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ORIGINAL ARTICLE

YOUNG ADULTS UNDERGOING HEMODIALYSIS: FROM THE DISCOVERY OF THE DISEASE TODIFFICULTIES FACED IN DIAGNOSIS AND TREATMENT

ADULTO JOVEM EM HEMODIÁLISE: DA DESCOBERTA DA DOENÇA AOS IMPASSES DO DIAGNÓSTICO E DO TRATAMENTO

ADULTO JOVEN EN HEMODIÁLISIS: DESDE LA DESCUBIERTA DE LA ENFERMEDAD HASTA LAS DIFICULTADES DEL DIAGNÓSTICO Y DEL TRATAMIENTO

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ABSTRACT

Objective: to present the speeches of young adults with chronic renal failure undergoing hemodialysis, with regard to first symptoms, diagnosis and treatment of the disease. ***Methods:*** This exploratory, descriptive qualitative study included eight young adults. The data were collected through narrative interviews, unsystematic and field journal observations. The analysis was conducted using an operative proposal. ***Results:*** Young adults narrated their stories from the onset of symptoms of bodily disorder to the search of a diagnosis of chronic renal failure and the impact of disease discovery and hemodialysis treatment. ***Conclusion***: To improve the quality of care, it is important that health professionals are prepared to provide holistic and individualized care to ill people. ***Descriptors:*** Chronic Disease; Renal Failure, Chronic; Renal Dialysis; Culture; Nursing.

RESUMO

Objetivo: apresentar a narrativa de adultos jovens com a doença renal crônica em hemodiálise, quanto aos primeiros sintomas da doença, ao diagnóstico e ao tratamento. ***Método:*** estudo exploratório e descritivo, de abordagem qualitativa, desenvolvido com oito adultos jovens. Os instrumentos para a coleta de dados foram entrevista narrativa, observação assistemática e diário de campo. Para a análise utilizou-se a proposta operativa. ***Resultados:*** os adultos jovens narraram suas histórias desde o surgimento dos primeiros sintomas de desordem corporal, a busca pelo diagnóstico da doença renal crônica, o impacto de sua descoberta e da necessidade do tratamento hemodialítico. ***Conclusão:*** percebe-se a importância de os profissionais da saúde estarem preparados para cuidar das pessoas em adoecimento de um modo singular e holístico, qualificando a atenção prestada. ***Descritores:*** Doença Crônica; Insuficiência Renal Crônica; Diálise Renal; Cultura; Enfermagem.

RESUMEN

Objetivo: presentar la narrativa de los adultos jóvenes con enfermedad renal crónica en hemodiálisis respecto a los primeros síntomas de la enfermedad, su diagnóstico y tratamiento. ***Métodos:*** Estudio exploratorio, descriptivo y cualitativo realizado con ocho jóvenes adultos. Los datos se recolectaron a través de entrevistas narrativas, observación asistemática y diario de campo. Para el análisis de los datos se utilizó la propuesta operativa de Minayo. ***Resultados:*** Los adultos jóvenes cuentan sus historias desde el aparecimiento de los primeros síntomas de desorden corporal hasta la búsqueda del diagnóstico de la enfermedad renal crónica y el impacto de su descubrimiento y de la necesidad de tratamiento hemodialítico. ***Conclusión:*** Se nota la importancia de que los profesionales de salud estén preparados para cuidar a las personas en situación de enfermedad crónica de manera singular y holística, calificando la atención proporcionada. ***Descriptores:*** Enfermedad Crónica; Insuficiencia Renal Crónica; Diálisis Renal; Cultura; Enfermería.

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INTRODUCTION

Chronic renal failure (CRF) is considered to be an important health problem, because it is complex and kits treatment requires different approaches.[1] Although the treatments available for terminal phase CRF reduce symptoms of the disease and increase and increase survival, none of them is curative.[2]

According to a census by the Brazilian Society of Nephrology, in 2013 there were 50,961 people registered for renal replacement therapy in Brazil. Of these, 31.901 were aged 19-64 years.[3]

In the context of CRF and hemodialysis treatment, patients experience a break with their way of life and have to the new condition.[4] Hence, there is a daily struggle for survival as well as for physical, mental and social quality of life. These facts are associated with the disease and with treatment and drastically affect the lives of patients, causing physical, social, nutritional and work limitations.[5]

In this scenario we observe the establishment of a 'partnership' between man and machine. After long periods of hemodialysis, patients start to understand the importance of the machine for the continuance of their lives and, at the same time, they despise it. It is plain to see that these people have mixed feelings, ranging from gratitude to anger.[6] In this context, accepting treatment and adapting to the new lifestyle imposed by the disease are paramount to having better quality of life.[7]

Given the above, we believe that getting to know how the diagnosis of CRF occurred and choosing a therapeutic modality based on people's singularity is very important in order to provide high-quality nephrologic care.

OBJECTIVE

To present the speeches of young adults with chronic renal failure undergoing hemodialysis, with regard to first symptoms, diagnosis and treatment of the disease.

METHODS

This descriptive, exploratory, qualitative study was based on concepts of cultural aspects developed by Madelaine Leininger[8] and Clifford Geertz.[9] Eight informants were recruited at a nephrology center in a city in southern Brazil. Inclusion criteria were age 20-41 years; more than six months of hemodialysis treatment; giving consent to the recording of the interviews and to the publication of the data.

The data were collected through narrative interviews[10] and unsystematic[11] and field journal observations,[12] between June and August, 2013. The interviews were conducted at the Nephrology Center and at the homes of two informants who consented to having the researcher going to their home. The study was guided by the following question: Tell us about the onset of you disease (chronic renal failure). In this study we only used narratives related to diagnosis and treatment.

Data collection involved two meetings with each informant, except for one case in which four meetings had to be held in order to comply with the study objectives. In order to guarantee trustworthiness, the interviews were recorded and then transcribed verbatim. The data were analyzed using Minayo's operative proposal,[12] according to the following steps: data sorting, data classification and final analysis.

To protect the identity of the informants, they were all assigned "research" names. They were identified as "Informant" followed by a number corresponding to the sequence of the interviews, as well as their age and duration of hemodialysis treatment. This study was approved by a Research Ethics Committee, under protocol number 195/2013. The informants were explained the objectives of the study and written informed consent in duplicate was obtained from each participant. One copy of the consent form was given to the informant and the other copy was filed by the researcher. This study complied with guidelines of Resolution #196/96 of the National Health Council.[13]

RESULTS AND DISCUSSION

In order to facilitate the understanding of the impact of diagnosis and treatment of CRF on young adults, the meaning units were divided into the following subcategories: Bodily disorder: the first symptoms of CRF; The kidneys have withered: diagnosis and treatment; Award and/or punishment: the impact of discovering that you have CRF. These subcategories are presented below.

♦ Bodily disorder: the first symptoms of CRF

This subcategory presents the first manifestations of the disease that were noticed by the informants and brought them to the attention of a physician. In this context, it is understood that, determining that one is ill is a process that is built in conjunction with the group in which they live.

In this process, they share notions about the body, its functioning and what seems to be wrong with it.[14]

Hence physical signs are the first indications that there might be something wrong in the body. Thus, the informants described their symptoms prior to diagnosis of CRF and what led them to look for professional health care. They searched medical attention in order to discover what was going on with their bodies and to find out why they were feeling so tired, had high blood pressure, were urinating blood, their body was swollen, and they had symptoms such as thirst, vomiting, pain, shortness of breath, urinary urgency and absence of urination.

> *I was at work and suddenly I had shortness of breath and started urinating a lot, I had to go urinate every two to three minutes [...]. The next day [...] I went (to work) like that [...] when I was done preparing the cement I felt something in my chest, then I tried to inhale, but I couldn't. Then I got dizzy and fell down, everything else is blank, next time I opened my eyes I was at the hospital. [...] Then I got nephrotic syndrome in the kidney, my body used to swollen up in all parts, I felt no pain, I felt nothing, it was just my body that was swollen. [...] I had shortness of breath, my body swelled, I had to be hospitalized all the time, and I was always in hospital. [...] I spent a month at the hospital and after two days back at home I already had to be hospitalized again [...].* (Informant number 3, 35 years old, eight years of HD).

> *Ever since I was 15 years old I used to urinate a lot of blood, but I didn't care, I just ignored it, and, in the end, I had to have it removed (kidney). [...] I used to think that that was normal. For me, it was normal, because it used to happen so often.* (Informant number 4, 28 years, one year and five months of HD).

We notice that each informant identifies the first symptoms of the disease differently, and that the pathology manifested itself through physical alterations. Some of the first perceptible symptoms of CRF are ocular and lower limb edema, foamy urine, severe anemia, fatigue and increased blood pressure.[7]

In the very moment people realize that the signal or symptoms is real, they grasp the disorganization of the organism and make choices to solve their health problem, according to their beliefs.[15] In addition, they wish to recognize, understand and trust their body signals, in the expectation of having self-knowledge and autonomy over their body and treatment.[16]

Recognizing a chronic disease from its symptoms is certainly not an easy task, for symptoms can be confounded with other diseases. This was the case for two informants.

> *I used to feel a sharp pain in the kidneys, but I didn't care, you know, I just guessed it was the spine, but it turned out it wasn't so [...].* (Informant number 8, 41 years old, two years of HD).

> *I felt very cold, then very hot, then cold again, like some kind of flu [...], pain in my legs, in the chest.* (Informant number 7, 35 years old, five years of HD).

Subjective experience with previous diseases leads people to "diagnose" themselves, often correctly, according to the symptoms that they present. However, in some situations this fails to occur, such as in the cases of these two informants who thought that they had other conditions. This facto may be associated with the popular belief that something as bad as a chronic disease will never happen to them, especially if they are young.

In everyday life, when people are not feeling well, they start paying attention and trying to notice and interpret body signals in order to discover the reasons for their malaise. Temporary diagnosis and the search for therapeutic alternatives are part of a sociocultural process that is initiated between people that are ill and their groups, in order to identify the problem and decide what should be done.[14]

♦ The kidneys have withered: diagnosis and treatment

Biomedical knowledge establishes the diagnosis of CRF by performing tests that confirm that the kidneys have lost their function, whereas the informants understand this process through the use of symbolism, using the image of withered organs. It is at this point that they face the confirmation of their disease and the need to replace renal function by dialysis.

> *And now they don't work anymore, I don't think they'll ever work again, my kidneys withered.* (Informant number 5, 41 years old, 10 years of HD).

According to Teixeira & Ferreira,[17] people's language is made up by their own vocabulary, and it is often metaphorical, such as in the case of the expression "the kidneys have withered". Additionally, it possesses a symbolic richness that reveals the personal and collective meaning of words in the world. For this reason, it cannot be separated from its socio-cultural meaning.

Other authors corroborate that people exhibit different behaviors and have singular thoughts about their experiences with the disease. Moreover, people have particular notions of health and treatment. These particularities are not derived from biological differences, but rather from socio-cultural differences, since they are based on the assumption that all people have culture and that it is culture that produces particularities.[18]

In this specific context, receiving a diagnosis of CRF may generate great distress in face of the unknown and scary world of a disease without cure and with a debilitating treatment that is often presented as the only alternative to death. In addition, these people have to adapt to permanent changes in their bodies and in their life routines.[16,19]

Thus, CRF brings several changes with it, including a new way of living and a life-long dependence on continuous therapy and help from others.[20]

The informants narrated how the moment when they received the diagnosis was, what was the health care facility that they visited and how they felt at the time.

> *I had to go to a hypertension meeting in A (city), I used to attend those meetings too and when I was finished there I always went to the health center to check my blood pressure. Then they took me to hospital, and doctor X examined me. He told me I had renal insufficiency and referred me to a hospital in B (city) [...]. I underwent the tests again and the diagnosis was chronic kidney disease.* (Informant number 5, 41 years old, 10 years of HD).

> *When I got ill, I was hospitalized on a Monday at Hospital X, the one I was referred to when I underwent the tests and found out I had the disease [...]. The symptoms had appeared three months earlier, and the physician sent me to Hospital X, to get a blood transfusion because I developed a strong anemia and so I went there [...] and I started hemodialysis on Friday already. Then I had a biopsy and the doctor thought I would no longer have to do it, but I took all the tests, and found that my kidneys had swollen and dried out [...].* (Informant number 2, 25 years old, seven years of HD).

In this study, we found that most informants reported going to high complexity healthcare facilities, such as hospitals, to receive the diagnosis of CRF. This is because people usually believe that their problems can only be solved at those facilities. Notwithstanding, informant 5, who participated in a hypertension meeting, reported going to the Basic Health Unit for follow-up care. Diagnosis, however, was made at other institution.

This fact may be associated with the difficulty of clinically diagnosing CRF. Thus, the responsibility of discovering a serious illness such as CRF is placed on facilities with greater technological resources, even though other health care levels are also capable of diagnosing this pathology. This is even more true because some of the tests used to detect CRF are of easy access, since they are low cost and are readily available at primary health care setting.[21]

Some study participants had to through the entire formal procedure in order to discover what their problem was, for they had first received a wrong diagnosis.

> *[...] I visited several health centers and everybody told me it was some kind of intoxication, something I had eaten or the like. Then one day I got really sick and my grandma took me to Hospital X, and there the physician examined me properly, like, she asked me if I was urinating normally, and I hadn't even thought about that, about whether I had stopped urinating or not, so I told her I didn't know [...], then she referred me to doctor Z. He ran some tests and told me that I had a kidney problem. [...] They (health professionals) had never talked about a kidney problem, or nothing of the like, they told me it was intoxication, asked me if I had handled any poisonous substances [...].* (Informant number 1, 37 years old, 18 years of HD).

> *I went to see a doctor because I was feeling tired and then I discovered that I had a kidney problem. I went to the city, to C (city), and started visiting doctors and taking tests, but the doctor couldn't find anything wrong [...]. Then I saw another physician and took the tests she asked and she referred me to this hospital [...]. They told me that it was a problem in the kidneys, that they had shrunk. Then they told me I would have to start hemodialysis treatment [...].* (Informant number 6, 40 years old, one year of HD).

In the formal procedure it is possible to notice that physicians and people with different diseases perceive health problems differently and use different systems for disease verification.[22] This may be associated with the medical system, its world of knowledge and the way of diagnosing and interpreting diseases and their causality, which are perspectives that are based on this group's culture.[14]

The informants narrated what they felt when they received the diagnosis and what this moment was like.

♦ Award and/or punishment: the impact of discovering that you have CRF

The first impact of the diagnosis of CRF may generate some perplexity and difficulty in understanding the new condition, leading to negative thoughts about the self and the world.[23]

After the diagnosis and appreciating the need for continuous treatment, the informants became aware of the meaning of having CRF, and a singular meaning was attributed to this experience. Informant number 2 referred to the disease as an "award", because she was the only one in the family who had it. Given the disturbances that she had experienced due to the need for continuous therapy, she reports that she prefers to be sick instead of her siblings who are also young.

> *[...] I never expected this could happen to me, I always thought anything could happen to me, except this. Sometimes I think I'm glad this happened to me and not to my siblings. I can't imagine what it would be like seeing them ill, with a problem like this, having to go there every week, my little sister, the boys, I can't imagine them being ill like this. Because actually I think I was awarded with everything because everything happened to me! All that's bad happened to me, I had all the diseases, I had high blood pressure, anemia [...].* (Informant number 2, 25 years old, seven years of HD).

For another informant, having CRD was considered as having bad luck. His speech implies the idea that the disease should be a punishment for those who have made wrong choices in life or who have committed crimes, which he has not. And despite that, he had had the joy of turning 18 years old interrupted by the disease. Informant number 4 considered that there is nothing worse than having this disease, because he lost all chance of enjoying life.

> *I felt, I don't know, like an ill-starred person who has no luck or maybe some kind of (silence) loser, I can't explain it. I used to ask myself why has this happened to me, I've never stolen anything, I've never raped or hurt anyone, I've always helped everybody, I worked and then I discovered that I had the disease when I was 18 years old. I always dreamt of turning 18, and the disease appeared when I was 18, and then everything in my life changed [...].* (Informant number 1, 37 years old, 18 years of HD).

> *I think that the worst thing that could ever happen to me was having this thing (chronic renal failure), it's like they say, if at least I were an old man already, I would have enjoyed life, then it would be ok! But no, just when we are starting to enjoy life this disease appears.* (Informant number 4, 28 years, one year and five months of HD).

Informant number 5 sees the disease as a hurdle sent by God. Although it is hard, she has to go through this in her life, for that is her destiny.

> *That's something I have to go through, I'm sure, I have to face it and be strong for as long as God chooses. I'm so sad that I have this thing (crying voice), but what can I do, God gives his hardest battles to his strongest soldiers.* (Informant number 5, 41 years old, 10 years of HD).

A study conducted in Jordan reported that faith and the belief in God were used by many as a means of coping with treatment and stressors related to it. Participants also believed that they had to go through it, because the disease was a divine test for them and they had to accept God's will.[24] Similar ideas can be found nowadays, as the participants in this study have shown by associating ideas of spirituality and punishment with the appearance of the disease.

As a consequence of not understanding the dimension of CRF and not knowing the effects of hemodialysis treatment because he had never experienced it, informant number 1 first wrongly thought that the disease could bring him benefits.

> *[...] so much so that, on the first day of hemodialysis treatment, the catheter was inserted and I was there for two hours, it was so at that time [...] and I felt nothing, then I said: "That's what hemodialysis look like? It's piece of cake, I'll get a salary, have some coffee here and won't feel anything". Then I walked out and "bam" , I fell to the ground, my blood pressure got low, and then I realized, I started to understand what it really was, and what it wasn't (silence).* (Informant 1, 37 years old, 18 years of HD).

Conflicting feelings such as anger about the condition and the side effects of treatment flourished when the informants realized the need for continuous hemodialysis treatment.

> *All I used to do was bother others, because I used to cry every time I had to come here, say I didn't want to stay, I made my mother crazy and my dad and everybody because I didn't want to stay. I didn't want to undergo it (hemodialysis), because I just didn't want to, I used to go out a lot, I was 17 almost 18 years old and I used to go out a lot with my girlfriends, so that seemed like prison to me and I was not allowed to do anything anymore because treatment*

> *suddenly was my whole life [...]. But I wasn't helping myself, I used to miss treatment sessions, I used not to go there, my dad would take me there and I would escape, just so I didn't have to stay there. Then I got used to it, I used to feel very sick, I didn't want to stay because I always used to feel very sick [...].* (Informant number 2, 25 years old, seven years of HD).

> *I used to get nervous, I guess the first three sessions, even the doctor used to tease me saying they would have to tie me down because otherwise I was going to run away. I said: "No, I'm not running away, doc", and that's when I started to calm down, I started to see that everybody else was sitting still, some were talking, some were trying to sleep.* (Informant number 4, 28 years, one year and five months of HD).

Changes in life are evidenced by the occurrence of illness. And the shock when it slowly becomes clear that you have a chronic disease, especially a renal chronic disease, was evidenced by negative feelings and reactions such as crying, trying to escape, non-acceptance, stress, suffering and fear of dying.

Thus, although hemodialysis treatment is necessary and indispensable for some people who depend on it to survive, it is also tiring, time-consuming, exhausting, unpleasant and full of restrictions.[24]

The interruption of activities of daily living, including work, becomes a reality and young adults see themselves unable to perform work duties. This makes this moment even more striking, especially because they are at the peak of productive life.

> *It was hard at the beginning, because I've always worked, I've always lived from my labor, and suddenly I had to stop doing everything. Thus, treatment is the only hurdle. [...] The first month of hemodialysis, I couldn't sleep. I felt agitated and constantly nervous [...].* (Informant number 4, 28 years old, one year and five months of HD).

The way each person experiences and deals with CRF is unique and personal, as it depends on several factors such as psychological factors, environmental and social conditions, and family support.[25]

Anger and rage were the feelings used by Informants number 3 and 5 to describe the pain of living with a chronic disease that crushed the dreams of the first and caused constant pain to the latter. Nevertheless, their words also showed resignation to their condition.

> *When I found out that I had the disease, I was getting ready to go to Porto Alegre to tryout for a soccer team. That's when I had a crisis. [...] I hate my disease, I loath it [...]. I already had the opportunity to get a transplant, but I didn't want to do it, I was so madly angry, also because I didn't accept the disease, and then I started using drugs. [...] I actually hate my disease, I hate it, but despite that, I was able to understand that there's nothing I can do about it, I feel angry, sometimes I just lose it, you know... Alone [...].* (Informant number 3, 35 years old, eight years of HD).

> *Sometimes I just lose it, I feel so angry, but it's no use, we have to keep our heads high and move on. That thing hurts a lot, and the needles are even worse. It hurts when they get it in, it hurts when they remove it, I doubt that somebody can ever get used to it, nobody, no one could ever get used to this life.* (Informant number 5, 41 years old, 10 years of HD).

The feeling of anger may be associated with the feeling of impotence in face of the disease and the lifelong dependence on treatment. This feeling is justified by the harms caused to a body that was healthy.[23] Hence, the appearance of a chronic disease and the initial fear in face of an unknown condition, in association with the possibility of death, justify the image of the disease as an enemy that requires permanent changes and adaptations, and may result in anger and aggressiveness.[16,19] The "world of drugs", mentioned by some of the informants, may be seen as an alternative to a life filled with problems. It is a fantasy world in which the existing load can become easier to carry.[23]

The "depression" mentioned by some informants is an indication that living with CRF is not easy and the interruption of previously performed activities is what most characterizes this process.

> *My world fell apart. "BAM!". I almost got depressed, it's like they say, why is it that a young person who was physically active, because I used to worked, I used to do something, why is it that suddenly, from one day to the next, I had to stop everything else in my life to undergo hemodialysis.* (Informant number 4, 28 years old, one year and five months of HD).

The informants mentioned depression as one implication of CRF. This may be due to the social symbolism of non-productivity in which they are immersed because they have the disease.

Depression is a major phenomenon of our time and is considered to be mankind's evil. It originates from modern social ideology that expects people to be operational in every context and at all times. In this context, those who are not able to produce as required by

the current model are considered as having some kind of disorder that needs to be treated. Depression is one of these "disorders", for it goes against the logic of efficiency and productivity.[26]

The narrative of the informants in this study reveals an ambiguous idea with regard to the real acceptance of the disease and of the treatment. At the same time that they say that they got used to the disease, they also say that they have no other choice but undergo treatment if they want to remain alive.

> *Of course I wouldn't do that today (run away from the unit), but I didn´t want to stay there. Then they would call my dad and tell him I hadn't shown up, and my dad would say: "But I dropped her there, I´ll be right there". Of course I regret doing that, I wouldn't do that today, but back then everything was new for me [...]. In my mind, I wouldn't have to do that for a very long time, but my mom and my dad, everybody already knew that I would have to do that forever [...], with time I realized that, and so I remain there until today. I got used to it after a while. I stayed there. [...] Now it's just normal to me. At the beginning it wasn't, it was weird, now I think I got used to it. At first I was afraid. [...] I just stayed there, after a while I got used to it, I went to see a psychologist and a psychiatrist to get some help [...] I just tried everything, and that helped, I kept going there.* (Informant number 2, 25 years old, seven years of HD).
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> *You have to accept it, because you have to accept it, because you have to come here, but it´s tough. I guess you never really accept it. You just come here because you have to, there's no other option [...]. You have to understand that somehow, you have to find a way to accept the situation, but it's really hard to do that sometimes.* (Informant number 5, 41 years old, 10 years HD).

After they receive the diagnosis of CRF, people go through a moment of both denial and acceptance of the need for treatment, and may show different reactions and behaviors in the coping process.[7]

The acceptance of the disease is filled with many different feelings such as fear, vulnerability and dependence, thus requiring individualized evaluation.[16] Nevertheless, the first step towards acceptance involves adaptation and awareness from the person that has the disease.[23]

Adaptation to hemodialysis treatment requires the adjustment of future perspectives and ambitions, because the patients have to make room in their lives for the disease, which demands flexibility and permanent changes.[16] However, this adaptation is singular, depending on psychological and social aspects.

The narratives of the informants indicate that some of them continue not to be able to accept the disease and the treatment, but rather conformed to it. It is assumed that acceptance may never occur in some cases because of the life condition that is imposed upon them. This is corroborated by a study that evidenced that patients conformed to the illness because they were aware of the need for hemodialysis treatment, presenting what could be seen as a false adaptation.[27]

Death is certain for all living beings, but it haunts especially people like the informants, who had had close contact with it by watching people die every week at the health care site.

> *[...] Somebody would die (while undergoing hemodialysis) and they would take the person to a room in the back of the unit, but that didn't happen once or twice in a year, that was something that happened very often, two or three times a month, people would die just like that, they would be sitting next to you, talking and laughing and the next thing you knew is that they suddenly started not feeling well and died [...]. That scared me, I started panicking. Nowadays I still see people die [...], but what can I do?* (Informant number 1, 37 years old, 18 years of HD).
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> *This life isn't easy. I ask God for help, because I don't want to die during hemodialysis, I want to last a few years more [...]. I'm get scared, so many people die, I even think about stopping (hemodialysis) [...]. I feel uneasy, when I get in there and I'm not feeling very well, I ask God to look after me [...], if I have to die, I would rather die at home instead of connected to a machine, during hemodialysis. That's what worries me.* (Informant number 8, 41 years old, two years of HD).

Due to the vulnerability of being mortal, death is a constant concern for human beings throughout their life journey. Hence, people undergoing hemodialysis are faced almost every day with a reality that is intrinsic to survival. At the same time that they experience symptoms relief, they also feel anxiety at the prospect of the end of life.[4] In addition to the fear of ceasing to exist, being ill and having to undergo hemodialysis are also perceived as a reduction of the amount of time dedicated to living, because of the number of days and hours that they spent connected to a machine.[19]

For this reason, people who depend on hemodialysis report living one day at a time

and making the most of every moment. In addition, pessimism takes over and there is a countdown to the end of days.[28]

CONCLUSION

The method used in this study made it possible to get to know the particularities of being a young adult with CRF undergoing hemodialysis, regarding the onset of symptoms of bodily disorder caused by the disease that led them to the search for a diagnosis in the formal procedure.

We notice that, despite important advances in the health system, there are still obstacles that need to be overcome, such as the difficulties experienced in diagnosis, which certainly aggravate the condition of people with CRF.

The informants highlighted not only the impact of diagnosis but also of treatment on their daily lives, filling them with struggles, restrictions, resignation, fear, anger, sadness, among other feelings that were evidenced in the expressions used to build their narratives.

Thus, to improve the quality of care, it is important that health professionals are prepared to provide holistic and individualized care to people with chronic renal failure.

One limitation of this study is that, in certain situations, informants refused to talk about the condition they were living with. We infer that this is due to the intense suffering that they were experiencing at that moment. Also, the approach used in this study does not allow generalizations due to the small number of participants. Notwithstanding, we stress that the focus on the individuality of people with CRF can be considered in different contexts.

Further studies on this topic and with an approach that encourages active and proactive participation from interested groups should be conducted, especially with the aim of improving nephrology care.

FINANCING

Coordenação de Aperfeiçoamento de Pessoal de Nível Superior - CAPES

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