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REPRESENTAÇÕES SOCIAIS CONSTRUÍDAS POR PESSOAS IDOSAS EM DIÁLISE: UMA CONTRIBUIÇÃO PARA O ATENDIMENTO INTEGRAL

Social representations constructed by elderly people undergoing dialysis: a contribution to comprehensive care Representaciones sociales construidas por personas mayores en diálisis: una contribución para la atención integral

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RESUMO

OBJETIVO: analisar as representações sociais construídas pela pessoa idosa em diálise. **Método:** pesquisa qualitativa fundamentada na abordagem estrutural das representações sociais, com pessoas idosas lúcidas, em diálise crônica atendidas pelo Sistema Único de Saúde. Foi utilizada a evocação livre de palavras com o termo indutor "diálise", cujo corpus foi submetido à análise prototípica e de similitude pelo software IraMuTeQ®. **Resultados:** participaram 51 indivíduos, com idade média de 66,76 anos, com tempo médio de 30 meses em diálise. Evidenciou-se um único elemento central – "Cura" – organizador da estrutura das representações sociais elaboradas, ao se conectar com os diversos outros componentes estruturais, muitas vezes com sentidos antagônicos, podendo explicitar diferentes experiências vivenciadas diante da nova realidade advinda da diálise. **Considerações finais:** as representações sociais contribuíram para a apreensão da realidade vivida pela pessoa idosa em diálise, possibilitando a construção de uma melhor prática clínica.

DESCRITORES: Pessoa idosa; Doença renal crônica; Representações sociais; Diálise.

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ABSTRACT

OBJECTIVE: to analyze the social representations constructed by elderly people undergoing dialysis. **Method:** qualitative research based on the structural approach of social representations, involving lucid elderly individuals undergoing chronic dialysis treated by the Brazilian Unified Health System. The free word evocation technique was used with the inducing term "dialysis", and the corpus was subjected to prototypical and similarity analysis using IraMuTeQ® software. **Results:** fifty-one participants with a mean age of 66.76 years and an average of 30 months on dialysis were included. A single central element—"Cure"— was identified, organizing the structure of social representations, as it connected with various other structural components, often with antagonistic meanings, elucidating different experiences faced in the new reality resulting from dialysis. **Final considerations:** social representations contributed to understanding the reality experienced by elderly dialysis patients, facilitating the construction of improved clinical practices. **DESCRIPTORS:** Elderly; Chronic Kidney disease; Social representations; Dialysis.

RESUMEN

OBJETIVO: analizar las representaciones sociales construidas por personas mayores en diálisis. **Método:** investigación cualitativa fundamentada en el abordaje estructural de las representaciones sociales, con personas mayores lúcidas en diálisis crónica atendidas por el Sistema Único de Salud brasileño. Se utilizó la evocación libre de palabras con el término inductor "diálisis", cuyo corpus fue sometido al análisis prototípico y de similitud mediante el software IraMuTeQ®. **Resultados:** participaron 51 individuos con edad promedio de 66,76 años y un tiempo medio de 30 meses en diálisis. Se evidenció un único elemento central –"Cura" – organizador de la estructura de las representaciones sociales, al conectarse con varios otros componentes estructurales, muchas veces con sentidos antagónicos, permitiendo explicitar diferentes experiencias vividas ante la nueva realidad derivada de la diálisis. **Consideraciones finales:** las representaciones sociales contribuyeron a la comprensión de la realidad vivida por personas mayores en diálisis, posibilitando la construcción de mejores prácticas clínicas.

DESCRIPTORES: Persona mayor; Enfermedad renal crónica; Representaciones sociales; Diálisis.

INTRODUCTION

Chronic Kidney Disease (CKD) is characterized by the progressive loss of kidney function for at least three months. It represents a global public health problem with serious implications, such as increased cardiovascular mortality and reduced life expectancy. When it reaches its terminal stage, renal replacement therapy, such as transplantation or dialysis, becomes essential for survival. In Brazil, the Unified Health System (SUS) funds most dialysis treatments (81.6%) and, despite advances in access to healthcare, the prevalence of end-stage CKD continues to rise. 1.2

Population ageing, as well as the increase in Chronic Non-Communicable Diseases (CNCD), such as CKD, brings new challenges for the care of elderly people, especially those who depend on dialysis, which imposes biopsychosocial limitations that affect their quality of life.³ In this context, the Theory of Social Representations (TSR) proposed by Moscovici⁴, allows us to understand the meanings and experiences influenced by the experience of these patients in the face of the disease and treatment.^{5,6}

SRT suggests that social representations (SR) are forms of shared knowledge that allow individuals to interpret the

world around them based on everyday experience shared by social groups, helping to make sense of new situations.^{7,8} Two mechanisms are fundamental to this process: objectification, which transforms abstract concepts into concrete ones, and anchoring, which relates the new to the familiar, facilitating adaptation to the new reality. In this way, elderly people on dialysis construct their own representations of their illness and treatment. Could knowledge of these representations have a direct influence on adherence to therapies, psychological well-being or the perceived quality of life of these individuals.^{4,9,10}?

In this sense, the structural approach of SRT stands out, aiming to identify the structure and organization of the SRs under study, understood as a socio-cognitive system divided into two subsystems, the central and the peripheral system, with functions that are both rigid and flexible, stable and changeable, made up of hierarchical elements and organized into two complementary systems with different functions. The central system is characterized by its function of generating and organizing meanings, and for being associated with sociohistorical and ideological norms and contexts, while the peripheral system predominates in its functional dimension,

linked to the immediate context, making it possible to anchor the representation. ¹²

This study is justified by the quest to promote a better care plan for elderly people undergoing dialysis treatment under the SUS in an attempt to understand their practices and attitudes towards dialysis, their perception of reality, as well as their daily challenges. By looking at the patient from their own point of view, their pain can be understood, allowing for the creation of more effective strategies for therapeutic adherence and promoting quality of life for these individuals. From this perspective, the following question arises: Is it possible to understand the SRs constructed by the elderly about "dialysis"? And with this apprehension would it be possible to create plans aimed at empowering them to face the challenges posed by dialysis treatment?

METHODOLOGY

This is a qualitative study linked to the Professional Master's Program in Gerontology.

The study was based on the TRS structural approach, aiming to identify the structure and organization of the SRs under study, understood as a socio-cognitive system divided into two subsystems, the central and the peripheral system, with functions that are both rigid and flexible, stable and changeable, made up of hierarchical elements organized into two complementary systems with different functions - the central system and the peripheral system.¹¹ The central system is characterized by its function of generating and organizing meanings, and for being associated with socio-historical and ideological norms and contexts, while the peripheral system predominates in its functional dimension, linked to the immediate context, making it possible to anchor the representation.¹²

The research site chosen was a dialysis clinic affiliated with the SUS, located in the city of João Pessoa/Paraíba. Here, patients stay for two to four hours at least three times a week for hemodialysis (HD) sessions.

For this study, the sample was chosen for convenience, and 60 patients aged 60 or over, with a minimum score of 18 on the Mini-mental State Examination cognitive screening test, who had been on HD for three months or more and accepted the invitation to take part in the study were invited to take part. Patients with clinical complications at the time of the invitation or who reported discomfort during the interview were excluded.

A free word recall (FWR) form was used with the inductive term "dialysis", as well as a set of open and closed

questions aimed at categorizing the subjects in relation to their sociodemographic characteristics and exploring content related to the object of study. The interviews followed the following stages: the first consisted of the ELP to identify the structural components of the representations under study, asking participants to name the first four words that came to mind when they heard the word "dialysis". They were then asked to choose the two words they considered to be the most important and to justify their choice. The second was made up of questions related to the social and demographic profile of the group studied.

All 60 patients who were interviewed during the HD sessions were identified. At the request of the clinic's management, they could not be interviewed in the first 15 minutes or the last 15 minutes of the HD session, as this could delay the schedule of the sessions.

The interviewers approached the patients inviting them to take part in the research, explaining how the interview would be carried out, its benefits and potential risks. After acceptance, the Informed Consent Form (ICF) was presented, requesting the participant's signature and permission to record the interviews, and the interview began.

This research was approved by the Research Ethics Committee of the Health Sciences Center of the Federal University of Paraíba, under opinion number 6.191.318 and Ethics Appreciation Certificate 71190423.0.0000.5188. The ethical standards in force in Brazil were respected, with the TCLE being presented, read and signed in two copies, containing the content of this research, guaranteeing the anonymity of participants, potential benefits and risks to participants and society.

The data was transcribed, with repeated readings, in order to establish the most reliable content possible of the corpus obtained.

The ELP corpus was analyzed using a procedure that associates the individual and collective dimensions in the evocation process.¹³ This was done by checking the frequencies of evocation (collective dimension) and calculating the average orders of evocation (individual dimension), allowing for the identification of the components of the structure of the representations under study, called prototypical analysis (PA).

This procedure allows the various representational components to be distributed into quadrants according to the attributes derived from the calculations made. The upper left quadrant (QSE) contains the most readily evoked elements with the highest frequencies, indicating their probable presence in the central system of the representations under study. The lower right quadrant (QID)

houses components with opposite characteristics, likely to be part of the peripheral system. According to Abric, the other two quadrants contain elements with mixed attributes: the lower left quadrant (QIE) contains the contrast elements, i.e. those with low frequencies and readily evoked; the upper right quadrant (QSD) contains those of the first periphery with high frequencies and late evoked.¹¹

The words considered most important were analyzed taking into account the frequency of indication. When the indication of a word as the most important has a frequency equal to or greater than 50% of its total evocation, it is considered an indication of centrality.¹⁴

After identifying the representational structure, we proceeded to evaluate the symbolic power of the elements identified in the PA, as proposed by Pecora and Sá¹⁵, through the analysis of similarity, by recognizing significant relationships between the sets they form.^{16,17} In the investigation of connectivity, we obtained a "maximum tree", which graphically synthesizes the set of connections between these elements.

IRaMuTeQ® software was used to carry out these procedures, prototypical and similarity analyses, making it possible to process the material more quickly.¹⁸

RESULTS

All elderly people who had been undergoing HD treatment for three months or more at the satellite clinic were invited to take part in this study, totaling 60 people. However, four (6.67%) patients refused to take part, three (5%) interviews were suspended by the interviewers when they noticed discomfort on the part of the participants and two (3.33%) did not obtain a minimum score on the MMSE showing cognitive impairment, leaving 51 participants.

Of the 51 participants, 21 (41.2%) were women and 30 (58.8%) were men. The average age was 66.76 years, ranging from 60 to 86 years. Around 36 (70.58%) were married or in a stable union. The average time since starting dialysis was 30 months, ranging from three months to 198 months

(three months to 18 years), with most patients on dialysis for more than two years.

With regard to socio-economic status, 42 (82.3%) were retired, six (11.9%) received some form of government aid and only three (5.8%) were economically active, and it should be noted that eight interviewees refused to answer about their family income. Among the 43 (84.3%) who answered, the average family income was 3.46 minimum wages, ranging from half a minimum wage to 20 minimum wages. Despite this average, 29 (58.1%) reported having an average income of up to two minimum wages, demonstrating their low socio-economic status.

In the preliminary analysis of the corpus, a total of 140 evocations were identified, covering 46 different related words. It should be noted that many interviewees were unable to evoke all four words, generating a smaller number of evocations.

The frequencies of evocations were then tabulated and it was found that the six most frequent were: "cure" (31), "treatment" (14), "faith" (10), "acceptance" (14), "time" (9) and "health" (9), making up 62.14% of the total evoked. It is important to note here that salience (frequency) is one of the properties of central elements¹⁷. Subsequently, the average frequency (Fm) and average order of evocation (OME) were calculated, resulting in values of 7 and 2.16, respectively.

These parameters made it possible to distribute the elements in a quadrant or four-house graph¹¹, where "cure", "treatment" and "fear" were located in the QSE, standing out for their rapid recall and high frequency, characteristics of central elements. In the EIQ, there was "sadness", "anguish", "nothing", "family", "dissatisfaction with the team, 'living' and 'hope', a set of contrasting elements reflecting the individual and situational traits of the participants, exposing the individual dimension. In the DSF, the first periphery, we found elements related to the collective dimension of the representations, in this case "acceptance", "faith", "time", "health" and "kindness of the team". Finally, in the QID, the second periphery, there were the elements of "illness", "tranquillity", "diet", "obligation" and "transplant" (Table 1).

Table I - Analysis of evocations of the inducing term dialysis

$OME \leq 2,$,16		OME > 2,16		
Evocação	F	Ome	Evocação	F	≥ ome
Healing	31	1,8	Acceptance	14	2,3
Treatment	14	2,1	Faith	10	3,0
Fear	7	2,0	Time	9	2,3
			Health	9	2,3
			Kindness_team	7	2,9
Sadness	5	2,0	Sickness	3	2,7
Anguish	5	1,4	Tranquility	3	2,7
Nothing	4	1,5	Diet	2	3,5
Family	4	1,5	Obligation	2	2,5
Dissatisfaction_team	3	2,0	Transplant	2	3,0
Living	3	1,0			
Норе	3	2,0			
	Evocação Healing Treatment Fear Sadness Anguish Nothing Family Dissatisfaction_team Living	Healing 31 Treatment 14 Fear 7 Sadness 5 Anguish 5 Nothing 4 Family 4 Dissatisfaction_team 3 Living 3	Evocação F Ome Healing 31 1,8 Treatment 14 2,1 Fear 7 2,0 Sadness 5 2,0 Anguish 5 1,4 Nothing 4 1,5 Family 4 1,5 Dissatisfaction_team 3 2,0 Living 3 1,0	EvocaçãoFOmeEvocaçãoHealing311,8AcceptanceTreatment142,1FaithFear72,0TimeHealthKindness_teamSadness52,0SicknessAnguish51,4TranquilityNothing41,5DietFamily41,5ObligationDissatisfaction_team32,0TransplantLiving31,0	Evocação F Ome Evocação F Healing 31 1,8 Acceptance 14 Treatment 14 2,1 Faith 10 Fear 7 2,0 Time 9 Health 9 Kindness_team 7 Sadness 5 2,0 Sickness 3 Anguish 5 1,4 Tranquility 3 Nothing 4 1,5 Diet 2 Family 4 1,5 Obligation 2 Dissatisfaction_team 3 2,0 Transplant 2 Living 3 1,0 Transplant 2

Source: research data, 2023

Note: Fm= average frequency; OME= average of average recall orders; ome= average recall orders; f= frequency

In the search for more evidence of centrality, we tabulated the words indicated as most important and calculated the differences between the frequencies of evocation and indication as most important, the results of which can be seen in Table 2.

Table 2 - Words indicated as most important and respective frequency differences

Element	Evocação	Mais importante	Δ %
HEALING	31	16	51,6
HEALTH	9	6	66,7
FAITH	10	5	50,0
FEAR	7	5	71,4
TIME	9	3	33,3
LIVING	3	3	100,0

Source: Prepared by the authors, 2024

Note: $\Delta\%$ represents the percentage of the difference observed between the frequencies

of the word evoked and the one indicated as the most important.

DISCUSSION

Among the central elements, "cure" and "fear" had frequencies of choices as the most important words above 50%, providing further evidence of centrality¹². The two words, although they have antagonistic connotations, were recurrent in the interviewees' discourse since, although they want to be cured of CKD, they know that this is not tangible, leaving them with the fear of not maintaining life as it once was. Not infrequently, there are reports such as the following:

[...] my biggest dream is to get off this machine [...]. (P50, female, 60 years old)

[...] fear, having lost a brother on the machine, I'm afraid of not being here tomorrow, I'm afraid of stopping on the machine, I've lost many friends who started on dialysis with me and are no longer on it [...]. (P25, male, 61 years old)

"Treatment", although located in the QSE, was not chosen as the most important term by more than 50% of the interviewees who mentioned it. However, it was often included in the justifications for choosing other terms as more important, perhaps to make it clear that not choosing it was a hidden way of expressing the desire to no longer need such treatment.

[...] today I'm accepting it, but when it started I was disgusted, you know? At first, I just cried. Today I'm accepting the treatment well, you know? In reality, I don't feel anything, I keep asking myself, am I really ill? That's what I think [...]." (P28, female, 62 years old)

The QIE shows negative and positive meanings in the evocations. "Sadness", 'anguish', 'nothing' and 'dissatisfaction with the team' are mediating negative meanings, while 'family', 'living' and 'hope' reflect cognitions that mediate positive meanings. This contradiction is an invariant present in the quadrants evaluated and we could see that it was implicit during the interviews, and that it was also present in the discourse of most of the participants.

[...] I can't explain it. I don't think about anything, think about what? If I think, it gets worse. Thank God I don't think about anything when I'm on dialysis, everything is good for me. The thing is to be alive. Sometimes I think about my health, but the bitch doesn't have any, so I don't think about anything [...]. (P18, male, 66 years old)

In the First Periphery, elements were found that are mediating meanings related to the collective dimension of representations, in this case "acceptance", "faith, 'time', 'health' and 'kindness of the team'. These elements are related to the search for a cure, support for treatment and overcoming fear. "Faith" and 'support from the health team' are mentioned by several interviewees, as well as acceptance of the illness in order to overcome fear and seek a cure.

[...] I have faith in God that I'll get well, one day I'll get off the machine, God willing [...]. (P39, female, 65 years old)

[...] I arrived here in a wheelchair, I couldn't walk, today I'm much better. But there are days when I want to rip out the wires, break the machine and run, but I'm lucky with the attention I get from the staff [...]. (P40, male, 61 years old)

The second periphery is dominated by cognitions that are mediating meanings related to CKD and its consequences, "disease", "obligation", "diet" and "transplant". These evocations treat kidney disease as a burden and show the challenges faced by these patients, who are obliged to attend the clinic at least three times a week, follow a strict and restrictive diet and wait a long time for a kidney transplant. "Tranquillity", another word evoked in the peripheral elements, may be suggesting that individuals crave greater peace and tranquillity in their lives.

[...] I wish I didn't have to do it anymore. Before, I could drink normal water, eat pineapple, jackfruit. I only eat meat and fish, bananas once a week [...]. (P29, female, 86 years old)

[...] I don't like doing it, but I have to, I have to. My wife is also on dialysis and sometimes she doesn't want to come, but I explain that it's necessary, so I come to give her strength, I come for her [...]. (P36, male, 65 years old)

Once the structure of the representations under study had been identified, a similarity analysis was carried out to grasp the organization of the AP13 components, making it possible to assess the symbolic value of these elements by identifying the significant relationships they establish with the sets they form, resulting in a "maximum tree", which graphically synthesizes the set of connections between the elements. Healing" was the element with the greatest power of connection or organization, establishing relationships with 12 elements in a star formation, confirming its symbolic value and, therefore, as a central element (Figure 1).

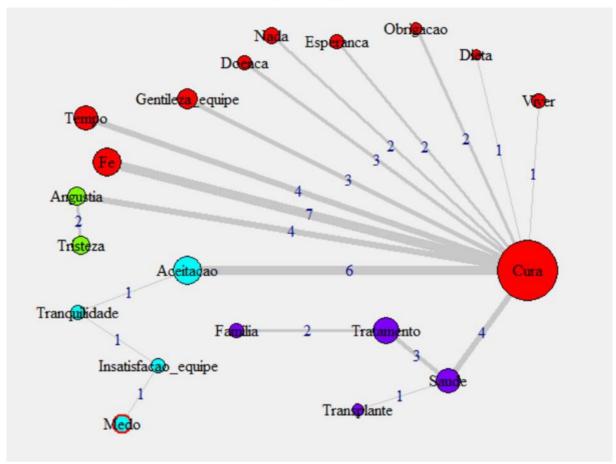


Figure I - Maximum Similarity Tree of the elements evoked by the elderly, João Pessoa, 2024.

Source: prepared by the authors, 2024

The term "healing", through the similarity analysis, shows the various meanings mediated by it, showing a direct relationship with other prominent elements such as "health" and "acceptance", while it showed an indirect relationship with the term "treatment" through "health", "sadness" through "anguish", and with the term "fear" through various other elements.

The strongest connection between "cure" and the elements "faith" and "acceptance" was graphically represented by the thickening of the rays between the elements, a fact that was confirmed by the participants when they justified indicating these elements as the most important. Although the interviewees were aware of the seriousness of their condition, the connection established with "faith" mediated meanings of the belief that healing could happen through faith.

[...] I never thought I'd go through a problem like this, but I haven't lost my kidney and I hope to recover in Jesus' name [...]. (P2, male, 78 years old)

[...] only through God, because through God I can recover my health [...]. (P19, male, 69 years old)

[...] waiting on God is the most important thing [...]. (P23, female, 64 years old)

The "cure" - "acceptance" connection may be mediating meanings by explaining that, as there is still no cure for the current situation, all that remains is to accept the condition of continuing their treatment in a resilient way, as can be seen in the following statements:

[...] I think it's working and I can't stop, because I have my children. I'm afraid of dying, I pray to God that I last longer

[...]. (P10, female, 67 years old)

- [...] there's no other option, you have to do it to stay alive
- [...]. (P14, male, 62 years old)
- [...] dialysis is saving a person's life, if you don't do it, you won't live
- [...]. (P17, male, 67 years old)

It is worth highlighting the link between the elements "acceptance", "tranquillity", "dissatisfaction_team" and "fear", highlighting meanings that allow a comparison of the quality of care provided at the satellite clinics affiliated with the SUS and the private network. It is important to note that none of the participants said they were dissatisfied with the care they received. In addition, "fear" also seems to mediate meanings related to death, given the experience that some participants had when they witnessed the death of other patients during the HD session or when death occurred the day after HD. No, the dissatisfaction was related to not knowing if they were in the transplant queue or the difference compared to the private clinic.

[...] fear, because I lost a brother to the machine, I'm afraid I won't be here tomorrow, I'm afraid I'll end up on the machine, I've lost many friends... I used to have health insurance and I was treated differently, the service was different [...]. (P25, male, 61 years old)

The "anguish" - "cure" connection makes explicit the experiences referred to by some patients when they revealed themselves to be anxious, nervous and worried during HD, perhaps wanting to show that this anguish would be extinguished by the cure. In addition, it is worth noting that the "sadness" - "anguish" connection may be mediating meanings related to external signs resulting from measures necessary for the good outcome of dialysis treatment, such as shame at the presence of the catheter and, at the same time, subjective experiences related to the hopelessness of the cure.

- [...] I get very anxious when I'm on dialysis... When I started dialysis I almost went into depression, I cried a lot at first... I spent five months without leaving the house because I was so ashamed of the catheter in my neck [...]. (P6, female, 66 years old)
- [...] I don't feel comfortable at home anymore, because I don't take my shirt off because I'm ashamed of the catheter [...]. (P42, male, 62 years old)

The return to family life or to work, expressed as dependent on the recovery of health, is contained in the meanings mediated by the association "cure" - "time".

- [...] never to go on dialysis again, to get off this old hemodialysis and go back to doing my activities (bread, cake, cookies [...].) (P34, male, 62 years old)
- [...] I just want to get off the machine... I get impatient with the time I waste at the machine. [...] (P40, male, 61 years old)

The subset initiated by cure-health may be mediating meanings linked to the possibility of recovering family life, which could be achieved with the acceptance of appropriate treatment, in this case HD, or perhaps with the more distant opportunity of a "kidney transplant".

- [...] The most important words are health and improvement of life (cure), because if we don't do hemodialysis we'll have more problems [...]. (P13, male, 61 years old)
- [...] The health I've lost. I think about my children, my wife and my health [...]. (P20, male, 67 years old)
- [...] I need the treatment, I don't think anything bad about it. We need to take care of our health and this is for the good of our health [...]. (P45, female, 70 years old)

The "kindness_team" [professional] in establishing a connection with "healing" may be highlighting the importance of empathy in the professional-patient relationship. The affection and encouragement present in this relationship are fundamental to ensuring proper compliance with treatment. For some participants, the attention they received reduced feelings of sadness and revolt, and often raised the value of life, love and obedience. During the interviews, the team's care for the patients could be seen; their affinity with each other was notorious; they were concerned about their diet and were ready to help with any changes. During one interview, the team realized before the interviewer that the patient was unwell. During the interviews, one patient died and the sadness on the team's faces was noticeable when they announced his death, as well as the need to hospitalize another.

- [...] when I started dialysis I almost went into depression, I cried a lot at first, but the girls (technicians) gave me a lot of strength [...]. (P6, female, 66 years old)
- [...] I like everyone here, they're nice to me (mentions various professionals), I like it here [...]. (P26, female, 63 years old)
- [...] I think their work is beautiful and we have to be obedient to them [...]. (P33, female, 68 years old)
- [...] some days I want to rip out the wires, break the machine and run, but I'm lucky with the attention I get from the staff [...]. (P40, male, 61 years old)

The main limitations of this study were the number of participants and the fact that they came from the same clinic. Despite these limitations, the interviewees lived in different municipalities, and when they came from the municipality of João Pessoa, they lived in different neighborhoods.

FINAL CONSIDERATIONS

The aim of this study was fully achieved and it could contribute to the creation of strategies to promote a better quality of life for elderly people on HD.

This study showed that although the participants are individually connected to a machine, they share a single central element - "cure" - responsible for organizing the entire structure of the representations under study.

The SRs identified make it possible to contribute to comprehensive health care for elderly people on dialysis, making it possible to build better communication and facilitating adherence to treatment.

The work contributes to generating a new view of the elderly person on dialysis, allowing us to understand their reality, their challenges and to improve clinical practice in order to improve the care provided to them, from a comprehensive and humanized perspective.

Finally, it is worth pointing out that, although this work has made a contribution, the subject has been little studied, and further research in the area may provide further evidence on the needs and demands to ensure comprehensive care for this population.

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