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EXPERIENCES AFTER THE DIAGNOSIS OF CHRONIC RENAL FAILURE FROM THE PERSPECTIVE OF PATIENTS

*Vivências após o diagnóstico da insuficiência renal crônica sob a ótica dos pacientes**Experiencias después del diagnóstico de insuficiencia renal crónica desde la perspectiva de los pacientes***Brenda Maria Tavares do Nascimento¹** **Alcivan Nunes Vieira²** **Kalídia Felipe de Lima Costa³** **Luana Adrielle Leal Dantas⁴** **Mariana Mayara Medeiros Lopes⁵** **Nicole Liv Ullman Freitas Rêgo⁶** 

ABSTRACT

Objective: to analyze the experiences of the diagnosis of Chronic Kidney Disease from the perspective of patients. **Method:** qualitative study conducted through semi-structured interviews conducted with patients treated in a hemodialysis service; the data were submitted to Bardin's Content analysis. **Results:** the experiences were organized into the following significant categories: Feelings experienced at the time of diagnosis; Impacts of diagnosis; Denial of the disease; The paradox of gratitude and Coping with the disease. **Final considerations:** the experience of the diagnosis of Chronic Kidney Disease acquires a unique perspective for each patient subsidized by subjective aspects, by the care and family support to which he has access. **DESCRIPTORS:** Doença renal crônica; Hemodiálise; Perfil de impacto da doença.

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RESUMO

Objetivo: analisar as vivências do diagnóstico de Doença Renal Crônica sob a ótica dos pacientes. **Método:** estudo qualitativo realizado por meio de entrevistas semiestruturadas realizadas junto aos pacientes atendidos em um serviço de hemodiálise; os dados foram submetidos à análise de Conteúdo de Bardin. **Resultados:** as vivências foram organizadas nas seguintes categorias significativas: Sentimentos vivenciados no momento do diagnóstico; Impactos do diagnóstico; Negação da doença; O paradoxo da gratidão e Enfrentamento da doença. **Considerações finais:** a vivência do diagnóstico da Doença Renal Crônica adquire uma perspectiva singular para cada paciente subsidiada por aspectos de ordem subjetiva, pelo suporte assistencial e familiar ao qual ele tem acesso.

DESCRIPTORS: Renal insufficiency, chronic; Renal dialysis; Sickness impact profile.

RESUMEN

Objetivos: analizar las experiencias de diagnóstico de la Enfermedad Renal Crónica desde la perspectiva de los pacientes. **Método:** estudio cualitativo realizado a través de entrevistas semiestructuradas realizadas con pacientes tratados en un servicio de hemodiálisis; los datos fueron enviados al Análisis de Contenido de Bardin. **Resultados:** las experiencias fueron organizadas en las siguientes categorías significativas: sentimientos experimentados en el momento del diagnóstico; Impactos del diagnóstico; Negación de la enfermedad; La paradoja de la gratitud y Enfrentamiento de la enfermedad. **Consideraciones finales:** la experiencia del diagnóstico de Enfermedad Renal Crónica adquiere una perspectiva única para cada paciente subsidiada por aspectos subjetivos, por el cuidado y apoyo familiar al que tiene acceso.

DESCRIPTORES: Insuficiencia renal crónica; Diálisis renal; Perfil de impacto de enfermedad.

INTRODUCTION

Chronic Kidney Disease (CKD) is defined as a progressive and irreversible deterioration of kidney function, in which the body's ability to maintain metabolic and hydroelectrolytic homeostasis fails, resulting in uremia, which is defined by the retention of urea and other nitrogenous products in the blood.¹

With its diagnosis, the patient needs to undergo substitutive dialysis treatment. Therefore, people on dialysis for chronic kidney disease are subject to several impacts on their lives, as well as on the lives of their families, since there are many psychosocial issues involved in adherence to and maintenance of this treatment. The difficulties faced, therefore, by patients and their families can range from physical discomfort to the side effect of medication, through the issues of changing eating habits, infections, rejection and decreased quality of life.²

Due to the installation of CKD and the adaptation to dialysis therapy, some body transformations become evident, such as: yellowish skin coloration, weight loss and scars resulting from arteriovenous fistula. In this perspective, from the patient's point of view, these alterations interfere in the establishment of affective bonds, according to their coping and adaptation processes.³

The process of adaptation to a chronic disease is related to the subjective and interpersonal aspects of each person, and is associated not only with the severity and characteristics of the disease, but also with the quality of social, family and support provided by health services. This condition can generate fear and much suffering associated with the lack of knowledge about the disease and its treatment in patients and their families.⁴

Considering the subjectivity inherent to the illness process and its relations with the contexts in which the patient is inserted (family, care, work, marital, among others), it is understood that the extent and proportion of the implications of the diagnosis of CKD in the lives of those who are affected by it acquire specificities inherent to the contexts mentioned.

The moment of diagnosis of CKD is experienced in a unique way and in accordance with other issues that circumscribe the widespread knowledge about it, its treatment and implications in the patient's life. In this perspective, although there are several published studies on the subject of CKD, it is necessary to recognize the need for research that broadens the understanding of the experience of this moment because, based on the experiences lived, it can impact on the acceptance of the new condition and the construction of coping strategies and resilience. Their findings can support nursing interventions in the patient care process in articulation with the care scenario and their life contexts.

Therefore, this research aimed to analyze the experience of the diagnosis of Chronic Kidney Disease from the perspective of patients.

METHOD

This qualitative study was conducted at the Hospital do Rim, located in the municipality of Mossoró - RN, between August and October 2022. Participants were 36 people diagnosed with CKD, of both sexes, aged between 18 and 77 years. The identification of the participants is coded with the word "P", which refers to the patient, followed by the number of the interview order.

We included male and female patients aged 18 years or older, diagnosed with CKD and who had been on Renal Replacement Therapy for at least one month. People who were on dialysis therapy for acute renal failure were excluded; those unable to narrate their own history and chronic renal patients diagnosed with some hemodynamic or metabolic instability.

Data collection was performed through a semi-structured interview guided by some initial topics such as: discovery of CKD; previous knowledge about the disease; feelings after diagnosis; expectations elaborated at the time of diagnosis. The interview was applied to the patients in the premises of the service where they had access to hemodialysis, and they were submitted to Bardin's content analysis.

In compliance with the ethical principles of research involving human beings, the study was approved by the Ethics and Research Council of the State University of Rio Grande do Norte, with protocol nº 5.505.823 of 07/03/2022.

RESULTS AND DISCUSSION

Based on the analysis of the content of the participants' statements, the experience of the moment of the diagnosis of CKD from the perspective of the patients was organized into significant categories: Feelings experienced at the time of diagnosis; Impacts of diagnosis; Denial of the disease; The paradox of gratitude and coping with the disease.

Feelings experienced at the time of diagnosis

The laboratory diagnosis of CKD is performed by measuring serum urea and creatinine, which attest to the accumulation of these metabolites in the blood. The presence of protein or albumin in the urinalysis are important alerts for a possible kidney disease. These tests are considered of low complexity, whose access is possible at the level of Primary Health Care, including smaller cities.⁵

It is a somewhat unexpected disease since the symptomatology and its clinical course, in general, appear late only when the renal function is severely compromised. Its onset is "silent" causing in diagnosed patients a feeling of strong nonconformity, often associated with a feeling that the discovery at an early stage would have freed them from the final stage of the disease. It is understood in the statements below:

[...] It took a long time to figure out the disease, I think... He said, "Your little kidneys are lazy." I didn't even take it into account, maybe you know, if I had taken it, maybe it would have worked, I don't know my God [...]. (P1, 77 years old)

The discovery only the tests that can tell... I was bloated, I didn't drink much water... (P12, 18 years old)

I felt only a little pain in the spine and I started to do all the checkups, which I did annually, but working there took a little work to do. My mom calling 'man, let's do

the exams' and me rolling, by the time I found out it was too late. (P15, 30 years old)

To this day I do not know why this loss happened in my kidneys, I do not know how to explain. [...] Then I didn't know why the cause of the loss of my kidneys and when I came to find out (the loss) I no longer had anything, I was all atrophied... they're atrophied and practically finished inside me. (P22, 54 years old)

This can be explained by an understanding that disease and health differ only in the manifestation of symptoms, generating a feeling of guilt for the supposed lack of self-care and self-perception of any indication of the pathology, even of the illness itself. This feeling is understandable from the perspective that the definition of what is disease or what is health can have different meanings for people, depending on the time, place and social class; of individual values, of scientific, religious and philosophical conceptions of each individual.⁶ This was experienced by the participants as demonstrated by the following statements:

Nothing, felt nothing. I was healthy, I didn't think I had any disease coming from any disease [...] I kept treating myself, but I thought I was healthy. (P2, 77 years old)

I thought that those who did not drink water had a lot of health, they were those who had a lot of health, I did everything the opposite. (P17, 63 years old)

Because I started to swell, fill up a lot, I thought it was spine, me taking medicine for spine, let it be kidneys. (P27, 51 years old)

[...] I was feeling very ill, I was vomiting, reflux, headache, high blood pressure... At first I blamed myself because it appeared after I went to invent to take anabolic, then I blamed myself a lot, because I thought it had been because of this, that I had caused it. But then when I was transferred to Onofre Lopes, there they investigated there and I found out that it was already chronic already, it was already a disease that was affecting. And I was less sad. (P34, 22 years old)

Impacts of Diagnosis

Because it is a chronic pathology, the moment of diagnosis produces impacts on the lives of patients represented by feelings of fear, sadness, resignation, fear of death, denial, fragility, resilience, coping, limitation, dependence and suffering, among others. There are reports about the moment of diagnosis expressing the feeling of sadness associated with resignation, suffering and fear of the unknown:

I lived my normal, supernormal life, which until then I did not do hemodialysis, but after I started doing hemodialysis, like, the personal life changes right, the routine, many things, you know?! (P3, 27 years old)

I was worried because I didn't know what it was, I had never heard or spoken of, just working, working, I had never heard or spoken of this kidney problem.

(P8, 59 years old)

I was a little sad, but then I said 'yes, God willing, if it's his will I thank him.' (P9, 30 years old)

At first I didn't understand, right? Because I never had contact with any kidneys, I didn't even know what hemodialysis was, I didn't understand, but so, it was a blow to know that it was chronic too, right? [...] It's a feeling of ambiguity, the will to live and the fear of living, right? Because it's very much a death sentence, because death is very present in the dialysis environment, right? [...] Because dialysis is that, it's what makes us live, but at the same time it's the fear of not knowing tomorrow. (P36, 24 years old)

Denial of the Disease

The denial of the disease at the moment of the discovery of a chronic disease is an attitude that is sometimes common and expected, precisely because the process of falling ill produces questions about life and about the probable imminence of death. The first stages of a disease are characterized by denial and nonconformity with the loss of a state of health and proximity to the idea of death.⁷ These feelings were expressed in some statements:

Hail Mary is horrible, I don't get used to it, because I feel a lot I live sick I... I live very sick, I feel a lot of myself. I feel unease, I feel everything you can imagine that the human being feels. [...] Sometimes I know it hurts the person, but sometimes I ask to die because I can't take it, believe me? Sometimes I get home I say 'oh my Jesus, if Jesus took me it would be much better, at least I would not suffer anymore for these things that I am going through', it is very difficult, very difficult...

(P18, 53 years old)

I was very downcast, I was sad because I had already lost one and then know that I was in trouble in the other... and looked at me very swollen. I thought I wouldn't resist, but thank God, God is great, I made it. I'm here telling the story. (P27, 55 years old)

Hemodialysis is like this, you only go to it when you are already at the limit, we did not understand it right? I didn't even know what hemodialysis was. (P32, 32 years old)

It was also observed that among the participants there is a persistence of these feelings since, even after a few years of dialysis treatment, their statements still revealed the denial of the disease considering only the perspective of facing it and not of living with chronicity. This persistence can be explained in the sense that, in order to overcome the process of denial of the disease, it is necessary that they acquire an understanding of its meaning, and perceive the reflexes

generated in their daily lives, in the relationships and in the meaning that life gives, because the physical and emotional changes to which they are exposed represent obstacles to the continuity of treatment.²

It is worth mentioning that the denial of the disease is not considered only when there is recognition of this condition by the patient, but also in the observation of resistance to the conducts and interventions necessary for the substitutive treatment of renal function, as observed in the following statements:

Then I didn't want to accept no, the treatment didn't, because I had never done it. I didn't want to accept no, then it took 5 months for me to accept. (P4, 23 years old)

[...] Ah, their joy I'm also happy, that they want to know right, 'but aunt is sick no, aunt just makes take the blood and filter, ready'. (P10, 55 years old)

I don't feel sick, my life is pretty much normal, I just don't work. That I go out, I go once on the farm, on my friend... not working now. (P15, 30 years old)

I eat everything, whatever is on the table I eat. (P29, 59 years old)

The Gratitude Paradox

Nevertheless, for some people, the diagnosis is marked by the feeling of relief and gratitude in the face of the previous doubt about what actually affected them. It is identified in these cases the recognition of the importance of the treatment and the existence of the hemodialysis machine, because they understand that they will finally be able to treat the symptoms that accompanied it for months or even years. This is demonstrated by the statements below:

[...] The rest of the material I had, I worked with underwear, I gave it to my neighbor that she was a seamstress too, I couldn't do anything anymore. Then even when I started hemodialysis I started to get better... (P1, 77 years old)

So for me I was feeling good, you know, because I was feeling a lot, let's say so, sedentary, although I did physical therapy every day, but it was that, that very slow pace, so for me it was easier, that I started, let's say so, to treat, isn't it?! [...] because for us, yes, the machine is a blessing, for all intents and purposes, because it's working right, for us, so it's the kidneys right, artificial... (P6, 42 years old)

It is such a good treatment, today if I had this machine in Apodi, as I did very well in the treatment, I would no longer go to the transplant queue no. (P11, 62 years old)

It was the best solution God gave me in my life. I guess if there wasn't that, I wouldn't exist today, right? I'm very grateful. (P35, 18 years old)

Coping with the Disease

The ways of coping with a chronic disease are subjective and can be based on various feelings, whether or not accompanied by the acceptance of this new condition. In the following reports it is perceived that the diagnosis of renal failure is seen as a misfortune of life and, even so, there is an acceptance of it from the understanding of the need to adapt to the changes imposed on life:

I am not afraid to face the life that I am today, for me from today onwards whatever comes, ready, I am not afraid. [...] And when I see that it gives that dryness that I have to drink a lot of water, I run to the shower, I stay there under the shower for hours and hours taking a shower, until that dryness passes, that warmth. (P22, 54 years old)

No, no, we don't eat all 'eat' no. yes, you have to go... Because if you don't follow it dies even lighter. (P19, 40 years old)

I accept everything, it was quiet. We have to accept, you know, the things in life?! (P26, 41 years old)

I think things happen, it happens to anyone, doesn't it? So I face, it's kind of a fatality right? It happened and we have to face it, I have to live right? Touch the boat forward and live as best I can. (P29, 59 years old)

A recurrent form of confrontation among the interviewees is the path of spirituality or even religiosity. The concepts of spirituality and religiosity differ in the form of expression; While spirituality is linked to the personal feeling that stimulates an interest in others and for oneself, a sense of meaning in life capable of making one endure debilitating feelings of guilt, anger and anxiety, religiosity in turn involves a system of worship and doctrine that is shared by a group and therefore has behavioral characteristics, specific social, doctrinal and evaluative dimensions representing a social and cultural dimension of human experience.⁸ In view of the following reports, it is noted that religiosity does not necessarily imply the acceptance of the disease, but the way it is faced in life:

There are days that we arrive badly and leave well, there are days that arrive well and leave badly ... and it's like this, we go on leading life the way God wants it right... (P1, 77 years old)

The person feels enslaved to the health problem, right? day in, day out it doesn't have to be here, but I praise and thank God for the opportunity of life anyway, because I would have already died if I hadn't started. (P14, 55 years old)

It's not easy, but I've clung to God. And it is He who sustains me to this day. (P28, 51 years old)

[...] But then things happen the way God wants, we are not to blame, but we adapt and it works out. But it really

shook up quite a bit, didn't it? It changed life a lot. (P34, 22 years old)

In this perspective, spirituality emerges as a sustaining and strengthening dimension of physical, mental and social health, pointing out direct benefits such as the reduction of stress, anxiety and depression; it also impacts on the reduction of the use of psychoactive substances and on attempts to consummate suicide.⁹

Therefore, it is understood that spirituality can strengthen the resilience of the patient and influence the achievement of a certain quality of life. Although it does not guarantee the acceptance of the disease, the search for comfort in spirituality prepares them to face the changes observed in life after the diagnosis of CKD, which can generate better adherence to care interventions.⁹ This resilience can be perceived in overcoming the adversities brought by the disease:

At first the guy doesn't feel well, but then he passes. (P16, 61 years old)

Then, in the first year I couldn't eat anything, everything offended me, then I was afraid to eat, I ate almost nothing. When it was this year God helped me, I started eating, I increased 2kg, I had lost 10, then I increased another 2kg. (P18, 53 years old)

First day it was crying, then I got used to it, I don't even care anymore. Then it was passing the time, it's going to be 3 years now, and I was understanding, I was improving, I was seeing that it is a situation that you have no deadline to leave, right? You have to come because it's your survival. (P32, 32 years old)

So I was very sad, right? Shaken by the situation, in a habit with it, it is not easy no, but we can adapt later. (P33, 33 years old)

In short, this category represents the feelings related to the first impact of the diagnosis of CKD. It is perceived that the initial fear is justified by the lack of knowledge of what the disease is and its form of treatment. In addition, the ways of coping with the disease are directly linked to the way the disease is seen in life; they go through denial to the state of resignation or resilience and so, even understanding the benefits of treatment and noticing the improvement in quality of life, for some, it is difficult to deal with the changes that the diagnosis of CKD has caused in their lives.

FINAL CONSIDERATIONS

The experiences after the diagnosis of Chronic Renal Failure from the perspective of the patients were organized into the following significant categories: Feelings experienced at the time of diagnosis; Impacts of diagnosis; Denial of the disease; The paradox of gratitude and coping with the disease.

The way the patient experiences the moment of diagnosis of Chronic Kidney Disease acquires a unique perspective for each patient, being subsidized by subjective aspects, by the care and family support to which he has access.

It is identified the need to investigate new systems to approach people diagnosed with a chronic disease, including CKD, in the perspective of guiding nursing care and multiprofessional care.

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