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Senses and Meanings of Conservative Treatment in People with Chronic Kidney Disease*

Theme: Chronic Care.

Contribution to the subject: It is hoped that this research can support health intervention strategies, in order to identify factors that reverberate in the life of the individual with chronic kidney disease so as to boost the qualification of the nursing care provided to the users.

ABSTRACT

Objective: To unveil the senses and meanings of conservative treatment in people with chronic kidney disease (CKD). **Materials and Methods:** A descriptive and exploratory study with a qualitative approach. It was developed in 2017, with a sample of individuals with CKD undergoing conservative treatment. A semi-structured interview was used and the data were analyzed using simple descriptive statistics and content analysis. **Results:** 25 individuals participated in the study, of which 56 % were female; 52 % belonged to the 60-79-year-old age group; 48 % were white-skinned; 48 % did not complete elementary school; and only 12 % worked. Content analysis revealed two categories: food restriction: anguishes and impacts that affect the daily lives of patients with CKD and the social imaginary and fear related to renal replacement therapy. **Conclusions:** The results revealed that diet and fear about dialysis therapy produce uncertainty, anxiety and insecurity, in addition to a wide and impacting change in people's lives.

KEYWORDS (SOURCE: DECS)

Chronic renal insufficiency; conservative treatment; feelings; emotions; renal dialysis; qualitative research.

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Sentidos y significados del tratamiento conservador en personas con insuficiencia renal crónica*

RESUMEN

Objetivo: develar los sentidos y significados del tratamiento conservador en personas con insuficiencia renal crónica (ERC). **Materiales y métodos:** estudio descriptivo, exploratorio y con enfoque cualitativo. Desarrollado en el 2017 con una muestra de individuos con ERC en tratamiento conservador. Se utilizó entrevista semiestructurada y los datos se analizaron mediante estadística descriptiva sencilla y análisis de contenido. **Resultados:** participaron en el estudio 25 individuos, de los cuales 56 % son del sexo femenino; 52 % tienen entre 60 y 79 años; 48 % son de etnia blanca; 48 % no han terminado la educación básica y solo 12 % trabajan. El análisis de contenido evidenció dos categorías: restricción alimentaria, angustias e impactos que inciden en la cotidianidad de los pacientes con ERC; y el imaginario social y el temor relacionados a la terapia renal sustitutiva. **Conclusiones:** los resultados señalan que la dieta y el temor a la terapia dialítica generan incertezas, inquietud e inseguridad, además de un amplio e impactante cambio en el vivir de las personas.

PALABRAS CLAVE (FUENTE: DECS)

Insuficiencia renal crónica; tratamiento conservador; sentimientos; emociones; diálisis renal; investigación cualitativa.

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Sentidos e significados do tratamento conservador nas pessoas com doença renal crônica*

RESUMO

Objetivo: desvelar os sentidos e significados do tratamento conservador nas pessoas com doença renal crônica (DRC). **Materiais e métodos:** estudo descritivo, exploratório e com abordagem qualitativa. Desenvolvido em 2017, com amostra de indivíduos com DRC em tratamento conservador. Utilizou-se de entrevista semiestruturada, e os dados foram analisados por meio de estatística descritiva simples e análise de conteúdo. **Resultados:** participaram do estudo 25 indivíduos, dos quais 56 % são do sexo feminino; 52 % estão na faixa etária de 60 a 79 anos; 48 % são de etnia branca; 48 % não completaram o ensino fundamental, e apenas 12 % trabalham. A análise de conteúdo revelou duas categorias: restrição alimentar: angústias e impactos que repercutem no cotidiano dos pacientes com DRC, e o imaginário social e o temor relacionados à terapia renal substitutiva. **Conclusões:** os resultados revelaram que a dieta e o receio/temor acerca da terapia dialítica produzem incertezas, inquietude e insegurança, além de uma ampla e impactante modificação no viver das pessoas.

PALAVRAS-CHAVE (FONTE: DECS)

Insuficiência renal crônica; tratamento conservador; sentimentos; emoções; diálise renal; pesquisa qualitativa.

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Introduction

The rate of people with kidney disease has been growing significantly, with more than 750 million affected individuals around the world. Chronic Kidney Disease (CKD), the most advanced stage of this important public health problem, affects a mean of 13 % of the adult population in the world, and it is estimated that 11 to 22 million inhabitants in Brazil are affected. A survey carried out in 2016 showed an estimate of 122,825 clients undergoing dialysis treatment in Brazil (1, 2).

CKD has been reaching the population of men and women at an increasingly younger age, a stage in which the individual is considered active and productive. This evidence warns to the fact that, in general, chronic degenerative disorders such as CKD have been manifesting in an increasingly early manner in the population (3).

In turn, there are care practices whose objective is to slow down or even inhibit the progression of the disease. After confirming the diagnosis, the patient begins to receive a profuse load of information, especially with regard to the possibilities of treatment, with a view to endorsing, at a favorable moment, a better condition to discuss and decide on the most appropriate and convenient therapeutic path for the more advanced stages of renal failure (4).

Conservative treatment aims to provide the patient with CKD a good and compatible clinical condition with the initial stage of progression of the kidney disease. In this sense, it points to the importance of adopting medication and a controlled and restrictive diet (5). Nevertheless, attention is paid to a scarcity of national publications referring to the perceptions and conceptions of renal patients undergoing conservative treatment, about their existential condition and how they relate and/or live with all the precepts and nuances of the therapeutic plan.

The psychological dimension represents the most affected human component during conservative treatment, which significantly interferes with quality of life (5). Thus, it is essential that, in addition to the treatment for the clinical improvement of the individual, a follow-up that meets the psychological aspects is implemented.

Considering the amplitude of the repercussions of a chronic disease (and its treatment), the relevance of developing a study about the beliefs and personal conceptions of chronic renal patients undergoing conservative treatment is emphasized, due to the

potential of representing a singular contribution to the improvement of nursing care. In this sense, the analysis of the information revealed from the interviewees' testimony may serve as a guideline for the development of strategies for guidance/nursing care, with a view to foster the understanding and adherence of the patients to the therapeutic plan outlined by the professionals involved.

Thus, this study aims to unveil the senses and meanings of conservative treatment among people with CKD.

Materials and methods

This is a descriptive and exploratory study with a qualitative approach, developed in a renal nutrition outpatient clinic linked to a federal university, and located in a municipality in the metropolitan region of Rio de Janeiro (Brazil). To carry out this study, the Consolidated Criteria for Reporting Qualitative Research were adopted (6).

Data collection was carried out during the months of October and November 2017. The sample consisted of 25 individuals with CKD in the conservative treatment phase. There was theoretical saturation of the data when no new information would change the course of the analysis (7). The inclusion criteria were the following: having a diagnosis of CKD of any etiology; and being in the conservative treatment phase. The exclusion criteria were the following: being under 18 years old; less than six months of treatment; and presenting some cognitive deficit.

Semi-structured interviews were conducted, using two questionnaires. One with sociodemographic questions with the following variables: gender, self-declared ethnicity, age group, schooling, profession/occupation, marital status, and family income. The second instrument addressed the comorbidities in addition to issues related to living with CKD and knowledge about the illness and treatment process, such as: What do you know about the conservative treatment? What type of food is recommended? How does the treatment affect the daily routine? Do you know other treatment modalities?

The interviews were conducted in a private room in the research scenario, with a mean duration of 20 minutes, based on the script previously outlined in the questionnaires. From the participants' prior consent by signing the free and informed consent form and a brief explanation about the research, all the subjects

were individually interviewed by the responsible researcher, immediately after the outpatient consultation (pre-scheduled) to monitor the disease.

It is highlighted that the interviews were recorded with the aid of technological resources, namely, an application with a recorder function, with the prior consent of the participants and the guarantee of confidentiality and privacy, as governed by Resolution 466 of 2012 of the Brazilian National Health Council. The data were transcribed using Microsoft Word 2016. To maintain anonymity, the respondents were identified by "Ent." for Interviewee ("*Entrevistado*" in Portuguese), followed by a number (Ent. 1, Ent. 2, ... Ent. 25).

The research was approved by the Ethics and Research Committee of the Fluminense Federal University, with opinion No. 2,341,881 (Certificate of Presentation for Ethical Appreciation No. 73678717.6.0000.5243). All the ethical aspects were duly considered, as well as methodological rigor in order to ensure the reliability of the data in this investigation.

The data obtained were organized, grouped and tabulated. Simple descriptive statistics were used, based on contingency tables with the calculation of absolute frequency and percentage.

Laurence Bardin's content analysis was used, which proposes the following phases for its conduction: a) organization of the analysis; b) coding; c) categorization; d) treatment of results, inference and interpretation (8). Various authors refer to content analysis as a research technique that works with the word, which allows in a practical and objective way for inferences of the content of the communication of a text replicable to its social context. In this type of analysis, the text is a means of expression of the subject, in which the analyst seeks to categorize the units of text (words or phrases) that are repeated, inferring an expression that represents them (9).

Results

Of the 25 participants, 14 (56 %) were female, 12 (48 %) reported being white-skinned and had not completed elementary school, 18 (72 %) were retired, and 10 (40 %) reported a family income of up to one minimum wage. As regards the age group, the highest frequency was between 60 and 79 years old, totaling 13 (52 %) individuals (Table 1).

Table 1. Distribution of the clients according to the sociodemographic variables. Niterói- RJ, Brazil, 2017

| Variables | N (%) |
|------------------------------|---------|
| Age group | |
| Up to 39 years old | 1 (4) |
| 40 to 59 years old | 10 (40) |
| 60 to 79 years old | 13 (52) |
| Over 80 years old | 1 (4) |
| Gender | |
| Female | 14 (56) |
| Male | 11 (44) |
| Skin color/Ethnicity | |
| Black | 3 (12) |
| White | 12 (48) |
| Asian | 1 (4) |
| Brown | 8 (32) |
| Schooling | |
| Illiterate | 3 (12) |
| Incomplete elementary school | 9 (36) |
| Complete elementary school | 6 (24) |
| Incomplete high school | 1 (4) |
| Complete high school | 2 (8) |
| Incomplete higher education | 2 (8) |
| Complete higher education | 2 (8) |
| Occupation | |
| Works | 3 (12) |
| Does not work | 4 (16) |
| Retired | 8 (72) |
| Marital status | |
| Single | 6 (24) |
| Married | 10 (40) |
| Divorced | 6 (24) |
| Widow/Widower | 3 (12) |
| Family income | |
| Up to 1 minimum wage | 10 (40) |
| 1 to 3 minimum wages | 11 (44) |
| 3 to 6 minimum wages | 2 (8) |
| 6 to 9 minimum wages | 1 (4) |
| 9 to 12 minimum wages | 1 (4) |

Source: Own elaboration based on research data, 2017.

Arterial hypertension was self-reported by 11 (44 %) individuals. In eight (32 %), arterial hypertension and diabetes *mellitus* were concomitant. Regarding guidance, 20 (80 %) reported that they received guidance from medical professionals and nutritionists. Regarding the diet, 14 (56 %) of the interviewees reported difficulties to follow the recommended diet. Many of those who reported not having adapted to the diet alleged feeling weak as a justification. Some said they still did not have the financial resources to follow it.

Regarding hemodialysis therapy, 19 (76 %) said they were afraid of this type of treatment. This feeling was almost always related to the death of acquaintances that were undergoing therapy and to obstacles in their daily routine. The majority claimed not knowing other treatment modalities for CKD, in addition to hemodialysis (Table 2).

Table 2. Distribution of the clients according to the variables related to comorbidity, professional guidance, diet, and perception of renal replacement therapy. Niterói- RJ, Brazil, 2017

| Variables | N (%) |
|-------------------------------------------------|---------|
| Comorbidities and/or underlying diseases | |
| Does not have | 3 (12) |
| Hypertension | 11 (44) |
| Diabetes mellitus | 1 (4) |
| Hypertension + diabetes mellitus | 8 (32) |
| Others | 2 (8) |
| Professional guidance | |
| Physician | 2 (8) |
| Nutritionist | 1 (4) |
| Physician + nutritionist | 20 (80) |
| Physician + nutritionist + psychologist | 1 (4) |
| Psychologist + nutritionist | 1 (4) |
| Difficulty following the diet | |
| Yes | 14 (56) |
| No | 11 (44) |
| Fear of hemodialysis | |
| Yes | 19 (76) |
| No | 6 (24) |
| Knowledge of other treatment modalities | |
| Yes | 9 (36) |
| No | 16 (64) |

Source: Elaborated by the authors based on research data, 2017.

In the treatment of data through the implementation of content analysis, it was possible to infer interpretations about the meanings in the speeches, from the translation of the feelings/emotions expressed in them. Thus, it was feasible to elaborate two categories: a) food restriction: anguishes and impacts that affect the daily lives of patients with CKD; b) social imaginary and fear related to renal replacement therapy.

Food restriction: anguishes and impacts that affect the daily lives of patients with CKD

Through the application of the second questionnaire, it was evidenced that most of the interviewees reported difficulties to follow the diet. In this sense, when asked about the reason for encountering difficulties, the following stand out: insufficient, repetitive and painful diet as shown in the following statements:

Because it's difficult to drink and eat little, it's very difficult [...] a damned sacrifice! (Ent. 2)

We skip some things. Sometimes you feel like it and you end up passing the limits. I avoid it, but if I feel like it, I eat a little more [...] (Ent. 8)

Sometimes, you want to eat different things and you also want to eat more [...] you eat and extrapolate a little, because this list they give us here is a sadness for us! (Ent. 15)

It is observed how the change in the dietary pattern implies alterations in the life of the individual with CKD. It is noted that the restrictions recommended in the treatment become complicating factors in the context of living with the disease, due to the need to change eating habits, which represents for many an inestimable suppression of customs, feelings and pleasures routinely shared in the family and/or in social groups.

Adapting to dietary limitations is essential for the treatment to provide well-being and reduce the risk of grievance to people with CKD. Nevertheless, there are cases in which the deprivations act as a "trigger" for disturbing and recalcitrant behaviors, with socio-behavioral repercussions that are difficult to manage, with the potential to generate deep and ultimate impacts with regard to adherence to the therapeutic plan.

Social imaginary and fear related to renal replacement therapy

Among the feelings covered in this thematic category in the interviewees' discourse, feelings of anguish, fear, denial/disgust related to the possibility of depending on a renal replacement therapy to live are highlighted.

Ah...! I'm very afraid [...] I'm very nervous to see that machine, that thing passing and drawing people's blood. (Ent. 3)

[...] I think that a hemodialysis chair is worse than having cancer and dying. I keep imagining that it must be very sad. (Ent. 5)

That's absurd! You get all punctured and full of lumps and you end up with no quality of life. I don't think it's worth it, it's very traumatic. (Ent. 7)

Just talking about it makes me want to cry here [...] I'm a guy who loves his life [...] Now in my old age that I was going to enjoy, I'm walking to death quickly. (Ent. 14)

Many have shown negative feelings about hemodialysis, due to the experiences of people they know. Others associated hemodialysis directly with death, as if it did not help in maintaining life, but rather in worsening the clinical condition, as commented by respondents 5 and 14.

In general, the view outlined from the perspective of the inevitability of treatment is seen with great difficulty and tension, in order to awaken an imaginary of disturbances, along with physical and psychological suffering, according to the analysis of the interviews. It is highlighted that many participants showed distressing thoughts, trapped by the idea of a feared and inexorable change in their daily lives, anchored in the severe and already familiar limitations dictated by the relentless daily life of dialysis therapy, with the addition of a permanent sense of imminence of death.

Discussion

The predominant presence of women in conservative treatment, that is, in the pre-dialysis phase, may be explained by the fact that they pay more attention to health. It is highlighted that, in this phase, the patient is not dependent on dialysis therapy so, in theory, he can have more time and tranquility to choose the type

of treatment that is most convenient/appropriate, according to the guidelines of the health team (10).

The prevalence of older adults in the sample was also evidenced, similarly to what was observed in a survey (11) where 54.3 % of the participants were in the age group of 60 to 70 years old, which warns to the increase of CKD in older individuals.

Similarities in the sociodemographic data are highlighted with those of a survey (12) carried out in the inland of the state of São Paulo, in which it was detected that the majority under conservative treatment were white-skinned.

In contrast, there is evidence that individuals of black skin color/ethnicity are four times more likely to develop CKD than Caucasians (13). In the past, it was thought that this difference would be attributed only to socioeconomic status and access to health care. However, records from the last few decades have shown an increase in important conjunctions of environmental, genetic and clinical factors to the risk of impaired renal function. Therefore, in this scenario, the alert for evidence of the association of socioeconomic combinations with the risk for CKD is relevant and points to the highest rates of kidney disease among people from the most disadvantaged social classes (2, 13, 14).

A number of research studies (4-10) indicate that having access to education is a health need, considering that the therapy implemented by the health team often presupposes strategies for training and health education in the search for success in the scope of treatment. In addition to schooling, the level of understanding, responsibility and commitment of the client are essential factors for the success of the treatment.

In this sense, it is warned that individuals with higher schooling and social levels tend to know and understand more about the disease and the treatment, which demonstrates more (self)care. Nevertheless, data from a study (15) in the Northeast region of Brazil reveal that the mean schooling time of the patients with CKD is 6.5 years, noting that low schooling is a strong characteristic in this group.

A number of research studies (16, 17) involving people with declining renal function revealed that the difficulty and impossibility of carrying out work activities as a result of clinical complication affect discomfort and suffering for those who have the disease, similar data to the findings of this research.

Work plays an indispensable role in the lives of the citizens, especially in the most productive age of life. CKD patients report work as a reference for everything in life, an essential condition for the preservation of mental health and quality of life, and also for personal valorization, including the consolidation of the individual's dignity (16).

The fact that the patients live with family members may be a positive factor, as CKD can progress with physical, social and emotional complications in addition to disabilities, which requires multi-referential care (12, 16). In this perspective, family support can be extremely valuable, contributing to the health of these patients, including the relief of depressive symptoms (18).

A number of studies report that hypertensive patients have more serious kidney damage and, because of this, suggest that they monitor the progression of kidney failure more rigorously, in order to delay its progress and avoid further comorbidities (15, 19). Thus, it is extremely important that health professionals have a more careful view and care with regard to the harmful potential of arterial hypertension from the perspective of CKD.

Considering their vulnerability, human beings need care that takes into account their authenticity and uniqueness. Therefore, it is necessary to identify their weaknesses, so that care can be provided according to the needs of each being (18).

The absence of the nurse in the care process was an alarming information. It is considered that the nurse has an essential role in the care of individuals with CKD, especially with regard to encouraging self-care in health in order to facilitate the patient's cooperation and adherence to the treatment, with a view to attaining satisfactory levels of quality of life and well-being (20).

There is a very close relationship between the nursing staff and the clients with CKD that is built on the basis of a frequent and assiduous presence of the latter in consultations for monitoring the disease. In this context, a valuable opportunity to establish interventions in the context of health education is emphasized, with a view to fostering self-care behavior and user co-responsibility in the treatment (21).

Diet is among the most sensitive issues for clients with CKD. This is worrying, since diet is a major factor in preventing, re-

ducing and controlling the progression of CKD. The adoption of new eating and living habits represents important support for the treatment. However, changes without proper and rigorous monitoring may have an impact on the loss of quality of life, often related to the renunciation of the consumption of some essential foods and the practice of certain habits considered pleasurable (12, 22).

Regarding dialysis therapy, most of the participants were apprehensive. This is explained by the fact that dialysis, an almost irremediable consequence of CKD, causes changes in the lives of the patients due to the treatment being painful and lasting, making acceptance more difficult in most cases (22).

In addition, it was observed that knowledge of other treatment modalities was scarce. This information is worrying, since knowledge is a condition that promotes change in the patient's behavior. In the case of CKD, adherence to the treatment in its early stages is essential in order to positively impact on its progression (23).

From the patients' perspective, the conservative treatment is commonly linked to dietary restrictions, so that, in most cases, they mention several difficulties in following the diet (24). This is because there is a symbolism related to diet, which differs from one population group to another, with variations in cultural patterns, values and beliefs of the individual; and food restriction, which is fundamental for the success of the treatment and the well-being of the patient with CKD, may represent a factor of immense dissatisfaction for impacting daily life (25).

Given the above, it is clear that educational actions with the client are essential, so that he is able to create new ways of living without exceeding limits. In this sense, for the individual to assume the care and control of the therapeutic scheme, it is necessary that educational interventions are carried out horizontally, respecting their individuality, beliefs and values (26).

In the imaginary of an individual with CKD undergoing conservative treatment, numerous meanings for dialysis therapy arise, ranging from the recognition of the severity of the disease stage and the treatment to its most lasting and painful consequences. In most cases, CKD causes negative thoughts and feelings, such as frustrations, limitations, feeling of being stuck with a machine, especially when the individual is faced with the real need for dialysis treatment (22-24).-

The possible need for renal replacement therapy, such as hemodialysis, brings along feelings of doubt and disturbance in the clients because, at the same time that it promotes maintenance of life, it makes the person dependent on technology. Thus, there is a symbolism linked to the dialysis treatment, because it makes the bond between living and dying, in addition to leaving marks on the body (27).

Conclusion

The results showed that CKD has been reaching men and women in very close percentages, especially individuals with low schooling and low remuneration. A major sample profile of older adults in the research is highlighted, which can be correlated with the onset of hypertension and diabetes *mellitus* as the main pre-existing diseases among the interviewees, being considered an important advent for the development and progression of renal dysfunction.

The emotional impact on the way of understanding the disease experienced by the study participants was perceived. In addition to a wide modification in the lives of people with CKD undergoing conservative treatment, the results revealed that diet and fear about dialysis therapy produce uncertainty, anxiety and insecurity. This reinforces the importance of educational actions

that may facilitate the understanding and symbolism of the nuances of treatment, in order to contemplate the peculiarities and needs of each individual.

Lack of knowledge about CKD treatment strategies/modalities was verified. This fact can be substantiated in the speech of the participants by the absence of the nurse as an active character in the multidisciplinary team. Therefore, there is an important and worrying gap in this scenario, in which the nurse's performance is of paramount significance, since renal therapies consist of a high-risk therapy and with a high potential for complications. This professional has the prerogative to act from a holistic approach in the full exercise of care based on his role as a health educator/advisor, which implies helping to better cope with the illness process, in order to have a positive impact on patient adherence to treatment.

Limitations of the study

The fact that it was conducted in only one unit of care for individuals with CKD undergoing conservative treatment is considered a limitation of the study; thus, the results cannot be used as a generalized expression of that group.

Conflict of interest: None declared.

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