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# Perception of chronic kidney disease patients about hemodialytic treatment

Percepción de los pacientes con enfermedad renal crónica sobre el tratamiento hemodialítico

Percepção de portadores de doença renal crônica sobre o tratamento hemodialítico

## ABSTRACT

**Objective:** Analyze / describe perceptions of hemodialysis patients with Chronic Kidney Disease (CKD). **Method:** Integrative literature review, with collection of articles from the PUBMED database from September 9 to 16, 2020. 11 articles were analyzed, the information organized in the categories: physical aspects versus quality of life; life perspective; physical perception and its implications. **Result:** concerning physical aspects versus quality of life, the patient with CKD is affected by physical aspects such as edema, loss of independence and autonomy in work activities due to symptoms. Regarding the perspective of life, CKD was seen as limiting social life and death sentence, however, it appeared as a postponer of this event. Regarding physical perception and its implications, women are more concerned with physical / aesthetic changes, while men are concerned with changing roles. **Conclusion:** the development of interventions to improve knowledge about the disease is indicated.

**DESCRIPTORS:** Quality of life; Chronic Kidney Failure; Dialysis; Hemodialysis.

## RESUMEN

**Objetivo:** Analizar / describir las percepciones de los pacientes en hemodiálisis con Enfermedad Renal Crónica (ERC). **Método:** Revisión integrativa de la literatura, con recolección de artículos de la base de datos PUBMED del 9 al 16 de septiembre de 2020. Se analizaron 11 artículos, la información organizada en las categorías: aspectos físicos versus calidad de vida; perspectiva de vida; percepción física y sus implicaciones. **Resultado:** en cuanto a aspectos físicos versus calidad de vida, el paciente con ERC se ve afectado por aspectos físicos como edema, pérdida de independencia y autonomía en las actividades laborales por síntomas. En cuanto a la perspectiva de la vida, la ERC fue vista como una limitación de la vida social y la pena de muerte, sin embargo, apareció como un postponer este hecho. En cuanto a la percepción física y sus implicaciones, las mujeres están más preocupadas por los cambios físicos / estéticos, mientras que los hombres se preocupan por los cambios de roles. **Conclusión:** se indica el desarrollo de intervenciones para mejorar el conocimiento sobre la enfermedad.

**DESCRIPTORES:** Calidad de vida; Insuficiencia renal crónica; Diálisis; Hemodiálisis.

## RESUMO

**Objetiva-se:** Analisar/descrever percepções de portadores de Doença Renal Crônica (DRC) sobre hemodiálise. **Método:** Revisão integrativa da literatura, com coleta de artigos da base de dados PUBMED durante os dias 09 a 16 de setembro de 2020. Foram analisados 11 artigos, as informações organizadas nas categorias: aspectos físicos versus qualidade de vida; perspectiva de vida; percepção física e suas implicações. **Resultado:** relativo a aspectos físicos versus qualidade de vida, o paciente com DRC vê-se afetado por aspectos físicos como edema, perda de independência e autonomia nas atividades laborais devido os sintomas. Quanto a perspectiva de vida, observou-se a DRC como limitante ao convívio social e sentença de morte, porém, surgiu como postergadora deste acontecimento. Relativo a percepção física e suas implicações, as mulheres preocupam-se mais com as alterações físicas/estéticas, enquanto os homens preocupam-se com as mudanças de papéis. **Conclusão:** indica-se o desenvolvimento de intervenções para melhorar o conhecimento sobre a doença.

**DESCRIPTORES:** Qualidade de Vida; Insuficiência Renal Crônica; Diálise; Hemodiálise.

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**INTRODUCTION**

**C**hronic Kidney Disease (CKD) is recognized worldwide as a public health problem. It consists of the progressive and permanent loss of kidney function, and is associated with aging and the demographic transition of the population. Among the main causes, arterial hypertension and diabetes stand out, however socioeconomic, racial and gender disparities are also determining factors. Early detection and appropriate treatment in the early stages help to prevent deleterious outcomes and subsequent morbidity related to kidney diseases.<sup>1</sup>

Kidney and urinary tract diseases are responsible for approximately 850 million deaths per year worldwide and the incidence of CKD increases by around 8% per year. In Brazil, about 12 million people have some degree of Renal Insufficiency (RI) and approximately 95 thousand chronic renal patients depend on hemodialysis (HD) to survive.<sup>2</sup>

The available modalities for the treatment of CKD with the purpose of partially replacing kidney functions are: hemodialysis and peritoneal dialy-

sis. HD can often present itself as a life expectancy for the patient, since the disease is irreversible. However, there are difficulties in accepting treatment, illness and personal image.<sup>3</sup>

The patient with CKD, undergoing hemodialysis treatment, presents physical and mental changes and restrictions, in addition to changes in his well-being, compromising his independence and autonomy. In this sense, changes in behavior, lifestyle, habits, social relationships, employment and income are likely to occur.<sup>4</sup>

The quality of life of patients with CKD can be affected by the intensity of the symptoms of the disease and by clinical complications or parallel complications, the amount of medication to relieve the symptoms and changes in social life, due to restrictions imposed on daily life by the chronic condition.<sup>5</sup>

Considering the relevance of HD in the lives of people with CKD and the importance of identifying the impacts that this treatment can cause on patients, this analysis of the literature on the perceptions of people with CKD on HD is made. Aiming to describe and analyze the perception of CKD

patients about hemodialysis treatment, and having as a guiding question: what is (are) the perception (s) of the chronic kidney patient about the hemodialysis process?

**METHOD**

It is an integrative review of the literature developed in order to synthesize available research findings on the subject and guide the practice based on scientific knowledge.<sup>6</sup> The study permeated the steps recommended by the Joanna Briggs Institute: formulation of the question for the elaboration of the integrative literature review; specification of study selection methods; data extraction procedure; analysis and evaluation of studies included in the integrative literature review; data extraction and presentation of the review/synthesis of the knowledge produced and published.<sup>7</sup> This study had as a guiding question which is (are) the perception (s) of the chronic kidney patient about the hemodialysis process?

Data collection took place through research in the PUBMED database during the afternoon shift of September

9th and 16th, 2020, using the descriptors: “percepção”, “Insuficiência Renal Crônica” and “Hemodiálise” and the boolean operator “and” available in three combinations: “perception and Chronic Renal Insufficiency”; “Perception and Hemodialysis”; “Perception and Chronic Renal Insufficiency and

Hemodialysis”. With the base filters: full text, period 2015 to 2020 and article format, 140 works were obtained. Then, the inclusion criterion was applied: to be the study related to a patient with Chronic Kidney Disease undergoing hemodialysis, excluding 129 articles, which escaped the theme.

## RESULTS

The review sample consisted of 11 studies, which describe evidence about the perceptions of patients with CKD about HD. The extracted data were compiled in table 1 and then discussed.

Table 1: Summary of studies included in the integrative review (n=11)

Titles	Authors	Results	Year
Living with dying: A narrative inquiry of people with chronic kidney disease and their family members	Anita E. Molzahn; Laurene Sheilds; Anne Bruce; Kara Schick-Makaroff; Marcy Antonio; Lacie White2.	The CKD patient and his family mainly highlighted the relationship between the finitude of life and the perception of death.	2019
Illness perception, coping and adherence to treatment among patients with chronic kidney disease	Esperanza Velez-Velez; Ricardo J. Bosch	Being a woman, having a greater knowledge of the disease and having a lesser sense of personal control affected adherence to treatment. Those who believed that their disease had a chronic course were more likely to cope, this was seen as a stronger trend among women.	2015
Refusal of Hemodialysis by Hospitalized Chronic Kidney Disease Patients in Pakistan	Salman Tahir Shafi; Mohammad Saleem; Roshina Anjum; Wajid Abdullah; Tahir Shafi.	Among those who accepted hemodialysis, trust in the doctor's advice was the most common reason. Among those who refused, the following stand out: frequency of HD per week, lifelong and permanent nature, advice from family or friends, perception of low quality of life, and fear of needles and complications during HD.	2018
Qualidade de vida de indivíduos com doença renal crônica em tratamento dialítico	Nadaby Maria Jesus; Gracielly Ferreira de Souza; Clesnan Mendes-Rodrigues; Omar Pereira de Almeida Neto; Deusdélia Dias Magalhães Rodrigues; Cristiane Martins Cunha;	The variables that most interfered with quality of life were: smoking; undergoing hemodialysis (health satisfaction) and session time.	2019
Body Changes and Decreased Sexual Drive after Dialysis: A Qualitative Study on the Experiences of Women at an Ambulatory Dialysis Unit in Spain	Miriam Álvarez-Villarreal; Juan Francisco Velarde-García; Lourdes Chocarro-Gonzalez; Jorge Pérez-Corrales; Javier Gueita-Rodriguez; Domingo Palacios-Ceña.	Bodily changes were observed, such as: being swollen or deformed, along with general decline. The catheter and/or fistula triggered changes in women's dress. Sexuality changes, affecting sexual desire and satisfaction.	2019
Invisible and intangible illness: a qualitative interview study of patients' experiences and understandings of conservatively managed end-stage kidney disease	Katherine Bristowe, Lucy E. Selman, Irene J. Higginson, Fliss E. M. Murtagh.	Participants described the invisibility and intangibility of kidney disease, and the challenges faced in the face of symptoms. They described a spectrum-like presence, undermining their energy and holding them back.	2018
O corpo marcado pela fístula arteriovenosa: um olhar fenomenológico	Dejanilton Melo da Silval; Rose Mary Costa Rosa Andrade Silva; Eliane Ramos Pereiral; Helen Campos Ferreiral; Vanessa Carine Gil de Alcantaral; Fabiana da Silva Oliveira;	The changes caused by arteriovenous fistulas cause low self-esteem, and attract the eye of the other, causing embarrassment in those who have a marked body, which, in turn, reacts by camouflaging the fistula. From this perception comes fear, which acts as a catalyst for self-care.	2018

To dialyse or delay: a qualitative study of older New Zealanders' perceptions and experiences of decision-making, with stage 5 chronic kidney disease	Sarah Lovell; Robert J Walker; John B.	It reports the importance of support or presence of a family member for decision making in dialysis. He also pointed out that participants saw dialysis as a way to stay alive. Just as hemodialysis was seen as a factor in changes in daily routines.	2017
Illness Perceptions in Patients on Predialysis Care: Associations With Time Until Start of Dialysis and Decline of Kidney Function	Yvette Meuleman; Moniek C.M. de Goeij; Nynke Halbesma; Joseph Chilcot; Friedo W. Dekker; Sandra van Dijk.	Perceptions of the disease are associated with its progression in patients with CKD undergoing pre-dialysis treatment. The relationship found indicates that stronger negative perceptions of the disease at the beginning of specialized pre-dialysis can be an important marker for an earlier start of dialysis and a faster decline in renal function.	2015
Exploring the nature of illness perceptions in people with end-stage kidney disease	Jessica Rees; Joseph Chilcot; Warren Donnellan; Laura Soulsby;	The potential for transplantation gave participants who underwent hemodialysis a hope of escape from dialysis.	2017
Burden of living with multiple concurrent symptoms in patients with end-stage renal disease	Marques Shek Nam; Cho Lee Wong; Eva Hau Sim Ho; Yun Ho Hui; Christine Miaskowski; Winnie Kwok Wei So.	A group of symptoms emerged and the following stood out: tiredness, shortness of breath, dizziness and sleep disorders. Three other themes were also described: "decreased physical functioning", "changes in social functioning" and "diet and fluid restrictions".	2020

## DISCUSSION

CKD is a morbidity with repercussions on individual behavior that, many times, questions the subject's existence in the family context and in social interactions. The reality configured in the perception of subjects in HD with Arteriovenous Fistula - AFV makes it possible to reconceptualize this new health/disease condition. However, these subjects are often part of a world of impossibilities and, when faced with the marks imposed by the disease on their bodies, they perceive themselves and are perceived as different beings in the world. It is noted that CKD marks the body esthetics in a striking way, either by the signs of the disease, or by the invasive approaches, such as the fistula.<sup>11</sup>

It is also considered a silent, invisible and intangible disease, this combination of invisibility and intangibility, along with the unpredictable nature of the disease, had a strong impact on the quality of life of individuals. In addition, it has a physical repercussion, which ends up making patients feel ashamed and upset. It is added that women see the physical re-

percussion of the disease from a different perspective, they recognize that CKD affects their sexuality, decreasing their sexual desire. Some associate decreased sexual activity with tiredness, especially after HD. Others feel less attractive due to changes in their body image and therefore reject sexual intercourse.<sup>8,9,16</sup>

Individuals with CKD have difficulty in establishing and/or maintaining employment due to the time they spend in RRT, and suffer from physical impairment and symptoms such as weakness, tiredness, sleep disorders, shortness of breath, dizziness and malaise, which in turn instead affect the performance of activities of daily living and produce psychological effects and emotional distress.<sup>8,10,17</sup>

People with the disease and family members often have very similar perceptions and desires, namely avoiding pain and minimizing suffering. People often share past experiences of death, and exploring these experiences can facilitate a deeper understanding of desires and fears.<sup>12</sup> In some moments, the patients declared themselves physically disabled due to the loss of energy and strength. The dialogues of the patients

were similar to those of the phrase "Carpe Diem" which means "enjoy the day". This sense is linked to mortality, in the sense of seeing the diagnosis as a "death sentence", however, for some it was seen as an opportunity to change daily activities. Participants also commented that they were not afraid to die, but they did not want to suffer. Most of them, mostly aware of the limited life expectancy associated with the disease, maintain hope for improvement and a commitment to live well as long as they live.<sup>12,15</sup>

It was also observed that, depending on the age of the patients, there is a dichotomy in the choice of dialysis or not. In a study of 17 elderly people in New Zealand, the authors noted that opinions and choices on whether or not to dialysis were based on well-individualized facts. Those who chose not to perform the procedure, believed that it would decrease the freedom to be carrying out their activities, as well as mentioning the lack of companions to the clinic. Those who chose to do it said that the treatment would prolong their years of life to enjoy with the family and even to have physical conditions to care for a family member who was in a more compromised state of health. Similar

results were seen in a study in Pakistan involving 125 patients.<sup>13,14</sup>

While for male patients, identity conflicts were the result of a change in social roles. Evidencing the statements that showed the feeling of inability to lift heavy objects as a result of their illness, leading them to become dependent on other people, making it difficult to watch a wife/partner or some other family member assume these duties.<sup>14</sup>

As express limitations for the development of this review, we can mention the scarcity of researches at national level, as well as stronger levels of evidence, because due to the type of theme, most of the studies developed are of

qualitative and quantitative approach, whose level of evidence it is VI, in addition, most of the articles used in this review present small samples, which ends up preventing the generalization of the findings.

## CONCLUSION

In the quality of life aspect, the patient with CKD is affected mainly by physical aspects, loss of independence and autonomy in the daily work activities due. Regarding the perspective of life, there was a dichotomy in perceiving CKD as limiting even the social life and death sentence, and at the same

time seen as a postponer of this event. Taking them to live one day at a time and changing ways of looking at life.

As for physical perception, it was possible to observe different ways of reaction and approaches when dealing with male and female sex, these are more concerned and focused on physical changes, while for those more focused on role changes.

Thus, the present research demonstrated the need to develop interventions aimed at the dissemination of knowledge about the disease, in order to prepare the patient to deal with the induced changes and change their general perceptions. ■

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