159 - CYSTIC FIBROSIS: MULTIPLE PERSPECTIVES OF BEING FIBROCYSTIC

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INTRODUCTION

Cystic fibrosis is an autonomic recessive hereditary disease that provides changes in the ions and water guiding through the cells, determining the production of a thick secretion by exocrine glands, resulting in impairments related to conditions such as an obstructive tube in organs like the lung and pancreas (RIBEIRO et al., 2002). It represents the most frequent cause of chronic progressive lung disease and pancreatic insufficiency in childhood (FAGUNDES et al., 2005). The respiratory disorder is related to high morbidity and 90% of deaths, and the pancreatic lack to cases of poor digestion, protein-energy, innutrition and changes in weight and height development (RIBEIRO et al., 2002).

It was first described in 1938, that time the life expectation was about 6 months (Davis, 2006). Guided studies in the last few years enabled the development of new therapeutic modalities (ALVAREZ et al., 2004) which increased survival and improved quality of life of patients (RIBEIRO et al., 2002). These days the average of survival can exceed 30 years (Davis, 2006). Due to that fact, happened an increase in the number of children, teenagers and young adults who has cystic fibrosis, changing the epidemiological board (PIZZIGNACCO and LIMA, 2006). Moreover social and emotional problems related came (REIS et al., 2000). The experience of chronic illness, is a personal. The routine of exams, evaluations, hospitalizations and treatments, change the schooling, development, and socialization of the fibrocystics (Vieira and Lima, 2002).

To treat people with chronic disease, it is important to help the human being to identify all their needs, making this process more efficient, because the physical care is joined to the affective and emotional care. The team treating the patient, most of time used to live with people presenting a heavy disease, can consider the situation common and simple to be solved, failing to offer a full and proper assistance (Pinto et al., 2005).

OBJECTIVE

Unveil the experience of being a fibrocystics, for understanding how these individuals live the health-disease process makes the act of caring more human, significantly affects treatment adherence and the outcomes of health interventions.

METHODS

This is a descriptive exploratory study of qualitative phenomenological nature. The population of study was compound of cystic fibrosis patients treated and followed to the Cystic Fibrosis Clinic, in the University Hospital of Western Paraná (HUOP), located in Cascavel city in the Paraná State, in 2009. It was scheduled visits to their homes, considering that the fibrocystics in this environment would feel more comfortable to talk. Data collection was performed using a semi-structured interview, based on the guiding question: "To you, what is to be a fibrocystics?" The interviews were all recorded and transcribed for later analysis.

The transcribed texts of the interviews were identified by the letter "C" for children, “A” for teenagers and "AD" for adults, followed by numbers and its analysis was based on some directions (GIORGI, 2003): reading of each text fully transcribed (dip in speeches), reading of each text keeping in the guiding question, identifying "claims" that show to relevant meanings; grouping of statements with similar meanings, claims joining and to know the essence of the phenomenon, it was made a comprehensive analysis of these "units of meaning." This study was approved by the Ethics in Human Research of the State University of Maringá (UEM) (661/2008).

RESULTS AND DISCUSSION

In the patients' list of the Cystic Fibrosis HUOP with names of 19 people interviewed, just a mother that had two children with the disease didn't agree to participate of the study. Regarding to fibrocystics, 3 were male and 14 female. 10 (58.82%) were children between 6 months and 9 years old, 5 (29.41%) were teenagers aged 12 to 18 years old and two (11.76%) were adults, one of them is 22 and another is 28. Of these 17 fibrocystics, were interviewed two children, five teenagers and two adults. The two children interviewed are 9 years old, and the others were not mentioned, because of the young age couldn't verbalize their experiences. A tiresome reading of the speeches of those people allowed showing the phenomenon to be a fibrocystics through three units of meaning, as described below.

Being a fibrocystics: having a treatment routine

Hearing the guiding question, the reactions were different among children, teenagers and adults. Children were thoughtful and took some minutes to answer. Maybe because they had never thought about the reality of "being a person who has cystic fibrosis." It was related their condition with the treatment routine that they must follow, which is not noticed as an obstacle in their lives. The teenagers expressed some surprise, and answered promptly that they were normal, like any other person of the same age, and that as children, also had a routine treatment because of cystic fibrosis. The adults showed tired facial expressions and a kind of stress while they were describing their treatment routine. However, keeping on with all care because of the illness is a reason of worrying and many of daily activities are influenced direct or indirectly by that routine.

“I feel good. [...] I do the right inhalations. I take all medicine "(C2)."[...] So normal, I just have to keep on taking some medicine stuff like that, but it is normal.[...] When I'm doing some tasks I must do the inhalation. Before eating, taking medicine. That's it! So it's normal. [...] When I go out, I can't forget to pick up my purse to take the medicine. Normal I go out with my friends, with my cousins” (A5).

"It sucks. It's exhausting. [...] Because it is not a thing you do and stop doing. It's a thing you do every day and you have to redo since you wake until the time you go to sleep. You can't eat without taking an enzyme, you can't leave home without a puff you can't leave home without an inhaler, seretide, something like that [...]" (Ad1).

Cystic fibrosis is a priority in those people's lives and their families (PINTO et al., 2005). Being a chronicle disease, one

of the things you can do is follow the treatment, because everything turns around the signs control (and DUPAS MOREIRA, 2006). The treatment is regular, it happens in more than a moment of the day, which requires time and dedication. The aim is not the cure, but keeping an enjoyable and independent life (PIZZIGNACCO and LIMA, 2006). All interviewed people related to the disease with this routine, who show the impact that the treatment has on their lives. However, it is lived in a different way by people as time passes by, as each part of life presents its own characteristics and also because this process is shared with parents (RAMOS et al., 2008). In childhood moment is the family, highlighting the mother's figure that care more.

Fibrocystic children of this study usually follow the guidelines and determinations of their parents. The teenagers have already begun to assume some responsibilities related to the treatment, but some needed to receive regular demands of the family for that everything runs properly, being encouraged to participate actively in treatment, as they grew with the disease by also be responsible for their health. Adults showed more conscientiousness of their real condition and an idea of ending related to the disease, although none of the interviewed had mentioned the word "death." To face this reality, they try not to think too much about their condition, they prefer to think that chronic illness is something they need to live (and DUPAS MOREIRA, 2006).

"[...] I take the fibrosis as a bronchitis as an asthma, as a normal illness, because if I even think of fibrosis, such as an illness, if I think I get desperate" (AD2).

Adolescence is a stage of transition to adult, where the individuals are going through a phase of changes of their development and personality formation. It is a frightening period marked by rebellion, challenges and self-seek (PELLOSO et al. 2002). Adolescence represents a phase where crises are lived and in these cases they are added to the conflicts related with the disease (RAMOS et al. 2008).

More and more the perfect body is appreciated and the search for health. So people that have some kind of disease are considered different. Therefore comparisons come and may cause changes in self-esteem of the fibrocystics and feelings of discrimination (PINTO et al., 2005). Having a chronic illness is a phenomenon that involves several objective and subjective changes for teenagers. It can mean that one is not like others (SOUZA and OLIVEIRA, 2007).

This is a moment which they want to have their identity and independence, with some difficulties of incorporating the illness into their self-concept. Given the guiding question they may had been confronted with the condition of being "normal" as their friends and to show some "thing" that didn't characterize that way. Perhaps this is one of the reasons why all teenagers interviewed declared that it is normal to have cystic fibrosis, that they lead a normal life like anyone else of their age. The fact they are cystic fibrosis does not change their way of being and living, it can also be another reason for teenagers consider themselves the same as others.

The fibrocystics and the society: the concealment and unveilling of the disease

One of the difficulties found by families visited was the lack of knowledge and information of the population toward to cystic fibrosis. In some homes visited, parents didn't tell the problem to anyone, even to family members outside their group. In other cases, mothers reported not receiving the necessary support of the family. In some situations the fibrocystics themselves chose not to tell other people that they had a serious and incurable disease. Cystic fibrosis, while not causing a noticeable physical change it is an unknown disease to the most of the population. Many people will not look for some information about it when they face with an individual who has it, because it is easier to avoid the situation than to keep in touch with something considered "different".

Health is usually noticed as the opposite of the disease. And who has a disease it is not considered as the others, a normal person. The Chronic illness leaves its mark on the fact of not being tem porary, to be with the person for the rest of his or her life. However, it doesn't mean that the person is always ill or abnormal (and SOUZA LIMA, 2007).

People who live with a cystic fibrosis person notice the signs and symptoms of the disease and because of that, they ask them about the symptoms. It was possible to understand the concern with the opinion and the society's reaction among adolescents and adults. On the other hand children didn't show that.

"At school is normal, just before I eat I take the enzyme, so my friends keep asking, what's that for? What's that for? All the students in the classroom ask, what's that for? I really don't know what to say, I say that if I don't take it, I have diarrhea. I say exactly that to them. They don't ask anything else. They stop nagging me "(A5).

"[...] I don't say what I really have, so people don't know, people of my living in my college, there is a girl she knows about it, because she came to me and said she heard someone talking about it, she doesn't know exactly from whom, saying I had a problem. [...] I explained something, nothing so detailed. But I don't worry about it. At college there are people that I won't see them in some few years, so there's no reason to talk about it, you know "(AD1).

Some hide their diagnosis because many people think the disease is contagious by the possibility of contagion, besides the prejudice and discrimination that leads the fibrocystics hide their illness, in order to avoid embarrassing situations (PIZZIGNACCO and LIMA, 2006). Individuals with chronic disease are afraid of being apart from the interaction of their social group (MOREIRA and DUPAS, 2006). Friends play an important role in their lives because of interpersonal relationship and friendship, characteristic of this phase (Ferreira and Garcia, 2008).

[...] Sometimes we're a bit tired, half breathless, sometimes people don't understand. Do you think…About not knowing the disease people may find it contagious, it can pass in any way, so I think the prejudice of people can mess me up a bit. But at this moment it's not bothering me because I didn't tell anyone, I'm not so close to people to tell them that, the other side of my life "(A2).

Day by day with cystic fibrosis: living with restrictions related to clinical manifestations of disease and hospitalizations

Pulmonary engagement in cystic fibrosis is characterized by a vicious cycle of infection and inflammation with an intense neutral answer, which leads to a progressive obstructive pulmonary disease (SAIMAN, 2004). The pulmonary changing has an early beginning, which would also need an early approach, with the aim of trying to prevent the decay of the lung function, the exacerbations episodes and premature death (ACCURSO, 2006). In the Cystic fibrosis is common the accumulation of viscous mucus in the airways and recurrent respiratory infections. The obstruction blocks the air and gases exchange, related to dyspnea, respiratory distress and effort intolerance. Shortness of breath and fatigue when performing a physical effort, limiting symptoms were reported by respondents in this study. They are common among fibrocystics and may influence some of their day to day.

"[...] I can play a little, but I can't play all the time [... I get tired, I cough (C1). "[...] When we do any effort, we are a bit like that, because you start coughing (A3)."I'm going to walk and I have to take an inhaler, because sometimes I have crisis, some thing (AD2).

Despite the restriction exists, the individuals interviewed didn't give up to accomplish the tasks that other people of their age do. They reported if they guide the treatment correctly they can have a kind of life as anyone else. They know that through self-care can control the disease, reducing its impact (PIZZIGNACCO and LIMA, 2006). So self-care is not understood as something bad, but a necessary attitude for their own well-being (and DUPAS MOREIRA, 2006).

"[...] we can do everything the other teens do. Of course, there are some restrictions, but if you do the right treatment you can have a normal life as anyone else "(A2).

The disease may do that the fibrocystics leave school temporarily and other activities as work. It happens because of clinical manifestations, hospitalizations for complications or a specific treatment.

"Some days you're more tired, you're breathless, then there are other days when you have a headache and you can't go to class, you have to miss classes, you have to do some treatments away from home. [...] There are some of them which you can do at home. Sometimes you have to take medicine in the hospital. If you have classes, you miss. Sometimes you can't work. And based on your health at that moment, you will not be able to work. How are you going to work? One week you work and two weeks you can't. So it's complicated in this way"(A2).

FINAL CONSIDERATIONS

The fact of the interviewed presents a serious disease with no cure didn't change their way of being and living making sure that all of them consider themselves as normal individuals, like anyone else. Cystic fibrosis became a part of their livesand they adapted to it and the treatments routine. Despite having added the disease to their self-concept, lack of knowledge from most of people towards to cystic fibrosis, fear of prejudice and discrimination can limit their social support net injuring the process of adaptation to the disease. Cystic fibrosis and their treatment are always a priority and self-care seen as something necessary and fundamental. They associate their illness to something that they can control and not something that can shorten their life. As time passes by as they grow and develop with the chronic illness, they begin to think more about their prognosis, but they are not limited because of it.

To assist an individual with an incurable disease must involve the understanding of their behavior and actions against a condition that will follow for the rest of life. Most of time is the health team that worries much about "death". Professionals are knownespecially when they have attitudes that are not concentrated only in the technical experience, but also in establishing an empathy bond, dedication and confidence. Patients in this situation consider the health team as a source of important information and support. In this sense, understanding how they understand their experiences enables the re-direction and health changes practices relates to this population.

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CYSTIC FIBROSIS: MULTIPLE PERSPECTIVES OF BEING FIBROCYSTIC

ABSTRACT:

This study aimed to uncover the experience of being a fibrocystic. This is a descriptive exploratory study of qualitative phenomenological nature. The study population consisted of 9 fibrocystic patients: 2 children, 5 teenagers and 2 adults. The data collection was carried out through a semi-structured interview. The analysis of the transcribed speeches allowed us to reveal the phenomenon of being a fibrocystic patient, they experienced that when living with the chronic illness. It was possible to realize that cystic fibrosis was incorporated into their lives and that they have adapted to it. The fact that they have a serious illness and without cure has not changed their way of being and living, making them consider themselves normal people, like any other. The routine of treatments, hospitalizations and self-care are not interpreted as a bad thing, but necessary practices to control the disease for their own benefit.

KEYWORDS: cystic fibrosis, chronic disease, child, adolescent, adult.

FIBROSE CYSTIQUE: MULTIPLES REGARDS DE L'ÊTRE FIBRO-CYSTIQUE

RÉSUMÉ:

Cette étude a comme objectif de comprendre le mode de vie de l´être fibro-cystique. Il s'agit d'une étude descriptive-exploratrice, de caractère qualitatif phenoménologique. La population de l'étude s´est composée de 9 personnes fibro-cystiques : 2 enfants, 5 adolescents et 2 adultes. Le rassemblement des données a été réalisé au moyen d'une entrevue semi-structurée. L'analyse des paroles transcrites dans leur intégralité, a permis de découvrir le phénomène de l'être fibro-cystique, vécu intensément par ceux qui vivent avec la maladie chronique. Il a été possible de comprendre que la fibrose cystique a été incorporée à leurs vies et qu'ils s´y sont adaptés. Le fait qu´ils présentent une maladie grave et sans guérison n'a pas modifié leur forme d'être et de vivre, en faisant tout leur possible pour être considérer comme des personnes normales, comme n´importe quelle autre. La routine des traitements, les hospitalisations et les soins quotidiens personnels ne sont pas interprétés comme quelque chose de négatif, mais comme des pratiques nécessaires pour contrôler la maladie.

MOT-CLÉS: fibrose cystique, maladie chronique, enfant, adolescent, adulte.

FIBROSIS QUÍSTICA: LAS MÚLTIPLES PERSPECTIVAS DE SER FIBROQUÍSTICO

RESUMEN:

Este estudio tuvo como objetivo desvelar la experiencia de ser un fibroquístico. Se trata de un estudio descriptivo-exploratorio, de naturaleza cualitativa fenomenológica. La población del estudio se compuso de 9 fibroquísticos: 2 niños, 5 adolescentes y 2 adultos. La colecta de datos se realizó por medio de una entrevista semiestructurada El análisis de las elocuciónes transcriptas en la íntegra posibilitó descubrir el fenómeno ser un fibroquístico, vivenciado por ellos. Ha sido posible comprender que la fibrosis quística se ha incorporado a sus vidas y que ellos se adaptaron a ella. El hecho que esta enfermedad es grave y que no existe cura no ha cambiado su manera de ser y de vivir, resultando que todos se considerem personas normales, como a cualqueiera otra. La rutina de tratamiento, las hospitalizaciones y el autocuidado no han sido interpretados como algo malo, sino como prácticas necesarias para controlar la enfermedad en beneficio propio.

PALABRAS-CLAVES: fibrosis quística, enfermedad crónica, niño, adolescente, adulto.

FIBROSE CÍSTICA: MÚLTIPLOS OLHARES DO SER FIBROCÍSTICO

RESUMO:

Este estudo teve como objetivo desvelar a vivência de ser um fibrocístico. Trata-se de um estudo descritivo-exploratório, de caráter qualitativo fenomenológico. A população do estudo foi composta por 9 fibrocísticos: 2 crianças, 5 adolescentes e 2 adultos. A coleta de dados foi realizada por meio de uma entrevista semi-estruturada. A análise das falas transcritas na íntegra permitiu desvelar o fenômeno ser um fibrocístico, vivenciado por eles ao conviverem com a doença crônica. Foi possível compreender que a fibrose cística foi incorporada às suas vidas e que eles se adaptaram a ela. O fato de apresentarem uma doença grave e sem cura não modificou a sua forma de ser e de viver, fazendo com que todos se considerem pessoas normais, como qualquer outra. A rotina de tratamentos, as hospitalizações e o auto-cuidado não são interpretados como algo ruim, mas práticas necessárias para controlar a doença em benefício próprio.

PALAVRAS-CHAVE: fibrose cística, doença crônica, criança, adolescente, adulto.