru, & Sandu, 2018), the issue of effectiveness of care strategies and balance can be raised in the degree of involvement of physicians and patients in the therapeutic process. The participation of professionals and patients in the care process involves, on the one hand, the availability of patients to self-respond in the care process (Popescu, 2018, Şerban & Tătaru, 2018), but also requires the support of care providers in informing patients and supporting their autonomy, as well as a collaborative process to optimize their long-term results.

The new concept of the term health behavior is related to the description of autonomous individuals who can choose whether to act in response to a disease, or in order to maintain their health.

Understanding the disease in relation to a number of biological and social predictors led to the development of risk factor medicine (Armstrong, 1995) and allowed the development of the lifestyle concept, and the behaviors of individuals were analyzed with a grid less deterministic, emphasizing the capacity of action, choice, and autonomy of the individual in matters related to his condition of health.
Over the past two decades, the new approach to health behavior has seen the patient as a person making autonomous choices about how to act or not to act concerning his health. This reflection has also expanded on the physician's behavior, or the potential impact it might have on patients. The benefits of this approach to individuals' health behaviors, which emphasize its social capacity, would be to reduce costs and lower pressure on the health system, increase individual autonomy and improve their health, but raises a number of other issues.

The relationship between the lifestyle / behavior of adolescents suffering from these chronic diseases and their own well-being can highlight the need to adapt health-related programs in the country or in the European Union, both preventive and for health check. In this respect, the international literature analyzes the impact of psychosocial counseling on the behaviour of young people with diabetes (Channon, Smith, & Gregory, 2003). This study concluded the importance of motivational counseling in improving the autonomy and responsibility of adolescents with diabetes.

Victoria Franklin and colleagues concluded that current strategies in working with insulin-dependent adolescents are costly, focusing on new ways of developing autonomy and responsibility towards their own health through the use of modern technology (Franklin, Waller, Pagliari, & Greene, 2003).

Increasing the responsibility (Frunza, Frunză, Bobb, & Grad, 2010) assumed by patients for self-care (Sachs, 1996) can create specific challenges for those with multiple problems, such as worsening a problem by treating another (Nolte & McKee, 2008).

A study conducted in Taiwan shows the importance of developing responsibility for one's own health and managing one's own life by developing a wide discussion of self-management in adolescents (Chang, Chiou, Lin, Lin, & Tai, 2005).

**Methodological design**

**Purpose:** The research aims at understanding the social construction of chronic disease from the patient's perspective.

**Objectives:** The research aims at highlighting the perspective of patients - diabetic chronicles - on the significance of their chronic illness and the dimensions of self-care management.

**Data collection:** The research is based on a secondary data analysis, focus groups and interviews with patients with insulin-dependent diabetes mellitus. The interviews and the focus group were taken in 2011-2012 in the
N.−E. area of Romania. The initial research aimed to answer the question: *What is the influence of the national diabetes program on the self-care behavior of the young diabetic patients?*, and in its entirety the research’s theme is the lifestyle and the health behavior of the patients with chronic diseases. The sample was a qualitative one, the participants being selected through the snowball method, 18 to 32-year-old patients in the studied region, diagnosed with insulin-dependent diabetes. The focus group was attended by 6 people, 5 female and one male, and four other patients, three female and 1 male, participated in the subsequent interviews, at the time of the study, the model for the topic considered in the research being saturated. At this time, there were selected un-analysed or only partially analyzed data at that time, being subject to a new coding process for qualitative analysis of the type of content analysis.

**Data Interpretation**

The results will be presented in the form of discursive categories, resulting from the analysis of interviews and focus groups. The phrases quoted by the assignment belong to the interviewees and are marked with I for the interview and FG for the participants in the focus group, the number following showing which of the interviewees is the one quoted.

**The experience of chronic illness is always unexpected.**

The subjective experience of the onset of chronic illness, especially one with disabling perspectives, and with minimal or no chance of complete healing, appears to both patients and caregivers as *unexpected* and unprepared. Symptomatology is usually difficult to understand for them, therefore, medical consultation can be a savior when the disease is detected early.

*The baby got sick and we did not know what he had. Having nothing to do with this in the family, having nothing in common with this disease, we did not know what was happening to him. He was drinking plenty of water and we took him to the doctor, and the family doctor told me: "He might have diabetes," he had 116 the first time he went. (...) We took him to take analysis and the first time he had 116 blood glucose. The family doctor when I went with the analyzes told me he might be diabetic. What means not to know. (FG1).*

The onset of chronic illnesses is experienced as an acute symptomatology, which sometimes requires intervention in emergency, even
in intensive care units, after which the anatomical and physiological changes specific to the disease are instituted.

I went straight to the hospital, instead of the family doctor, went straight to the "St. M", and there they put him directly into intensive care, I was asked to sign that I agreed to the treatment. When he got better, they took him to the salon (FG2).

Psychological response to diagnosis

The experience of contact with the chronic illness appears as an expression of impotence, in the face of the inevitable, often expressed in desperation, anxiety, and tears.

I started crying. This is the first reaction and I always cry when I think about it (FG1).

(...) I went out to the window ... there were those bars ... I grabbed the bars, I just did not have the power, I was all the way down. By the time I started to learn what it was like, when they let me go home it was really hard, for my mother had to go to work, father is gone and I did it myself (FG4).

Chronic illness generates a major trauma for both the patient and their caregivers, and can lead to their health being impaired.

We, as parents ... He then did not realize this at 7 years old. Our reaction as parents was disastrous. My husband immediately, 2 weeks after, had a stroke. You realize that it has not been easy at all. We still had problems (FG2).

I’m still not happy about it, even 2 years later, something is wrong. Nothing consoles me (FG5).

Sometimes the patient searches online about the symptoms he feels, having a potential idea about a diagnosis,

When I got to the hospital I was already firmly convinced that I had diabetes, my reaction was tough when I looked over the internet and I saw that, yes, these are all symptoms, and something told me that I definitely had diabetes (FG3).
The outlook for chronic illness and the necessary lifestyle is attributed to the degree of discomfort experienced by the patient during therapy, and later in everyday life, and also to the way in which people around the world present their perspectives on the disease and the problems they will face.

They had given me glucose in the infusion, and I was taken to reanimation. When they took me to the 6th floor, there I did not know what this diabetes was, and there was a girl in the lower salon that started telling me that I can not have children anymore, not that, not that ... When I heard about the stuff I would do daily, all my life with 4 injections a day... tears started to flow (FG3).

A truly dramatic situation can occur when comorbidities, and associated illnesses occur. Chronic illness affects the patient’s social functioning, making it impossible to integrate into work, and with it drastically limiting access to the material and financial resources needed for self-care. In this context, it is the state's duty to create compensatory social policies.

As long as I worked, I did not say I had diabetes so they would hire me, and went into a coma and so they caught me there, I can not work anymore. Now, I experience as many as four crises, these hypoglycemic comas have been combined with cognitive crises, the staff from neurology explained to me, so convulsions occur ... When I worked at pedagogical high school, I fell in the middle of the class and the children believed I was drunk, and filmed me all very happy that they found a teacher who was drunk and fell in the middle of the class. There was a medical system, I was lucky, they took me out of the coma, they put it right in the corner of my mouth because I had convulsions and I could drown, and they saved me. These comas have destroyed my cerebral cortex and things got a lot more complicated (FG2).

**Awareness of the (chronic) disease**

The condition of chronic illness requires a certain awareness of the disease as a life situation, of your limitations that occur due to the chronic illness status, and the life perspectives, including the lifestyle and the quality of life that arise from the disease.

(...) they ended up having problems because they really did not want to become aware of the disease (FG1).
Chronic condition. Between rigor of self-care and therapeutic odds

As far as the care of the chronic illness is concerned, they regard their medical situation as a waste, sometimes resorting to religious exposures, in terms of guilt, sin, the punishing intervention of the Divinity, or, on the contrary, of malevolent, demonic beings.

I always wonder why I did my diabetes when I was 12, as long as I did not hurt anyone, which is why I'm not interested in anything about the Divinity (FG2) anymore.

The outlook for chronic disease is correlated with survival chances, being expressed in terms of appropriate medication, disease detection capabilities, medical equipment, competent physicians.

Madam, you're lucky, my saloon colleagues have not lived since 1986, who were children back then. So they were born at a time that had tests, and insulin, and specialists. (...) In the sense that you have all the medication needed to be alive for a long time (FG2).

The experience of disease as a burden is correlated with the perseverance of life as a gift, for which the patient give thanks to nature, divinity, physicians, or himself.

Anyway, there are a lot of children besides the 25-year-olds who were with me in the salon, that is, I say thank you that I am still alive and ... I would have wanted to do diabetes at age 40 or later, not at 12 (FG2) ..

Another frequent position in the face of the frustration of the chronic illness is the hope of discovering a miraculous remedy either by medical research or by other therapists, such as the natural medicine, but also the magico-ritual practices, traditional or new ones.

We still hope that something can be invented, maybe ... (FG1).

Attention is drawn to the need for information on lifestyle and the specific way of self-care. In the absence of such information, the quality of life, as well as that of self-care, leaves much to be desired.
As nurses who treat illness, they come out of school benches and know nothing, but they are at the diabetes department. You go and ask for information, the baby is in the hospital and they have a phase when they get hungry for one thing or the other, when they start the insulin. Nobody told me to give him a piece of meat, something to chew, because it does not have carbohydrates. The baby cried and wept that she was hungry, I told her she had to eat by the hour (FG2).

The illness between social acceptance and discrimination

The chronic patient needs a series of affirmative measures to be able to perform normally in the society. One of the participants in the focus group showed that his child was admitted to school under chronic illness, the school adapting their schedule to his needs, placing the disciplines that were more difficult and required a stronger focus first, in order for that child to able to cope with school requirements.

So they changed the schedule because she was the only child with diabetes in school, and of course in the classroom. And they put the classes that got them tired, such as mathematics first, because if they put them last, he could not face it anymore. He was in third grade when he was learning in the afternoon, had to leave the house with the package, you can imagine there is a long way from home and with the insulin... the teacher told me that since he had to do it there, he lost almost an hour every day because he has to inject, test and eat, and he went behind the class in the last bench, and of course it takes time. It's as if he was absent for that class, and he also distracted the class's attention (FG3).

For the patient, in this case the diabetic, it is a positive experience to be accepted by and in the community. The support received from colleagues, and the feeling of belonging may be the binder of a therapeutic alliance that includes the patient, and in which, along with him and the attending physician, to include the caregivers, as well as various support networks in the patient's social environment.

From the point of view of my colleagues and teachers, the teachers are really .... They have never had anything to complain with the fact that I get out of the class to get my injection or I have to go to the cabinet or eat during the hour, even if it is not quite a normal thing ... (FG5).

Patients with chronic illnesses can often be subjected to different forms of discrimination, ranging from physical isolation due to the fear of
contagion that members of the patient’s entourage have, to social isolation due to the refusal to accept a person who is clearly different from others, due to the lifestyle required by the state of health. In the case of certain illnesses whose triggering may have, among other causes, also a series of risk behaviors, smoking, food consumption / excessive sweet consumption in case of diabetes, sedentary behavior, erotic behavior considered to be promiscuous, etc., lead to the patient’s blame for his condition, either on the basis of an alleged lack of responsibility for the state of health, or from beliefs of religious nature that presume that certain illnesses arise as a result of committing sins, being a divine punishment.

In the beginning I was in middle school, about 5th grade, very few people knew about diabetes and many did not know where it would transmit if they touched me ... they were not educated (FG1).

In the case of diabetes, social exclusion is rarer but still present, which is why many patients do not declare that they suffer from the disease, in order not to be socially marginalized.

There are many children at the high school (x. N. N.), almost in every series, but of course, they have not declared themselves. (FG5).

The different... normality

The daily routine of the chronic-diabetic patient begins in the morning, upon waking-up with glucose testing and then the insulin injection, dosed according to the blood glucose level indicated by the test. The existence of such a routine goes beyond simple therapeutic compliance, resulting in a genuine concern for self-care as a daily management of one's own health. Self-care requires patient’s responsibility for their own health condition, doubled, where possible, especially in the case of child patients, by supervisors.

In the morning if I wake up and ... so he has to do his injection at 7 o'clock, and if I woke up at 7 o'clock or 8 sometimes, and I notice there is no movement through the house, I shout and ask, and if he injected it, I leave him alone. No, he is conscious and takes care of the injection (FG3)

Self-care requires the formation of daily routines for diabetic disease, these routines are related to insulin administration and diet, constant
glycemic measuring, and insulin dose adjustments to body needs based on self-testing of blood glucose levels.

*He never takes what is necessary to school (to do the insulin injection n.n.), he does it when he comes home. He does not even eat or even if (…), God forbid, if there was an emergency. He immediately comes home and makes the injection and eats and then leaves. (…) It's up to him whether he's taking it with him, if he knows he's late, he's going to go to a colleague or something, be either take his injection with him, or he comes home and does it. So, if he goes to a party, I told you, he takes the injection with him. (FG5).*

The necessary lifestyle for the care of the patient's chronic health interferes with his daily duties, either of service or otherwise, diminishing his ability to perform in the chosen social roles. As such, the patient has to place his health care in the first place, avoiding its damaging. When the lifestyle followed is appropriate, besides discomforts related to glucose control and correct calibration of insulin levels, diabetic disease can be considered as a normal state of life with the obligation to exercise an effective lifestyle control. This does not apply to other chronic diseases such as renal or psychiatric illnesses. However, the diabetic patient may feel the necessity of a particular lifestyle as a limitation of his / her functional autonomy, due to his / her health condition, seeing himself in a social position of inertia, of social disadvantage.

*I have the schedule ... I work in shifts, in 3 shifts and depending on what shifts I am in. If I'm in the morning, I wake up at 5 and do the test, insulin and have something to eat if I'm hungry then. If not, I take a snack to work, I also have insulin and tests at work and according to that. When I come from work the same way and I check my blood sugar in the night shift, then it's a bit more delicate. For example, I talked to the doctor the last time I went, and I told her this and she told me that at 3 o'clock in the morning there may be a minimum of blood glucose (…) (FG6).*

In the daily routine of the chronic-diabetic patient arises a certain form of body knowledge, familiarity with the symptoms, according to which the patient adjusts the lifestyle and even the therapy he / she self-administers in accordance with the therapeutic schemes learned in time.
I do not live with my parents and I have to take care of myself. I wake up in the morning the same way, I get my blood sugar checked, I make my own injection, I quickly boil an egg, that when I eat... For example, at noon maybe I do not eat I'm not hungry or, I do not know, I do not... In the morning I eat, at 1 o'clock, usually I initially did a quick act and I got used to somehow, after the program that I had with a quick act. I do it at school if I feel like I have high blood sugar, and I feel the same way when I do hipo, or when I have the same high blood glucose, I get dizzy, my head hurts (FG5).

An important problem with self-care is the patient's ability to care for himself, the functional autonomy of the patient. If, for example, due to its deficiencies, in view of the person interviewed, he/she can not perform the necessary self-care operations, checking that the needle from the syringe is not blocked with blood, in the interviewee's vision, limits the quality of the therapy with major implications for the patient's state of health.

(...) because the needle gets stuck, and he does not see it, it gets stuck with blood, there is no point in doing it, why does he have high blood sugar? The fact is that the needle is full of blood and he does not see to verify that it needs to be checked (FG3).

The self-care capacity is dependent on the physiological peculiarities of the individual, and this is a significant cause of stress for the patient. Biological limitations are perceived as psychological limits by the patient, which considerably increases his anguish but also of his or her caregivers. The perception of certain dysfunctions may be understood by some patients as personal failure in self-care management.

I really can not do it, I often get angry when I see it. I have insulin, I have 340, for example, glucose. I make 11 units of insulin, that’s approximately how much I have to do to reduce it. I go somewhere, and when I return I get my blood sugar back - big. It often does not diminish and not that I do not do it right like before, yes, it happened that I was doing it to myself in the same places and it was not absorbing (FG2).

Self-care of the chronic-diabetic patient depends on a timely schedule, and the assessment of medical technology/glucose meter, type of insulin injected etc. depends on the degree of functional autonomy allowed to the patient. Continuous measurement of the glycemic index indirectly
generates a responsibility for their own health condition, expressed in the efficiency of self-care and therapeutic adherence, including lifestyle.

In the morning, at 7 o’clock I injected myself, whether I went to into college or not, and it happened that I did not do it again at lunch because I was in college and I did not eat, but I had my test and I was taking my blood sugar. If it was good, let’s say I ate a pretzel. And if not, I did not eat. And when I was ... I was still taking my tests, taking a break to the bathroom and taking tests and having 200, I made 2-3 units of blood sugar and skipped the meal. It’s not exactly as the ladies say that at 8, 1 or ... depends on the program. I’m doing 2, 3, but before I test it and according to my blood glucose I make my own doses and for now I see that I’m doing okay like this, I have no complications, I have nothing (FG5).

The limitations imposed by the chronical patient status may extend to the reproductive autonomy of the person, the health condition, giving birth becoming counter-indicated. However, some patients may choose to take a number of risks and give birth to some children even if the birth is severely counter-indicated. The decision-making autonomy of the patient, even if the decisions made involves a major risk, is a key element in accepting the chronic condition as a personal normality.

I have a perfectly healthy little girl I gave birth to, although doctors did not let me have her after 20 years of diabetes. I checked in the family, there was no diabetes, so I asked the grandparents, grand-grandparents, and then the doctor encouraged me and I did it (FG4).

Patients feel the need to change their lifestyle to be traumatically, especially when the disease occurs at an age when the individual has an already well-determined lifestyle.

I was lucky, I can say it’s good luck, they discovered my diabetes at 6 years old and I was too young to have a life then, and so I lived with the diabetes. I learned to live with diabetes. But in their case, they unfortunately have it at older age, however, when they have a certain lifestyle, it’s harder to change it. I was diagnosed at 6 years old and I find it very normal (FG5).

The „Export” of Lifestyle

Chronic patients’ belonging are a unique care resource that supports the patient, including by addressing an alternative lifestyle that is consistent
with what is required for the patient. Changing lifestyle can be voluntary, or the result of behavioral changes of most family members, eating habits, free time, daily activities, etc.

For me as a parent is hard, because I have another baby, a little girl who is healthy. When he got sick, the little girl was 6 months old and you realize what I had to give her or what I bought from ... I avoided sweets in the house or cook anything else at the stove or bake anything else because of him, or make jam ... And the program, the hours of meal, where if the small one ... well, after he grew up, I give an example, she ate together with him and he saw it too. We had to make a schedule exactly after him (FG1).

Family support is particularly important for patients, contributing to their therapeutic process. On the other hand, family members who choose to support the patient may sometimes adopt a different lifestyle than the majority, but in accordance with the patient's needs. Lifestyle also turns the lives of people involved in caring for the chronically patient, which in turn becomes more autonomous - the decision to adopt a lifestyle is an autonomous one - but also of responsibility, including to their own health condition.

First of all the family, because you have support, it's good if you have support ... And in my family, they all have adapted to my schedule. That is, before it was to eat differently, now everyone started it, even if I'm not home, they are eating at lunch, in the morning. First of all, for their health, it is good to eat regular meals, so the family is what counts for me the most (FG2).

In the case of families with a diabetic parent, there is an export of intergenerational lifestyle, from parents to children, children being involved in the care of the chronic patient from an early age, at least partially adopting a lifestyle adapted to the needs of the chronic patient. The long-lasting stress caused by the need to care for a family member can generate significant discomfort among the belongers. Discomfort to others leads to a series of frustrations felt by the patient, which is considered socially useless, or even a burden on the shoulders of people. Patients can develop feelings of deep gratitude for family members involved in the care process that they consider to be their personal heroes.
I mean, it's the only person around me who cares about me because when I'm in a coma there's no one to call the ambulance, and she's the only one who does this as long as the state does not grant me the right to a companion (FG2).

Success stories ... in chronic disease

The moments in which the patient experiences a near-normal state is felt as a state of well-being and at the same time as a success of self-care. Efficiency in self-care provides a very good psychological tone, making the patient feel happy, confident and able to overcome the health barriers in living a life as the individual desires. We therefore speak of a particular form of expressive autonomy resulting from the overcoming of the obstacles given by the health condition. Expressive autonomy is correlated in this case with the idea of authenticity, living life as much as possible in accordance with own aspirations.

(...) when I took insulin, after school I got home, made the insulin, I ate and then felt the need to go somewhere, I just felt good, that is, I was happy to have my insulin properly and everything was under control, that is, it made me more (...) First of all this and that helps you very much, I try tomorrow to do the same, if today I could, tomorrow, why could not I? And so, this motivates you to get good blood sugar for the next few days (FG6).

The ability to control disease progression and own health condition allows the chronic patient to trust his self-care capabilities. Once this confidence is generated, the patient feels more comfortable in his / her own position towards the disease, which threatens less the autonomy and control over life. Chronic illness remains a discomfort, a permanent threat to the quality of life of the patient, but as long as the health status of the patient is controled, patients feel in charge of their own life.

That is what I did everyday I did better, I knew I could keep it under control. Then we see how a normal man lives (...). There are few moments like this (FG4).

An important achievement is to accept chronic disease as a condition, a state of being, and not a barrier in one's own life. In this process of chronic disease alchimization, both the psychological state of the patient, and the support he receives from his or her immediate relatives or members of the social networks to which he belongs, are important. The fact that the
individual can generate in his own consciousness an interpretive derivation of the term disease, to the idea of a particular condition of existence, allows us to understand a series of mechanisms of constructing chronic disease as constructive interactions, in which, in the central position, that of expert in his / her own life, we place the patient - the expert patient. Along with him, there are the different health care instances, family and the socio-professional environment, the hospital and the hospital care staff, the polyclinic, the outpatient clinic, the treating physician and other institutions with which the patient has a relationship, and which allows him to manage his / her state of health by making autonomous decisions from the point of view of understanding the situation in which he / she is and of his / her own health condition, but also of expressive autonomy as the authenticity of the patient's experience in the whole system of interactions in which he is involved.

\[ \text{because diabetes simply is not something} \ldots \text{I do not consider it a disease, first of all. For me it is an inconvenience, so to say, that I have to respect a schedule, a treatment, but in the rest it does not prevent me from doing anything. At least in my mind I finally managed to get it down as a barrier, whatever I wanted to do, I did (FG4).} \]

**Discussions and limitations**

The generated model is based on a socio-constructive foundation that emphasizes the analysis of the constitutive elements of the person's discourse about how he takes note of his status of patient, and how he internalizes and generates his meanings through specific processes of interpretative drift from situations impossible to subjectively manage, to special situations, but which can be assumed and can generate a form of expressive autonomy that allows the subject to regain authenticity. The limits of the discursive universe are those of the specificity of the Romanian cultural space, but the results can be extrapolated in general, and there are no sufficiently sensitive cultural responses to enter this secondary data analysis. The limited number of respondents does not allow an analysis of the validity of the model, but a sketch of a working perspective, which can be extrapolated and validated by subsequent quantitative research. Analysis of constructive content analysis has a series of intrinsic limitations due to the adherence to social-constructionist epistemology, which rejects the idea of evidence-based medicine, at least in the sphere of subjective physician-patient relationship and the conditions specific to chronic care.
The key elements of the model of chronic care as a form of social construction of chronic illness

Disease, just like pain, is only an apparently individual experience, being in fact a social experience that is learned during the socialization process. No child understands, from the beginning, from childhood, the significance of the disease as such. It is only after integrating, into a network of explanations and social rules, its own experience gained from contacting certain diseases, that it assimilates what might be called the "social experience" of the disease. The social experience of chronic illness is almost unexpected and instills itself as a state of impotence in the face of the inevitable, being felt as a major trauma that alters the existential perception of both the patient and his or her peers. Often, the condition of a chronic patient is perceived or self-perceived as a result of guilt, either explained in religious terms or in moral terms, more specifically in the form of punishment for sin and / or risk behaviors.

The perception of chronic illness as an alternative normality allows the patient to develop a series of coping strategies to reposition himself at the center of his life, generating his ability to be an expert in his own life. The expert patient becomes able to enter into a therapeutic alliance with all persons involved in the care process, from doctors, medical staff, belongers. It takes place in the process of interpreting the meaning of the concept of chronic illness, from the meaning of disabling disease to the condition of chronic condition, a special existential condition. This existential condition generates a particular form of expressive autonomy, which we can understand as authenticity.

Conclusions

The chronic patient condition requires the patient to have some awareness of the disease as a life situation, the limitations that arise due to the chronic disease status, the lifestyle and the quality of life that arise from the disease. The chronic patient experiences the chronic condition, the normality of his life as what defines him, or will define his whole life.

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