

## Cotidiano de pacientes renais crônicos submetidos à hemodialise: expectativas, modificações e relações sociais

Chronic renal patients everyday on hemodialysis: expectations, modifications and social relations

El cotidiano de pacientes renales crónicos sometidos a hemodialisis: expectativas, modificaciones y relaciones sociales

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### ABSTRACT

**Objectives:** to know the perception of chronic renal patients undergoing hemodialysis about the disease, list the expectations, changes and social relationships after the establishment of the diagnosis. **Method:** this is a qualitative descriptive research approach developed in a hemodialysis unit in the Northeast of Brazil with 39 patients affected by CKF. A semi-structured interview guide was used for data collection. The study was approved by the Ethics Committee for Research CAAE: 14153513.2.0000.5180, Case n°.147/431. Data were analyzed with conceptual basis of the Collective Subject Discourse (CSD). **Results:** the categories that emerged from the discourse of respondents were: Rim paralyzed; Lack of knowledge; limitations; optimism; hopelessness; support; Prejudice and isolation. **Conclusion:** the daily life of hemodialysis patients requires changing eating habits, water restrictions, travel is not possible because the frequency of sessions, work deprivation and activities of daily living due to the weakness imposed by the treatment.

**Descriptors:** Chronic Renal Failure; Renal Dialysis; Self-Care.

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## RESUMO

**Objetivos:** conhecer a percepção de pacientes renais crônicos submetidos à hemodiálise sobre a doença, elencar as expectativas, modificações e relações sociais após o estabelecimento do diagnóstico. **Método:** trata-se de uma pesquisa descritiva de abordagem qualitativa desenvolvida em uma unidade de hemodiálise no Nordeste do Brasil com 39 pacientes acometidos por IRC. Para a coleta de dados, utilizou-se um roteiro de entrevista semiestruturado. O estudo foi provado no Comitê de Ética em Pesquisas CAAE nº 14153513.2.0000.5180, processo nº 147/431. Os dados foram analisados com base nos conceitos do Discurso do Sujeito Coletivo (DSC). **Resultados:** as categorias que emergiram do próprio discurso dos entrevistados foram: Rim paralisado; Falta de conhecimento; Limitações; Otimismo; Desesperança; Apoio; Preconceito e isolamento. **Conclusão:** o cotidiano dos pacientes em hemodiálise requer mudança de hábitos alimentares, restrições hídricas, impossibilidade de viagens devido à periodicidade das sessões, privação do trabalho e das atividades da vida diária devido à debilidade imposta pelo tratamento.

**Descritores:** Insuficiência Renal Crônica; Diálise Renal; Autocuidado.

## RESUMEN

**Objetivos:** conocer la percepción de los pacientes renales crónicos sometidos a hemodiálisis sobre la enfermedad, la lista de las expectativas, los cambios y las relaciones sociales después del establecimiento del diagnóstico. **Método:** se trata de un enfoque de investigación descriptivo cualitativo desarrollado en una unidad de hemodiálisis en el noreste de Brasil, con 39 pacientes afectados por IRC. Para recopilar los datos, se utilizó una guía de entrevista semi-estructurada. El estudio se demostró por el Comité de Ética para la Investigación CAAE nº. 14153513.2.0000.5180, proceso nº. 147/431. Los datos fueron analizados con base conceptual del Discurso del Sujeto Colectivo (CSD). **Resultados:** las categorías que surgieron del propio discurso de los encuestados fueron: Lamer paralizado; La falta de conocimiento; limitaciones; El optimismo; La desesperanza; apoyo; El prejuicio y el aislamiento. **Conclusión:** la vida diaria de los pacientes en hemodiálisis requiere cambiar hábitos alimenticios, las restricciones de agua, no es posible el viaje porque la frecuencia de las sesiones, la privación del trabajo y actividades de la vida diaria debido a la debilidad impuesta por el tratamiento.

**Descritores:** Insuficiencia Renal Crónica; Diálisis Renal; Auto-Cuidado.

## INTRODUCTION

Chronic Kidney Failure (CKF) is a disease with high morbidity and mortality with increasing incidence in Brazil and around the world in unsettling scale, as currently being seen as a public health problem. In Brazil, the prevalence of patients on chronic dialysis program more than doubled in the last eight years. From 24,000 patients on dialysis program in 1994, there were 59,153 patients in 2004. The incidence of new patients grows about 8% per year and was 18,000 patients in 2010. Spending on dialysis and kidney transplantation in Brazil situations is around 1.4 billion reais per year.<sup>1</sup>

The CKF is a progressive and irreversible disease of the renal excretory function due to reduced Glomerular Filtration Rate (GFR) of endocrine and metabolic functions, as well as electrolyte disturbances and acid-base, given

deep endothelial, hematological, cardiovascular and nutritional changes.<sup>1-2</sup>

The main risk groups for developing this disease are those with hypertension, diabetes mellitus, and family history of chronic kidney failure. Besides these factors are related to loss of kidney function, glomerulopathy, polycystic kidney disease, autoimmune diseases, systemic infections, recurrent urinary infections, urolithiasis, obstructive uropathy and neoplasms. However, both diabetes and high blood pressure if prevented and detected early, treated properly and monitor by a multidisciplinary team hardly evolve with such serious complications.<sup>2</sup>

The treatment modalities currently available are peritoneal dialysis, hemodialysis and renal transplantation. Both partially replace the renal function, alleviate the symptoms and prolong the patient's life, however, none is curative. Hemodialysis is the most common dialysis method that aims to remove liquid and nitrogen patient excreta away for a dialyzer apparatus (also referred to as an artificial kidney) which serves as a synthetic semipermeable membrane, replacing the renal glomeruli and tubules as a filter for compromised kidneys.<sup>2-3</sup>

Hemodialysis treatment most often generates frustration and limitations, since it is accompanied by various restrictions, among them maintaining a specific diet linked to water restrictions and change in body appearance due to the presence of the catheter to access vascular or arteriovenous fistula. The multidisciplinary approach to patients who are on hemodialysis process is essential to know all the conditioning factors on the disease.<sup>3</sup>

Many professionals do not offer openness to dialogue, acting as absolute masters of truth, disregarding what the patient brings, sometimes judging some patients, not respecting their uniqueness. In this sense, chronic renal patients end up becoming despondent, desperate and often for these reasons or for lack of orientation, they end up abandoning the treatment or not giving importance to the constant care they should have. It is necessary to stimulate their capabilities to adapt positively to the new lifestyle and take control of their treatment.<sup>3-4</sup>

From these assumptions, interest in research development arose from the researchers' experience in a hemodialysis unit with chronic renal patients, who in the course of care practices they observed changes in daily life of people from the diagnosis, resulting impact on social life and some difficulties arising because of treatment. In this perspective, the screen study emerged to the following questions: "How do patients understand kidney failure?"; "What are the changes in daily life in patients with chronic kidney failure undergoing hemodialysis procedure?"; "What are the expectations about treatment?"; "What is the relationship of these clients with family and social life after the diagnosis?"

The objectives were to know the perception of chronic renal failure patients undergoing hemodialysis on the

disease, list the expectations, changes and social relations after the diagnosis answer the research question.

The relevance of the study aims on the possibility to point out the care needs of these individuals, strengthening debates about the importance of a comprehensive, warm and humane care, to consider not only biological, but also psychosocial; which, if not identified and worked, can harm the chronic renal patient.

## METHOD

This is a descriptive study with a qualitative approach, developed in a hemodialysis unit in northeastern Brazil. This unit assisted the patients' participants. Data collection was from April to May 2013.

For the selection of the sample with 39 patients, the following inclusion criteria were adopted: age group above 18 years old; patients who are assisted by the clinic and show no cognitive deficits or mental disorder. Participants who did not meet the criteria above and refused to participate in the study were excluded. The determination of the number of participants is related to the data saturation criterion, which occurs when the collection of data to produce new information or redundant.

The project was approved by the Research Ethics Committee of the University of Santa Maria (WSF), Paraíba, Brazil with CAAE No 14153513.2.0000.5180, Case number 260,795. Before starting the data collection, it was explain to the study participant about the objective of the research being performed a reading of the Consent Agreement and Informed (TCLE) and finally the search was initiated.

Data were collected by a semi-structured interview, which was duly recorded and, a device MP3 player was used for this purpose, ensuring greater reliability and accuracy of the information collected. After this step, the material was fully transcribed and analyzed based on the relevant literature. The instrument for data collection was through a semi-structured questionnaire with six objective questions that sought to trace the socio-demographic profile of the participants and four subjective questions that aimed to the analysis proposed by the study, with questions related to the purpose of the research.

The interviews were transcribed in full and after successive reading material, it was proceeded to the codification of the study participants taking the categories of speeches grouped by similarity, and forming the collective corpus of the speeches.

Thus, the characterization of the sample were organized in a table built in Microsoft Office Excel Program 2009. The qualitative data were analyzed according to the literature and following the conceptual basis of the Collective Subject Discourse (CSD), and based on the construction of collective thought that aims to discover how people attribute the senses, think and position on certain topics.<sup>5</sup>

This study followed the standards of Resolution #466/12 of the National Health Council,<sup>6</sup> which deals with regulatory guidelines and standards for research involving human beings, and COFEN Resolution 311/2007, which shows on the Code of Ethics for Professional Nursing.<sup>7</sup>

## RESULTS AND DISCUSSION

The age of participants was from 20 to 60, with higher prevalence among 50 to 59 years old (28%), most female (51.3%), married (66.7%), illiterate (30.9%), retirees (64.1%) and hemodialysis treatment time was one year to two years. After the brief sociodemographic characteristics of the participants, the Collective discourse was listed interposing the central ideas.

**Table 1** – Central ideas (CI) and Subjects Collective discourse (SCD) on the question “What do you understand about kidney disease?”

CI	SDC-1
Paralyzed kidney	I understand that the kidney stopped, no more filters impurities atrophied and does not work, kidney finished and need this machine, a chronic disease that is cured only by transplant or a miracle of God, hereditary disease came from diabetes, high blood pressure, and polycystic kidney
CI	SDC-2
Lackof knowledge	I do not understand nothing, chlorine in the water problem, serious problem that leads to death, just know that I cannot urinate if missing sections feel shortness of breath, fatigue and does not survive.

In Table 1, it was found that patients have a variety of functions, concepts and adjectives for the pathology having being found certain level of understanding of renal failure or no knowledge about it, so knowledge is a condition that promotes behavior change, in the case of renal disease in the early stages of the disease, it is essential to adherence to intervene in the progression of CKD.<sup>8</sup>

Education can make a difference in the ability of patients and their families to adapt to chronic health condition. When informed and educated, patients often worry about health and do what is necessary to keep it. They longer control symptoms, recognize the onset of complications and early seek health care because knowledge helps to make choices and decisions at all stages of the path of chronic disease.<sup>8-9</sup>

The reasons for the delayed referral to secondary level may be due to lack of understanding of the epidemiology of the disease, the diagnostic criteria or the objectives and results of nephrology care in the early stages. It should also be considered that the competence to deal with a problem is achieved through training and practice. Studies state that it is necessary for the health team to establish relationships based on trust and understanding, as well as solid technical

and scientific knowledge. Otherwise, the lack of adherence to treatment is an additional complication in terms of quality of life of the chronic kidney disease patient.<sup>9</sup>

**Table 2** – Central ideas (ICs) and Collective discourse (SDC) on the question: “What were the changes from the hemodialysis treatment?”

CI-1	SDC-3
Limitations	Life was very bad, I cannot work, I have to come three times a week, take weight on the fistula arm, traveling for over two days, I did not enjoy myself anymore, go to parties, and not drinking, I'm just at home, I feel tired without spirit, food and limited water not killing my thirst.

In the table above, it is possible to see in the speech of participants from the hemodialysis several restrictions in daily lifestyle, interfering directly in their quality of life due to the changes in their physiological functions imposed by the intrinsic evolution of the disease.<sup>10</sup>

The fact is that the chronic kidney failure coexists with an incurable disease that forces them to submit to a painful treatment. When long-term it causes many limitations, usually these problems are social isolation, loss of employment, dependency social security, loss of authority within the family, alienation from friends, inability to long walks and trips due to the frequency of hemodialysis sessions, decreased physical activity, sexual dysfunction, among others.<sup>11</sup>

The relationship between work and health is of concern, considering that the work activities are linked to the physical, mental and social conditions, sometimes compromised in chronic renal patients, contributing factors to the onset of psychological problems.<sup>12</sup>

The basic human need for comfort is compromised in each hemodialysis session due to submission to a puncture with a large gauge needle in a painful process that leaves many marks, but necessary. Thus, there is possibility of performing the treatment, reporting feelings of anxiety, sadness and expected to undergo a new puncture, and the pain considered a discouraging factor to perform the treatment.<sup>13</sup>

**Table 3** – Central ideas (CIs) and Collective discourse (SDC) on the question: “What are your hopes on the treatment (hemodialysis)?”

CI	SDC-4
Optimism	I hope to be transplanted, be cured and do not need the machine, I do prayers, have faith, I feel good in the machine, I do not want to transplant.
CI	SDC-5
Desperation	I do not expect anything good, only the day you die just to go and deceive the time, a palliative, I do not transplant because several friends have died, I'm afraid.

In Table 3, the central idea of “optimism” in the face of a problem that generates suffering and causes reduced support sensations, have feelings of self-acceptance acknowledging and accepting the positive and negative characteristics resulting from therapy as a treatment. It is observed, reported by most participants, the importance of faith in a higher being as a source of hope and strength to cope with difficult situations and conformation on the facts, which cannot be modified.<sup>14</sup>

In a study conducted by the Federal University of São Paulo-UNIFESP, it becomes necessary that the person with a disability to accept their condition, since in the face of adversity and suffering can make sense. The study also indicates that it is important to find meaning in suffering for the person to get over in the best possible way. Drawing positive lessons from painful experiences is growing in deeper dimension that a human being can achieve make sense of his pain as bad as it may seem.<sup>15</sup>

In the central idea “desperation”, respondents reported feelings of disbelief on therapy that are submitted, committing beyond the physical aspect of the psychological factor, favoring functional disability reflected in their daily life.<sup>16</sup>

Patients with chronic renal failure experience a sudden change in their life, going to live with numerous variations of negative thoughts and feelings under the circumstances, think of death because of the irreversible kidney disease, besides the painful treatment resulting in a restricted daily and monotonous.<sup>17</sup>

**Table 4** – Central ideas (CIs) and Collective discourse (SDC) on the question: “How is your relationship with family and social life after the diagnosis?”

CI	SDC-6
Support	The family got closer, they give me a lot of support, I just cannot accompany them everywhere, never liked to go out, I am still having fun with my friends.
CI	SDC-7
Prejudice and isolation	The family moved away, I think it is contagious, I walked away from society, I prefer to stay at home to do what I cannot.

Study participants reported that the support of family and friends provides strength and courage to continue to fight the fears and suffering inherent in their situation, making them feel with the feeling of not being alone, of being supported by the people participating in their world. The support of family can be beneficial, and as a coping strategy. Thus, social support can serve as support for the negative consequences for the decay of physical function in the process of becoming ill.<sup>18</sup>

In the central idea “Prejudice and isolation”, changes both in family life and social are observed. This is linked to the reflections caused by the disease itself, which in the course

of their evolution brings many changes in lifestyle due to the source of stress. Chronic illness affects the entire family and creates difficult times, with advances and setbacks in relations between its members. Sometimes leading to social and emotional isolation, especially if the family has no knowledge about the disease, treatment and available resources.<sup>19</sup>

Depression is the most frequent complication in dialysis patients, and usually means a response to any actual loss, threatened or imagined. Persistent depressed mood, impaired self-image and pessimistic feelings are some psychological manifestations.<sup>20</sup>

## CONCLUSION

From the data obtained in this study, it could be seen that the hemodialysis treatment entails several changes both in the patient's life as the family axis. In this context, the daily life of hemodialysis patients requires a change in eating habits, water restrictions, travel is not possible because the frequency of sessions, work deprivation and activities of daily living due to the weakness imposed by the treatment.

There was the presence of ambiguous and conflicting feelings because on one hand, hemodialysis is the possibility of prolongation of life was found, on the other hand, its achievement requires changing habits and customs that will certainly have repercussions in the usual routine. Therefore, the performance of listening in CKD patients on dialysis leads to reformulation of a more comprehensive care, considering the individual as a subject and not service user.

In this sense, it is necessary to resize the therapeutic actions in the attention and care process, from the sensitive listening to help in the understanding of the person's daily life with chronic kidney disease. Once the care team are a doctor, psychologist, dietician or nurse to work together to achieve, the objectives expected in the health education process, so that the patient can their autonomy.

Thus, it is expected that the results of this study may contribute to the development of strategies that contribute to improve nursing care for patients with chronic disease who are on hemodialysis process. Study limitations were highlighted by the fact that this was done with a specific audience, which has intrinsic peculiarities of the disease and treatment.

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