



Understanding the experience of patients who have Crohn's disease*

Compreendendo a vivência do paciente portador de doença de Crohn

Comprendiendo la vivencia del paciente portador de enfermedad de Crohn

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ABSTRACT

Objective: To understand the meaning of having Crohn's Disease. **Methods:** Qualitative study, with a hermeneutic approach. Eight interviews were held, with patients who have a confirmed diagnosis of the disease. The main question of the study was: "what is it like to have Crohn's Disease?". **Results:** The analysis was performed according to a category identified as: changes in the life perspective. The main changing factors of the category were: having a chronic disease, food, fear, lack of freedom, prevention of complications and hope. For doing so, they use a few strategies to overcome the difficulties, developing their own skills to move forward. **Conclusion:** Trying to understand the human nature, knowing how a person is and their feelings are a construction that needs to be improved in the healthcare courses, so that the professionals can provide the necessary support to the patients and offer adequate nursing care.

Keywords: Crohn disease/psychology; Crohn disease/nursing; Chronic illness; Qualitative research

RESUMO

Objetivo: Compreender o significado de ser portador da doença de Crohn. **Métodos:** Estudo qualitativo, com abordagem Hermenêutica. Foram realizadas oito entrevistas com pacientes com diagnóstico confirmado da doença, tendo como questão norteadora "como é ser portador de doença de Crohn?". **Resultados:** Foi identificada a seguinte categoria: Alteração no projeto de vida, a qual teve como principais fatores modificadores: ser doença crônica, alimentação, medo, falta de liberdade, prevenção de complicações e esperança. Os pacientes utilizam para isso algumas estratégias para superar as dificuldades e desenvolver habilidades próprias para seguir em frente. **Conclusão:** Tentar compreender a natureza humana e conhecer o ser e sentir da pessoa é uma construção que precisa ser melhorada nos cursos da área de saúde para que os profissionais possam dar o suporte necessário aos pacientes e oferecer uma assistência de enfermagem adequada.

Descritores: Doença de Crohn/psicologia; Doença de Crohn/enfermagem; Doença crônica; Pesquisa qualitativa

RESUMEN

Objetivo: Comprender el significado de ser portador de la enfermedad de Crohn. **Métodos:** Estudio cualitativo, con abordaje Hermenéutico. Fueron realizadas ocho entrevistas a pacientes con diagnóstico confirmado de la enfermedad, teniendo como pregunta norteadora "¿cómo es ser portador de la enfermedad de Crohn?". **Resultados:** Fue identificada la siguiente categoría: Alteración en el proyecto de vida, la cual tuvo como principales factores modificadores: ser enfermedad crónica, alimentación, miedo, falta de libertad, prevención de complicaciones y esperanza. Los pacientes utilizan para eso algunas estrategias para superar las dificultades y desarrollar habilidades propias para seguir adelante. **Conclusión:** Intentar comprender la naturaleza humana y conocer el ser y sentir de la persona es una construcción que precisa ser mejorada en los cursos del área de la salud para que los profesionales puedan dar el soporte necesario a los pacientes y ofrecer una asistencia de enfermería adecuada.

Descriptores: Enfermedad de Crohn/psicología; Enfermedad de Crohn/enfermería; Enfermedad crónica; Investigación cualitativa

* Extracted from the term paper in Nursing at Universidade Federal de São Paulo - UNIFESP - São Paulo - (SP), Brazil.

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INTRODUCTION

Crohn's Disease (CD) is an inflammatory bowel disease of unknown genesis, which can affect any part of the gastrointestinal tract⁽¹⁻²⁾. The disease is characterized by variable intestinal manifestations, with periods of remission and exacerbation⁽³⁾.

The main clinical symptoms include: fever, abdominal pain, most frequently as a colic of uncertain location, diarrhea and generalized fatigue. Weight loss can also occur. Diarrhea and pain are more frequent when there are colonic involvements⁽⁴⁾. The CD prognostic is not favorable⁽⁵⁾. In most patients, the course is chronic and intermittent, no matter which part is attacked.

Due to its unknown etiology, the clinical treatment of CD is mostly empirical, aiming at decreasing inflammation⁽⁶⁾.

Corticosteroids, which were the first type of medication evaluated systematically, are efficient, although their toxic effects and problems related to corticoreistance often limit its use⁽⁷⁾. Regarding antibiotic therapy, metronidazol is effective as a for treatment anal disease, being as effective as sulfasalazin⁽⁸⁾. Long-term maintenance of the treatment can be necessary, because reincidence is common after interruption. However, extended use of these drugs can cause peripheral neuropathy⁽⁹⁾.

There are two phases of the disease, the active and the silent. In the active phase, the patients desire to eat less and less because of nausea, colic and abdominal distention, and can develop anorexia. Fistulas, diarrhea and fatigue can emerge, which compromises the patient's everyday actions. The silent phase happens when the disease recedes or is pharmacologically controlled, and the main goal is to minimize the emotional tension of these patients, since this tension can trigger the active phase of the disease⁽¹⁰⁾.

The physical and emotional responses to the disease are vary widely. CD, characterized as chronic, can cause inconveniences both during the patient's treatment and concerning the patient's psychological status. Both inconveniences can have impacts on the patient's social life⁽¹¹⁾.

The increased CD incidence helps nurses address the patients, because of an increased contact during hospitalization and outpatient treatment⁽¹²⁾.

An American study observed the importance of inflammatory bowel disease specialist nurses. The patients who were accompanied by these nurses showed significant improvements in their self image, their psychological problems and social relations when compared to patients that had only the usual type of monitoring in the CD patient group, without the active specialist nurses⁽¹³⁻¹⁴⁾. The benefits of this intervention were clear: medical appointments were reduced by about 40% and

hospitalizations by 20%.

Nurses who work with patients with CD should understand the challenges that the patient undergoes and the physical symptoms that lead to great psychological and social impacts. Nurses in these areas need to understand the patient's experience, offer support and express sympathy so that the patient can start accepting the disease, move on and trust the assistance received. As such, the patients can contribute with their own improvement⁽¹⁵⁾.

Although new studies are being developed, only a few of them deal with the patient's experience to understand the changes occurring in their lives due to the disease. It is believed that not only the clinical and surgical treatments should be provided for such patients, but also they should also be provided care, in order to take consider facts that the patients believe to be important for their own improvement

So, this study was made in order to understand the meaning, for the patient, of having Crohn's Disease.

METHODS

We sought a method that could be suitable to understand the meaning of having CD, . Therefore, we decided for qualitative research, because "it deals with the meanings, reasons, beliefs, values and attitudes, which correspond to a deeper connection space"⁽¹⁶⁾. The questions of this study need to be answered through an analysis that considers the reality of the meanings, values, history and culture, which means Man himself⁽¹⁷⁾. In this context, qualitative research appears as a promising type of scientific investigation, because it is different from positivism. In other words, it is comprehensive or interpretative.

Besides, one of the main characteristics of qualitative research is the possibility of dealing with subjective data, because statistical methods do not allow us to reach the meanings inside the social relations. Qualitative research tries to understand the human being as a part of the universe, and how man and universe are constantly related⁽¹⁶⁾.

With the goal of understanding the meanings and to analyze them, we chose qualitative research with a Hermeneutic approach. Although there are no generally accepted definitions, hermeneutic means understanding and interpretation. We can say that human beings generate meanings, and that their world is built on exchanges between people and the language. So, the meanings can be understood as testimony resulting from dialogue⁽¹⁸⁾.

Therefore, we can say that there is a mediating act between the interpreter and the interpreted. In other words, meanings can not be placed on the interpreter or the interpreted, only to the result of this intervention.

The meaning comes from an interpretative act and is better understood during the period of comprehension, but it depends on the effective participation in the story, so that whatever is understood starts to make sense, based on its union with the things we already know⁽¹⁸⁾.

A person who is keen on understanding someone should listen to what the other person has to say, and this can only be done based on the listener's experiences. It seems like there is no way to understand a person who belongs or not to our culture, based in our own meanings. Understanding is more than just recreating the meanings from the other person. It involves having the interpreter delve deeply in what he wants to understand, based on the expectations related to the senses⁽¹⁹⁾. Language is how hermeneutic works. According to Ricoeur, the man is the language, and, through language, the human being can express their awareness and critical view of the world⁽²⁰⁾.

The study was performed in the Gastroenterology outpatient clinic of Hospital São Paulo, and data collection occurred between March and April, 2007. Eight patients of both genders, aged 20 to 59 years, were interviewed. In order to be included in the study, the patient had to have a confirmed CD diagnosis and be over 18 years old. The number of people was determined by the saturation criteria based on the collected data.

After receiving approval from the UNIFESP Review Board (File #0153/07), the patients were informed about the purpose of the study and signed the term of consent.

Data was collected by the interviewers through an interview, which was recorded and transcribed afterwards. The main question was: "what is it like for you to have Crohn's Disease?"

Data analysis followed the Giorgi⁽²¹⁾ method, that suggests four steps for the analysis: general reading of the interview, to have a general idea about what was said; re-reading it, in order to identify each "unit of meaning" inside the desired perspective; expressing the contents of each unit of sense and, finally, the researcher summarizes a consistent declaration, related to the most important part of the person's experience and identifies the category by joining the main ideas taken from each interview.

RESULTS

The analysis is made based upon a category that appeared at the end of the process of joining the significant ideas. This category was called "changes in the life perspective". Parts of the patient's declarations are used as examples at the end of the descriptions. The interviews have identification numbers from E1 to E8, to preserve the patients' anonymity without losing the identification of each interview.

"Changes in the life Perspective" is the situation that occurs when the patients have to change their old habits,

attitudes and behavior in the long, medium and short terms due to the disease. It causes huge transformations in their ways of acting and thinking, related to eating, the emotional aspects, the fact they have a chronic disease, physical changes and also some positive changes in their daily attitudes.

Many different ways of coping with the new health situation have been found in the declarations of these patients. One of them, focusing on the complications that the disease brings, that - as in any other kind of disease - also exist and are prominent through most of their life. These complications were strictly related to the changes in eating habits, which changed because of the fear of pain; the fear of transmitting the disease to their offspring; the behavioral changes related to family, spouses and children; chronic disease itself and the lack of freedom.

The other way, however, was a positive change, in which the patient starts develop healthier eating habits, do sports, prevent complications and have an optimistic view of the disease and the future, and they hope for a possible cure.

The information that CD is a chronic disease is among the first that the patient receives from the physician. The fact of being incurable causes fear in the patient, because many of them have never had any disease before. From that moment on, they will have to have periodic appointments, take medicine, make periodic exams and go to hospital and consulting rooms.

"Yeab, I was shocked because the first time I came here I had to be hospitalized and they found the disease, and then they said that it was a chronic disease... chronic... that was the worst part, because chronic is something for the rest of life... chronic... then they said "medicine you will have to take for the rest of your life", it was something, it was a shock..." (E2)

Changes in eating habits were important to some patients, who had no choice but to change their habits. They had difficulties with the food, because they missed other types of food they used to eat before and were discouraged because of the restrictions caused by the disease. Some were afraid of eating and feeling pain, or even vomiting. That was the reason why they did not eat a proper quantity of food and or as often as they should to keep their bodies well. That happened because they related food with pain.

Some patients try to prevent the pain caused by the inappropriate food by avoiding the food that caused the pain. They believe that this is the best way to keep a good diet, without pain.

Not being able to participate in social activities such as dinners and parties causes depression in the patients, who feel sad as a consequence.

Some of them realize that changing their diet can be a

positive factor, because now they eat adequately and have a healthy diet. They believe that the disease increased their self care and concerns about health, which did not exist before.

"That has changed: I had many things that I liked to eat and today I can't anymore. Sometimes I go to a party or a wedding or an anniversary and there is a lot of food, and I have to avoid eating all these things. There are some times that I get sad, I see everybody eating and I can just keep on looking" (E3)

"I have also lost a lot of weight, I was not like this. In the beginning I thought it was good, I thought 'at least I am going to get thin'. But it is another kind of thinness, it is sad". (E7)

Fear is another emotion that follows patients with CD. The possibility of feeling strong pains and having to go to the hospital to undergo surgery is dreadful for them.

"Yes, I am afraid of getting worse and to go to the surgery and to take off my intestine and to excrete through my belly, I think that if it happens I'd rather die, I can't handle this... It is very difficult..." (E7)

Another concern is self-image. The patients feel that their body is not attractive enough, because of the surgeries or the thinness. They develop low self-esteem and believe that other people observe their bodies. In younger patients, the fear of not being able to keep up with their plans of having a family (marrying and having children) was very important.

Self-esteem is also affected when the patients start to think that they are different from other people, and many times worse than them, because they have a disease. It affects their relationships, because they feel guilty for not making their partners happy. They also feel lonely because they think that they have to face the problems of the disease by themselves.

"I get sad, because when I am walking everybody looks at me. Yeah, of course, everybody looks at me, if you see a very thin person or a very fat person you are going to look at them, other people are going to look at them, there is no way. Your eyes are there, if you see an obese person you are going to look at her, if you see a very thin person... But I don't know what this person is going to feel". (E1)

The fear of transmitting the disease to their descendents, specially the children and closest relatives was very important for the patients. They feel guilty and are afraid of causing the disease in another person.

Many of them believe that emotional instability can bring back the crisis and activate the disease. Besides, the of instability their health brings uncertainty about what can happen to them. As such, they feel weak, susceptible and are not sure about setting commitments in advance.

Many times they feel like they are in prison because of the disease, and it upsets them. The lack of freedom to decide what they can or cannot do with their own lives is one of their complaints.

"I am afraid of many things, afraid of not being able to have children, feeling pain when I am with my boyfriend. When I am with my boyfriend I am afraid of feeling pain, and I don't know if it is because I think about it, but sometimes I really feel the pain. We have almost broke up, but he is very nice to me. Life changes, you are never the same again, you get scared of everything you do, it is a very depressing disease" (E7)

There are some patients who face this moment as a positive situation in their lives, which has improved their health and showed that even if they have a chronic disease, they can lead a normal life.

Some of them have already undergone difficult moments, and they might have felt unhappy at that time, but they found something positive in the disease.

For some of them, the beginning of the disease was painful and with a lot of suffering. But when they were informed of the diagnosis and started the treatment, they gradually felt better. They realized that there were some limitations, but they adapted themselves to these limitations and learned how to live with them.

"There is nothing for me to complain about, I am feeling good, I am happy, I'm ok with the medicine and with the rest of the treatment, everything is just fine. I know that I have my limitations, that I can't go out and eat a lot of junk, or skip going to the restroom because it makes everything worse, but this is not a reason for me to stay home, depressed. I think I have started to see life in another way, in a positive way". (E5)

Besides, some patients believe that having a chronic disease is a challenge and it is necessary to adapt at and accept that the disease is a part of this process. Some of them say that the disease made them improve themselves, because it was necessary to understand how the disease works for them to be able to make the right decisions about the adaptation. Also, it was important to listen to people that were able to help and take concrete action for these improvements.

Another important factor was looking for and finding other people with the same diagnosis, so that they could share their fears, insecurities, experiences and provide support for each other.

Some patients read about the disease and try to take good care of themselves so that they can prevent complications. They take action to prevent crises and general changes, so that they can better coexist with the disease, and not be afraid of the complications.

They realize that the disease brought many changes,

but most of these were good for them, turning them into better people, less stressed, happier, braver to fight against problems, happier in their lives and with their friends, and also healthier. That is why they believe that the disease was good, because of the positive changes that everybody should promote in their lives, even without the disease.

"I started to enjoy life in a healthier way. Actually, the disease was good, I started to take care of myself, and it makes me happy." (E8)

"The diet has changed a little, but it changed to a better diet, because now I eat healthier things and it is good for everyone, having a disease or not" (E6)

Many patients hope that a cure will be found. Some believe that it would be easier to keep on living without the disease. For others, however, this hope is a way to keep on living, which means that the hope makes them wish for life. Many do not want to lose this expectation; otherwise it would be very difficult to find strength to fight the disease.

"It is good for me to know that the scientists are researching about the disease, I hope that they will find the cure soon, that I can be free of the disease. This thing, hope, I think it helps as well, and since I am feeling good, I think I get more excited to keep on living. But that's it, the most important is to feel good, right?" (E4)

DISCUSSION

CD jeopardizes more than the biological aspects. The disease interferes in the patient's lifestyle in different ways, in their family and the society.

When they are informed about the diagnosis, many of them experience emotional disarray. Afterwards, they start feeling that important changes will take place in the course of their lives.

The patients start to have different feelings and behaviors because of the changes in physical and emotional capacity - as observed in the analysis of the interview, and one of the main factors is the chronic disease itself.

The complexity and the extension of the problem of having a chronic disease has led many authors to develop studies to analyze the impact of this condition in a person's life and all the changes in their lives, regarding several aspects such as: fear, self-control, self-image, family changes, food⁽²²⁾.

Authors observe that patients start to take on new responsibilities when realize that their disease is chronic. One of them is starting treatment, which means taking medicine for the rest of their lives, and, studying about the disease and dealing with the physical and social consequences. The patients lose part of their social

relations, work and leisure time, and realize that their appearance is threatened⁽²³⁾.

There are also changes in family relations, which depend on the structure of each person's family. Family changes with the patient, by searching for stability and trying to accept the disease⁽²⁴⁾.

Fear is also a common feeling for a person who has a chronic disease, and is shown in different ways. Some of these ways is the fear of being incapable and of worsening clinical symptoms, which can bring anxiety. Fear is "a feeling of inquietude when presented with a real or imaginary hazard, i.e., a threat"⁽²⁵⁾. The patients start to fear the pain or that it will worsen, and feel insecure about the state of their health. Often, they face their fear and overcome it, but sometimes they can also accept them and make changes in their lives because of this fear.

Besides the emotional difficulties, there are also physical changes that can hinder social life. One of them, related by CD patients, is the loss of weight. The patients feel that they are different from other people and sometimes feel estranged. It happens because everybody builds an image of their own body that is adjusted according to their habits and their environment. This image has to be compatible with their needs, so that somehow they can be situated in the world⁽²⁶⁾.

Food restriction and changes in dietary habits are the causes of weight loss in CD patients. With these restrictions, they start to wish that they could "eat like a normal person would" and face these restrictions as "punishment", which brings them to a feeling of indignation. Polivy⁽²⁷⁾ explains that food restrictions can cause psychological manifestations, such as concerns about food and eating, increasing emotional instability, mood swings and lack of concentration⁽²⁸⁾. All of this increases stressing situations in these patients.

Stress is composed by some physiological reactions that, when amplified in intensity or duration, can cause disorders in the organism⁽²⁹⁾, affecting the whole body and bringing symptoms that are variable in each person. There is a personal sensitivity that reacts when we face a problem, and this sensitivity shows how we deal with challenging situations, deciding to either face them or not. All the important changes we undergo in life are stressful situations, even if they are good changes and make us happy⁽³⁰⁾.

Therefore, it is possible to understand that having a chronic disease such as CD affects their individuality and the way in which each person. Patients use some strategies to adapt to their new reality, overcome difficulties and develop their own skills to move on in life.

It seems that patients search for resources when they explain that the chronic disease brought positive aspects, such as the concerns for their health and body, the increase of self-care and the search for information about the disease.

These results seem to find answers in the Coping's theory, which states that one way for a person to respond to a stressing situation is by searching for alternatives, so that they can cope with having a chronic disease. The patient searches for internal resources to escape from the problems, starts to see the positive points and learns how to live with the negative ones⁽³¹⁾.

CONCLUSION

We realized that the modifications that occur in patients who have CD are extremely important and capable of changing completely their lifestyle, turning them into different people after being informed of the diagnoses. That happens because the patients suffer physical changes when they lose weight, an inadequate diet or even when they undergo surgical procedures. Also, there are psychological changes, such as fear and apprehension, which they did not have before.

We could also realize that these changes not only affect the patients but also their families and social life, because they start to behave in ways that change their environment

and the lives of other people.

They are patients who have to undergo long-term treatments and be monitored for a long period, and sometimes they do not have the chance to express themselves freely to physicians and other healthcare professionals. These professionals sometimes cannot understand them or adequate the treatment in ways that will improve their quality of life.

Trying to understand human nature, knowing people and their feelings through sciences such as Philosophy and Psychology, are constructions that need to be improved in the healthcare courses, so that professionals can provide the necessary support to patients.

Most of the time, the nurse is the professional that approaches the patient. As such, it is necessary to introduce concepts in their education that make their self-knowledge, as well as knowledge of other people easier, so that they can better understand the patients' necessities and experiences.

Humanistic education is necessary to better qualify the nurse, as well as contributing to better care for the patient with a chronic disease.

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