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RESEARCH

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Patients undergoing hemodialysis: perception of changes and constraints regarding the kidney disease and its treatment

Pacientes em tratamento hemodialítico: percepção acerca das mudanças e limitações da doença e tratamento

Los pacientes en hemodiálisis: la percepción de los cambios y las limitaciones de la enfermedad y el tratamiento

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ABSTRACT

Objective: The study's aim has been to know the perceptions about the changes and limitations faced by patients having kidney disease and undergoing hemodialysis treatment. **Methods:** It is a qualitative research with 12 patients undergoing hemodialysis at a Hemodialysis Center in the Northwest region of the *Rio Grande do Sul* State, Brazil, in 2014. Data were obtained by semi-structured interviews submitted to the Content Analysis. **Results:** The study's results showed that feelings of indignation and denial change as the patients strengthen to face both disease and treatment. Restrictions to food, water, and daily activity were identified in their lives. However, there was a strengthening of their family and friendship bonds, as well as religiousness. **Conclusion:** There have been negative perceptions due to the restrictions imposed by hemodialysis. Hence, supporting and strengthening the relationship networks of these patients are essential to improve their life quality, which can facilitate their experience with the limitations imposed by both the kidney disease and its treatment.

Descriptors: Chronic kidney disease, hemodialysis, perception, nursing.

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RESUMO

Objetivo: Conhecer as percepções dos pacientes hemodialíticos acerca das mudanças e limitações da doença e do tratamento na sua vida. **Métodos:** Pesquisa qualitativa, com 12 pacientes que hemodializam em um centro de hemodiálise na região noroeste do Rio Grande do Sul, Brasil, em 2014. Os dados foram coletados por entrevista semiestruturada submetidos à análise de conteúdo. **Resultados:** Evidenciam que os sentimentos de indignação e negação se modificam, enquanto os pacientes se fortalecem para o enfrentamento da doença e tratamento. Restrições alimentares e hídricas, bem como limitação das atividades de trabalho foram as dificuldades identificadas. Entretanto, ocorre o fortalecimento de vínculos familiares, de amizades e uma proximidade com a religião. **Conclusão:** As percepções negativas devido às restrições impostas pela situação deste adoecimento. Aponta-se a necessidade de apoio e fortalecimento da rede de relações destes pacientes, que lhes facilite o convívio com as limitações impostas pela doença e tratamento visando à melhor qualidade de vida. **Descritores:** Insuficiência Renal Crônica, Hemodiálise, Percepção, Enfermagem.

RESUMEN

Objetivo: Conocer las percepciones de los pacientes de hemodiálisis sobre los cambios y las limitaciones de la enfermedad y el tratamiento en su vida. **Métodos:** estudio cualitativo con 12 pacientes hemodializantes en un centro de hemodiálisis en el noroeste de RS, Brasil, en 2014. Los datos se recogieron mediante entrevista semiestructurada sometido a análisis de contenido. **Resultados:** Este estudio evidencia que los sentimientos de indignación y la negación del cambio, mientras que los pacientes están fortalecidos para hacer frente a la enfermedad y el tratamiento. restricciones de comida y agua, lo que limita las actividades de trabajo eran las dificultades identificadas. Sin embargo, no es el fortalecimiento de los lazos familiares, amistades y la cercanía a la religión. **Conclusión:** Las percepciones negativas debido a las restricciones impuestas por la situación de esta enfermedad. Apunta a la necesidad de apoyar y fortalecer la red de relaciones de estos pacientes, lo que facilita la vida con las limitaciones impuestas por la enfermedad y el tratamiento de la mejor calidad de vida. **Descritores:** La Insuficiencia Renal Crónica, Hemodiálisis, La Percepción, Enfermería.

INTRODUCTION

Kidney diseases cause high morbidity and significant mortality in the world. Among these is the Chronic Kidney Disease (CKD), which “occurs with the slow and progressive destruction of individual nephrons for prolonged periods of time” producing great damage to kidney function because of the decrease in glomerular filtration rate.¹ The main consequences of CKD are Uremia (retention of nitrogen metabolites) and Progressive Insufficiency of Tubular Function, which leads to early failure of the concentration of urine and biochemical homeostasis anomalies, such as sodium and water retention that can cause hypertension.¹

Patients may also develop secondary hyperparathyroidism due to deficiency of the kidney activation of vitamin D and reduction of the levels of erythropoietin, resulting in anemia. Systemic Arterial Hypertension (SAH), glomerular diseases (Glomerulonephritis and Diabetic Glomerular Disease) and

tubule and interstitial diseases (infectious or toxic ones) are examples of diseases that can lead to CKD.¹

When the failure of kidney function occurs, the person needs urgent intervention, called Renal Replacement Therapy (RRT). There are three treatment options: kidney transplant, peritoneal dialysis, and hemodialysis.²

Hemodialysis is the execution of the kidney functions by means of a machine, which is performed three times a week with daily sessions of four hours. The patient moves to the care center or hospital where the procedure is performed, which often can cause him discomfort. The CKD patient, when undergoing hemodialysis, “constantly lives with the denial and consequences of disease evolution, the painful treatment and the alterations and limitations that can have repercussions in his life quality.³

In Brazil, there are 658 active and registered dialysis units with a chronic program. Of these, 139 (21%) are located in the South Region. The total of patients undergoing hemodialysis reached 100,397 in 2013.²

The impact caused by a disease and its treatment is different among individuals. In this sense, studies that value individual aspects are needed because they can lead the actions of the professionals, specifically those of the nursing team.

Therefore, the lifestyle changes induced by CKD and hemodialysis lead to alterations in feeding habits, sex, body image, skin, and hair, as well as to halitosis. Moreover, the interruptions in the work routine may lead the patient to move away from his social group, leisure, and sometimes from his own family, changing his values, ideals and beliefs,⁴ which may affect his quality of life.

As a result, it is required that the nurse considers the relevance of these questions when approaching the patient and elaborating his care plan.⁵ For this, the nurse needs to stay with the patient more closely, know his perceptions towards the limitations imposed by the hemodialysis and possible compromises, as well as the changes in his life, all this in order to improve the effectiveness of the treatment.

The performance of the nurse for CKD prevention and progression depends on the actual patient needs. Detecting risk and sick groups is fundamental, in addition to evaluate the kidney function of the people in these groups. The nurse, besides knowing the CKD evolution in patients, must intervene in their condition, demonstrating the important role of the nurse in the treatment of chronic kidney patients, not only during hemodialysis, but also in their emotional, psychological, and social assistance, with the purpose of improving their quality of life in addition to better facing the treatment.^{3,6}

In this sense, the question that has been raised in this study was “How do patients perceive the changes and limitations of hemodialysis in their lives?”

Consequently, the study's objective is to know the perceptions of patients undergoing hemodialysis about the limitations and changes in their lives imposed by the CKD and its treatment.

METHODS

This study was conducted as a qualitative research, which seeks to understand a specific phenomenon deeply by analyzing the subjectivity of the participants, including the unquantifiable reality, beliefs, values, and actions, which totalize a deeper space of relationships.⁷ The study was carried out in a Kidney Clinic in the municipality of *Frederico Westphalen, Rio Grande do Sul State, Brazil*.

The participants of this study were 12 CKD people undergoing hemodialysis. They were chosen by means of convenience sampling and they agreed to participate voluntarily. The inclusion criteria were: being able to answer the research instrument and over 18 years old. The exclusion criteria were: undergoing hemodialysis for less than two years.

Semi-structured interviews were employed to obtain the data before the hemodialysis sessions, in both shifts inside an appropriate room of the clinic in order to maintain the patients' privacy.

The interviews were recorded, transcribed and submitted to Content Analysis, which have three techniques, namely: Categorical Analysis, Evaluation Analysis, and Enunciation Analysis.⁸

As stated in the Resolution No. 466/12 of the National Health Council, all the procedures regarding the research involving human beings were obeyed. This study has been approved by the Research Ethics Committee, *CAAE nº 34902614.3.0000.5352*. All the participants signed two copies of the Free and Informed Consent Term (FICT). For maintaining the anonymity of the subjects interviewed, they were labeled from P1 to P12.

RESULTS AND DISCUSSION

Hemodialysis and CKD progression cause limitations and losses in the mental, physical, functional, general well-being, social interaction, and satisfaction of the patients.⁹ The CKD, and consequently the hemodialysis, changes the patients' lives, making it often difficult to accept. Besides being a permanent and painful treatment, hemodialysis limits many of the activities that gave pleasure and autonomy to an individual, such as work, feeding, and leisure.

Furthermore, patients with CKD experience frustration and restrictions, such as maintaining a specific diet associated to water restriction and living with the body modifications caused by the hemodialysis catheter or arteriovenous fistula. This results in dynamic life changes, and new adaptations to habits and behavior,² according to the testimony below:

[...] due to the hemodialysis and the disease, I have to change all my everyday life routine and program my feeding and work schedules [...]. (P9)

[...] There are days in which I do all my things, and there're others I do nothing because I know I have to get here [...]. (P4)

The changes in lifestyle generated by CKD and hemodialysis lead to physical, sexual, psychological, family and social limitations, which can affect the quality of life. In everyday life, the studied patients expressed negative feelings, such as fear of prognosis, incapacity, financial dependency, and self-image alterations. On the other hand, they recognized that the treatment allows them to wait for the kidney transplant, and, which can improve their quality of life.⁵

The most highlighted change among those expressed by the interviewees was water restriction. A person with CKD experiences great restlessness and dissatisfaction because of the food and water restrictions, changing the eating habits formed throughout life.¹⁰ These changes provoke distress and suffering which interfere with the everyday life of the patients.¹¹ This was stated in the following testimonials:

[...] My greatest problem was the water because I have to lower the water intake. In my case, I don't pee at all, so all liquid I take will remain inside my organism, [...] it's my greatest problem. I feel thirsty a lot, I take water, but sometimes in the hemodialysis session, I have to lose 3 kg or 4 kg. [...] (P5).

[...] regarding the water, it's been so hard. Only now I'm managing to control myself more, but it's too terrible regarding the water. I can't control myself. When I realize it, I already have taken two liters of water, and I got here popping [...]. (P12)

[...] my family was too hard on me about the food. They didn't let me eat this or that. I only ate weak savory food, so I started to eat in secret [...]. (P3)

[...] It's difficult, especially about liquids. [...] in hot times, aren't you gonna take water? [...] And there's this thing about food when you go out, to a restaurant, or with your friends, and you think "what do you eat?" [...] when I go out with my friends, they ask me "uh, can you eat this? Or that? Do you need something? Can they make something different? So, now they have this concern. (P9)

In this sense, the participants pointed out that the friendship bonds observed are something that provide strength and courage to fight their fears and suffering. For the participants, these bonds bring the feeling of not being alone as well as supported by people who are part of their world. Their close friends are like a wall supporting them, which have great impact on how they face the treatment, and on their well-being and quality of life.¹¹ According to the testimonials:

[...] when I started the hemodialysis, they supported me a lot, so I guess it was the force I had for reverting this situation. It was the support of my friends [...]. (P3)

[...] the hemodialysis has given me more friends, a lot of friends. Some of them still go on. All of them give me support, strength, a lot of hope, and courage. I've got friends here on hemodialysis. [...]. (P5)

Some interviewees reported that their friends moved away because of their ignorance about the CKD. This is consistent with a study,⁵ which highlighted the ignorance of the population regarding both the CKD prevention and hemodialysis, as stated in the following testimonials:

[...] some of my old friends, it's not that they didn't move away from me completely, but we notice when a person seems to be afraid of you. It seems you'll gonna pass something on to that person. (P5)

[...] I received more friends in my house, but now it barely happens. They talk to me, but far from me, not close to me [...]. (P12)

Just as the outside support network for the treatment is important, the support network between the patients proves to be fundamental. There is a supportive bond among the patients, whose disease identifies them as a family. They become sensible to the conflicts experienced by their peers.¹¹ It was confirmed by the following testimonial:

[...] here in the clinic, we became a family. When the guys aren't here, they call and ask for advice. We pay a visit to some of us [...] there's a strong circle of friends here. I make friends, family [...], so we share experiences, doubts, afflictions. This is important, this circle here, because all of us have to go through the same thing, so the friendship we got here from hemodialysis is very important because the friends help you, they are in the same situation you are, and they help you to go on. If you have a struggle, you can talk to them. In another time, you help them. If you are feeling down, one of them raises you [...]. (P9)

Family, neighbors, and friends can help facing CKD and its consequences since this disease is integrated with the individual's context.¹² The support from society towards the CKD treatment is also an important tool for the acceptance and adherence to the treatment. This is because the patients reported having a good relationship with the clinic hosting the hemodialysis services. Yet, outside of the treatment environment, the patients experienced poor treatment from other services, such as the Basic Health Unit (BHU). Additionally, a weak link between the patient and the BHU might happen.¹³

The support for patients provided by the multi-professional team has an important role for treating acceptance. Also, this support is essential so that an individual can live better with CKD. The link between patients and professionals leads to sharing hemodialysis success and failures among themselves.¹¹ These ideas were confirmed by the following testimonial:

[...] I think people are very warm to me, you know, so I always try to treat them well. I really love my "hemo" colleagues, the nurses, and the nursing chief. This gave me strength to my health and survival... I felt very well when I come here [...]. (P6)

The CKD affects not only the patient but also all their family, which can experience various feelings, such as stress and anxiety. The severity of this disease causes fear and much suffering in the patient's family. When the patient has the family support, he can live better with CKD and its treatment is less painful because he can feel the security of having valuable people who are always ready to help him when he needs.

[...] My family always have supported me, [...] they only try to help me; if something happens, they help me with it. I never got problems with my family. If a problem shows up, I just need to call them and they come to rescue me. They are so available [...]. (P10)

The family is an important and fundamental source of support for the patients, allowing them to proceed with the treatment and face the adversities imposed by CKD. Therefore, the family is a dynamic organization that seeks to obtain solutions to the limitations caused by CKD. Many times, the family restructures itself, changing their member's roles and creating new responsibilities.

[...] My family accepts me, you know. They respect me even I'm having this problem, and help me [...]. (P2)

[...] My family, a blessing of God. My family is always on my side, always supporting me. I have no words to express what they do for me [...]. (P5)

[...] speaking in family, I only have to thank my family. They support me a lot [...], the friendship we have is very nice, and it's strengthened after I've discovered this disease [...]. (P6)

The participation of the family in the whole treatment is essential since the patient will be feeling supported and safe to continue the treatment. Furthermore, this participation induces the formation of other support networks, either providing care or even financial support.¹³ The changes caused by the treatment affect the patient's relatives. As a result, they need to adjust their own everyday routine to the family member affected by CKD.⁵

On the other hand, the interviewees reported that the hemodialysis is a problem concerning the family relationships, for its treatment force them to distance from the family, which generates feelings of sadness:

[...] I feel quite distant from them after I started hemodialysis because I have to leave them alone [...] we don't pay too much attention. There are days we don't come well [...] I feel distant from them on the days I have to do hemodialysis [...]. (P3)

At the same time, undergoing this treatment produces stress, social isolation, loss of a job, dependence on Social Welfare, and partial loss of locomotion which affects the performance of physical activities.¹⁴ The patients emphasized the importance of work in their lives. They feel the satisfaction from meeting their needs and executing pleasurable activities.

The limitations in work cause loss of financial autonomy and financial dependency in a CKD patient. In some cases, the family maintenance is transferred to another person. This is because the hemodialysis makes it impossible for patients remain employed since it has an average of four hours of duration, and the patients need to undergo it three times per week. Additionally, they need to deal with the emotional consequences of CKD.¹⁵ The testimonials below confirm this:

[...] I (silence) worked on the farm. I received disability insurance. I don't work anymore. I can't do it (silence). I can't do any effort (silence). Sometimes I try it but then I suffer because I can't do it [...]. (P3)

[...] I have to left my job. I was a domestic worker but I have to stop everything [...]. This was my only income. I earned my money doing that [...]. (P4)

[...] In the moment I begun the hemodialysis, I left my job because we have to do it three times a week [...]. (P5)

[...] regarding the work, three times a week makes it impossible if you have a stable job [...]. (P9)

The physical inability in performing work activities produces bad feelings that affect the patient's life, both in family and society. A study conducted in women undergoing hemodialysis showed that the work disability also interferes with the subject's life since it is very difficult to maintain formal employment relationships, as a result of the treatment routine and physical disabilities, as well as its complications, from the CKD.¹⁶

Faith, spirituality, and religiousness were also emphasized by the interviewees as a support for rehabilitation. For them, believing in something superior is an important source of support, in which they seek strength to face the disabilities imposed by the CKD and its treatment.

A study showed that among the factors promoting the adherence of hemodialysis, the faith in God was cited by 13% of interviewees. For them, God is the only capable of producing relief and curing sicknesses. Religious practices provide support throughout the CKD and even in death, since the person who feels God in his life is able to adapt to unexpected changes.¹⁷

[...] sometimes we rebel against God, but it's not for diminishing your faith. My faith has increased. I was a person with very little faith, but only now, from some time now, my faith has increased. [...] what happens to me [...] I always put God in the first place. It's the first thing to do, you know, and it's in God's hands. If He wants me to do it, if He want it happens, it'll happen, and if He don't, It's OK for me [...]. (P12)

[...] It's a matter of faith. [...] I think after that happened I became even more attached. You have to have something which can hold you up. Sometimes when you are down you meditate, you pray. Sometimes this brings an energy for overcoming it and move on because you can't be 100% every day. So you have to have something to be attached to. In this case, faith [...]. (P9)

There is also stressed that, for them, there is a strong link between faith and cure, as they put they healing expectations in a superior being. According the interviewees, the faith in God increased after having CKD, even for those who had already had it. Those who didn't believe in God so much felt a need to believe more, revealing that all we need a spiritual/religious support during the affliction moments.

Beliefs, as vertical dimensions of spirituality, presented scores closer to the maximum value. Consequently, the spirituality is a valuable tool, which helps human beings to face deadly diseases.¹⁸

Another issue pointed out by some of the patients was the changes in the sexual performance, cited by them as a factor that causes discomfort. A study¹⁹ showed that sexual dysfunctions are common in people undergoing hemodialysis. Psychological, pharmacological and neurological factors, as well as physical appearance problems, were cited as possible causes of these dysfunctions. The lack of knowledge about CKD by the spouses also influences these issues. According to the following testimonials:

[...] I don't have sex anymore. Since I found the problem, she became a little suspicious, so I said: go with me and talk to the doctor to inform yourself. He'll tell you. It's not that I'm escaping [...]. (P8)

[...] we don't sleep together anymore. It's been for four years that one sleeps in a room and the other sleeps in another. We had a good relationship, but now [...]. (P1)

Regarding the male patients undergoing hemodialysis, they link sexuality with the sexual act itself, becoming something special, chemical, and even obligatory. Factors such as fatigue and sadness from the treatment interfere with their sexuality.²⁰

In this sense, it is important to help people to discover their abilities, accept them and confirm them both positively and unconditionally. This is the best way to make them more confident to face the everyday life even it becomes difficult.²¹

CONCLUSION

After knowing the perceptions of the patients undergoing hemodialysis about the changes and limitations of this treatment in their lives, we found that their bio- and psycho-social modifications, which are present in feeding habits and even in family and friend relationships, are mostly expressed as negative perceptions due to the restrictions imposed by CKD. In this context, it is necessary to support and strengthen the patients' relationship networks, which can, in turn, facilitate the exposure to these limitations and improve the quality of life.

Indeed, the nursing team is an important support link since the studied patients believe in these professionals. Thus, we highlight that the nursing team must care about the needs of the patients and their relatives, providing not only excellent treatment services but also emotional support for them. Each of the studied patients has unique behaviors associated with emotions, caused by the CKD and hemodialysis.

This research contributed to rethink the patients' needs caused by CKD and hemodialysis, as well as to reconsider intervention types that help these patients to live more harmoniously with the disease and therapy. Thus, it is emphasized the need for research that presents the CKD patients' priorities aiming to handle health practices and to contemplate users in their real needs.

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