

The context experienced by family members and people under hemodialytic treatment

O contexto vivido pelo familiar e pessoa em tratamento hemodialítico

El contexto vivido por familiares y personas en tratamiento de hemodiálisis

Bárbara Ebilizarda Coutinho Borges¹ , Nathália Luiza Cândido de Oliveira^{II} , Marília Rute de Souto Medeiros^{III} ,
Jose Lenarte da Silva^{IV} , Maria Leonor Paiva da Silva^V , Allyne Fortes Vitor^{VI} , Rafaela Carolini de Oliveira Távora^I 

^IUniversidade Federal do Rio Grande do Norte. Natal, Brazil; ^{II}Universidade Federal do Rio Grande do Norte. Santa Cruz, Brazil

ABSTRACT

Objective: to understand the context experienced by the family member and person undergoing hemodialysis treatment. **Method:** exploratory, qualitative and cross-sectional descriptive study, approved by the research ethics committee, carried out with patients with chronic kidney disease and their families, in a municipality in the interior of the state of Rio Grande do Norte, between June and July 2019. Used semi-structured interview, with guiding questions for the structural composition of the genogram and ecomap. After transcribing the speeches, the categories were read and constructed based on the information found. **Results:** comprising nine participating families, 18 interviews were carried out, obtaining the categories: Family support, External support to the family, Resignation and Coping with the disease. **Conclusion:** the way in which each patient and family will experience being sick and interpret this meaning will make this particular and personal adaptation, as well as coping, particularly when considering that, within the family nucleus, a restructuring occurs amid the demands of care. **Descriptors:** Nursing; Chronic Disease; Renal Insufficiency, Chronic; Renal Dialysis; Family.

RESUMO

Objetivo: compreender o contexto vivido pelo familiar e pessoa em tratamento hemodialítico. **Método:** estudo descritivo exploratório, qualitativo e transversal, aprovado pelo comitê de ética em pesquisa, realizado com pacientes com doença renal crônica e seus familiares, em um município do interior do estado do Rio Grande do Norte, entre junho e julho de 2019. Utilizada entrevista semiestruturada, com perguntas norteadoras para a composição estrutural do genograma e ecomapa. Posteriormente à transcrição das falas, seguiu-se a leitura e construção das categorias a partir das informações encontradas. **Resultados:** Foram realizadas 18 entrevistas, compondo nove famílias participantes, obtendo-se as categorias: Apoio da família, Apoio externo à família, Renúncia e Enfrentamento da doença. **Conclusão:** a maneira com que cada paciente e família irão vivenciar o estar doente e interpretar esse significado fará essa adaptação particular e pessoal, assim como o seu enfrentamento, particularmente ao considerar que, no núcleo familiar, ocorre uma reestruturação em meio às demandas de cuidado. **Descritores:** Enfermagem; Doença Crônica; Insuficiência Renal Crônica; Diálise Renal; Família.

RESUMEN

Objetivo: comprender el contexto vivido por el familiar y la persona en tratamiento de hemodiálisis. **Método:** estudio descriptivo exploratorio, cualitativo y transversal, aprobado por el comité de ética en investigación, realizado con pacientes con enfermedad renal crónica y sus familiares, en un municipio del interior del estado de Rio Grande do Norte, entre junio y julio de 2019. Se utilizó una entrevista semiestructurada, con preguntas orientadoras para la composición estructural del genograma y del ecomapa. Luego de transcribir las declaraciones, se leyó la construcción de las categorías a partir de las informaciones encontradas. **Resultados:** Se realizaron 18 entrevistas, comprendiendo nueve familias participantes, obteniendo las categorías: Apoyo familiar, Apoyo externo a la familia, Rendimiento y Enfrentamiento de la enfermedad. **Conclusión:** la forma en que cada paciente y familia vivirá el estar enfermo e interpretará este significado, condicionará esa adaptación particular y personal, así como su enfrentamiento, particularmente si se considera que, dentro del núcleo familiar, se produce una reestructuración en medio de las demandas del cuidado. **Descriptor:** Enfermería; Enfermedad Crónica; Insuficiencia Renal Crónica; Diálisis Renal; Familia.

INTRODUCTION

Chronic Kidney Diseases (CKD) generally commence with an injury, accompanied by a progressive and irreversible loss of renal function. This affliction may manifest at the glomerular, tubular, or endocrine level. Its primary etiologies are Systemic Arterial Hypertension and Diabetes Mellitus¹. In Brazil, an estimated 144,779 individuals undergo dialysis treatment, with prevalence and incidence rates of 684 and 209 per million, respectively. Among these patients, 92.6% opt for hemodialysis as their treatment modality. The mortality rate stands at approximately 24.5%².

Identification of renal involvement in its early stages allows for therapeutic options aimed at halting the progression of the disease, thereby delaying or even preventing the need for kidney replacement through peritoneal dialysis and hemodialysis. However, degeneration occurs insidiously, hindering a favorable prognosis³. With the onset of illness, diverse physical and/or psychological sequelae may arise, affecting both the individual and their family.

Corresponding author: Bárbara Ebilizarda Coutinho Borges. Email: barbara_ebilizarda@hotmail.com
Editor in chief: Cristiane Helena Gallasch; Associate Editor: Felipe Kaeser dos Santos

The caregiving role constitutes a chronic stressor due to the emotional burden, coupled with persistent and often physically demanding activities, as well as the administration and management of symptoms and treatment associated with the dialysis process. Simultaneously, the daily and prolonged caregiving routine detrimentally impacts the health of caregivers, with physical and emotional implications due to the demands of therapy and continuous care, exacerbated by economic difficulties that frequently preclude them from experiencing a conventional family, social, and professional life³.

Upon diagnosis of the chronic condition, family members embark on an adaptation process in an attempt to restore balance. Consequently, the entire family context is altered; individuals within the patient's environment seek to fulfill the necessary care demands, transcending their customary social roles. Concurrently, a new reality emerges, necessitating adjustments to plans, goals, and expectations due to the presented condition and limitations. Consequently, a coping strategy is developed⁴.

In this scenario, the afflicted individuals may develop a dependency on their family, which, in most situations, assumes the role of caregiver, dedicating themselves extensively to the care of their relative and exerting a significant impact on family structure and functionality. Simultaneously, when assuming complete responsibility for providing the quality of life for an ailing individual, there is a surprising repercussion on one's daily activities and social connections, contributing to a restriction of their quality of life⁵.

During this interim, nursing must extend its care to the family with comprehensive assistance, guided by ethical and moral principles, taking into account the emotional aspects of these individuals. Therefore, fostering a collaborative and participatory bond involving the family and nursing, with interventions aimed at improving the patient's condition⁶.

It is noteworthy that tools for evaluating the families of patients with CKD are scarce. Consequently, researchers have sought to implement scientific approaches to family assessment and applied them to the framework of this study in the pursuit of a deeper understanding of the subject.

For instance, the genogram and ecomap are essential elements for visualizing and recording families' perceptions of their structures and roles in social and support relationships, enabling the retrieval of everyday memories, and enumerating the presence of individuals, places, or activities involved^{7,8}.

This work is justified by the escalating increase in individuals with chronic renal conditions associated with challenges in self-care and care assisted by family members. Additionally, the chronic condition, coupled with the stigma of the disease and the expectations brought about by the patient's condition, induces a profound change in family dynamics.

The study aimed to comprehend the context experienced by the family and the individual undergoing hemodialytic treatment.

METHOD

This was a descriptive exploratory study with a qualitative approach and a cross-sectional design. Its design was operationalized using the instrument for qualitative research known as Consolidated Criteria for Reporting Qualitative Research (COREQ)⁹.

Participant recruitment took place at a Nephrology Center located in a city in the state of Rio Grande do Norte, which serves as a referral center for hemodialysis treatment.

Sampling was intentional, with participants indicated by the clinic professionals on-site, determined by theoretical saturation¹⁰. Inclusion criteria were established as follows: patients over 18 years of age, undergoing hemodialytic treatment with a minimum of 12 sessions, corresponding to the first month of treatment and the initiation of therapeutic adaptation, accompanied by a caregiver considered by the patient to be family. The inclusion criterion for the caregiver was the patient's indication of them being part of the family, defined as "the family is who its members say they are"⁶.

Exclusion criteria included patients whose caregiver did not agree to participate in the study, individuals with impaired hearing due to communication difficulties during data collection, and those with cognitive deficits according to the clinic team, as this could introduce bias into information collection. In the case of the exclusion of the family member, the patient would subsequently be withdrawn from the study.

Data collection occurred from June to July 2019, within the nephrology center, with the participation of both the patient and their caregiver. Guiding questions were employed for information gathering to construct the genogram and ecomap⁶: Can you tell me who is part of this family? Does anyone else live with you? How many children do you

have? Where do your parents live? How often do you have contact with them? What community services does your family use? Do you participate in any temple, church, or synagogue? Would talking to someone about church, temple, or synagogue help you cope with the disease? Are your religious beliefs a support for you? What was the most challenging aspect after the diagnosis?

Initially, the interview occurred with the patient and subsequently with their family member. Data collection took place before hemodialysis sessions in a reserved room. Participants were coded to maintain the confidentiality of their identity.

The organization and analysis of the qualitative data involved transcription of the statements, reading, and selection of essential excerpts from the interviews. Subsequently, categories were constructed, and analysis was conducted based on similarities between the texts according to the adopted methodological framework¹¹.

The study adhered to the National Health Council's resolutions regarding research involving human subjects, commencing data collection only after approval from the Research Ethics Committee of the institution involved and obtaining the participants' consent.

RESULTS

A total of 18 interviews were conducted, with two individuals from each family, comprising nine participating families. Among the chronic kidney patients, females predominated, accounting for seven of the total interviewees, while among the caregivers, six were children. Regarding social information, none of the patients were engaged in remunerative work, and two family members were employed. The time interval from the initiation of hemodialysis therapy varied from two months to 23 years.

The nine genograms and ecomaps constructed were essential for understanding the families, contributing to categorization and analysis of the narratives obtained, adding to the appropriate structuring of the categories, namely: Family Support, External Support to the Family, Renunciation, and Coping with the Disease.

Family support

Support sources are crucial for an individual, particularly for chronic kidney patients, considering the structural changes in their routine or experience. Support from people around them, who are part of their network, was indispensable for facilitating actions and behaviors in overcoming the disease and treatment.

It can be observed that the family sought to adjust to providing care, as highlighted in one of the interviews, mentioning siblings and stating that someone had to take on the care role, without expressing resentment:

Everyone has their problems, but they all worry about her. If it weren't me, it would be one of them. (FP2)

For other individuals in a routine where all siblings help, caring was seen as "easier":

[Caring is] calmer. (FP3)

Or they mentioned that the children took turns traveling, and their younger sisters always call to inquire about news:

One day one comes, another day another comes. (P4)

In the statements and arrangements of the ecomap, which visually presents the significant relationships and the social and family network of the dyad through drawings, lines, and shapes, support came from family members, especially those accompanying the patients on the day of dialysis:

I feel good, she took care of me [...] I thank God for having health to take care of her [...] we are united when one has a problem. (FP4)

They live in our house. [...] I like it most when one cooks. (P5)

External support to the family

With intense modifications in the disease-coping process, the family members created their own networks for support in this process and managed the healthcare. External sources of support to the family included religiosity and attending the clinic.

The statements highlight the support that religiosity provides in dealing with the health condition, the repercussions, and the specific adversities of therapy.

Nothing is difficult, I hold on to God, you have to do it and just go ahead and do it. (FP5)

I hold on to God a lot, at all times, it's not even every minute, it's in every moment. (FP5)

My religion teaches what is good, it doesn't teach what is bad. (P6)

I hold on to Our Lady of Lourdes, and I'm sure that in difficult times, she helps me. (FP7)

The connection of social support from the clinic was characterized by the discourses:

All the team members are people she can count on if she has any problems. (P3)

They do care, every time I call, they answer me, my mother praises them a lot, saying they are caring, and that they take care of her properly. (FP8)

They care a lot [...] the family can count on them. (FP9)

Renunciation

For health care, it is common for there to be a renunciation of activities previously performed, to spend more time with the chronically ill. The family experiences anguish and exhaustion similarly to the ailing individual, while also being their support. As highlighted in the statements of FP1:

[the family] suffers more than the patient [...] my life is taking care of her, summarized in hers [...] only those who care know, they're not pitiful [...] my care is not indulgence. (FP1)

Renunciation can be seen in a particular statement, expressing that their life was summed up in that of their mother (FP2). They completed by narrating that the most challenging aspect after the diagnosis was their adaptation to taking care of her:

It was difficult! Very difficult [...] I abandoned everything, sold all my places [...] I was alone for everything. (FP2)

It is perceived that the involvement of the patient in their care is necessary, as demonstrated in the statement:

I don't like to lean on anyone much [...] I do my part, and she does hers [wife]. (P6)

The discourses regarding feelings of renunciation expressed discreetly by renal patients are seen from statements about their limitations for daily activities:

I can't do household chores [...] I can't exert force on my arm. (P3)

He is the one who bathes me because I get tired! I get upset because I've never seen my things like this for no reason. (P5)

Coping with the disease

The often-unexpected diagnosis elicited numerous feelings and emotions until the real situation became clear, which varied from not understanding the pathology to denial in the face of a new reality:

She [referring to the patient] thinks that one day the kidneys can return to normal, right? (FP3)

We received a shock. (FP4)

Everything changed [pause] (P4)

Having to do hemodialysis was something we didn't expect! [...] having to take medication every day, three times a day, and three types. (FP7)

I've been stuck in this place for nine months. (P6)

One statement stood out:

It's difficult [pause] she says she does [hemodialysis] because it's the way, she doesn't like it. (FP9)

Others believed that:

It's not a matter of liking it; she fights for her health! She fights! (FP4)

This battle was also permeated by living with the loss of companions who were also undergoing treatment:

After I entered here, I've seen more than 20 people die. (P6)

The obstacles that the treatment poses to daily life were observed, and in relation to having the strength to move forward:

Lack of health, if I had health, it would be easier [...] it's been the most difficult thing. It's accepting, it's been difficult [...] in this life, you have to be a fighter. (P6)

However, there was also an understanding that the therapy, while cutting various aspects of life, enabled its continuation:

I like it, my life is these machines! (P5)

In another statement, the participant mentioned that today they had "conformed" (P3) more with the disease and accepted it.

In some statements about the challenges and responsibilities brought by the disease, a positive coping perspective was identified.

[the family] never complained. (FP1)

An upbeat behavior was observed, to the point of singing on the way between cities:

[the patient agrees] I don't feel tired. (P1)

There was a demonstration of joy and a willingness to go to the clinic:

Because I'm doing the treatment [...] everything is fine, there's nothing to complain about. (P3)

DISCUSSION

The caregivers providing care for individuals with chronic kidney disease (CKD) were predominantly female, either wives or daughters of the CKD patients, aligning with the premise that this role is centered around women within the family nucleus. It is pertinent to consider that social, cultural, and economic aspects influencing the dynamics of care, such as the responsibility placed on women and the perpetuation of a culture of caregiving without specific knowledge, contribute to an excessive physical and emotional burden on the caregiver, even when they are a member of the family¹².

Therefore, due to the high demand imposed by patients, these caregivers often sacrifice and realign their plans in social and economic aspects to dedicate themselves to providing care¹³. According to the category "Coping with the Disease," when the centralization of care becomes a family competence, it is necessary to understand how the disease will be faced and how this assistance will be provided, given the various unexpected contexts and how they will be maintained for an extended period.

The components that make up the universe of chronic kidney patients and their families, when interacting with each other, harmonize to create networks capable of ensuring the improvement of the patient. This exchange between individuals and their environment favors coping with their condition⁶.

The authors observed that family members moved to realign the care of the sick individual, leading to a reorganization of the role of each member and their adaptation. Therefore, family homogeneity strengthened the bonds, encouraging the desire to overcome the disease through "Family Support," as highlighted in the findings of the first category.

According to family systems theory, family relationships are compared to a mobile, where all its pieces are interconnected and in balance, some heavier and others lighter, moving at different speeds. However, when there is interference, such as a breeze, there is a change in the rhythm or movement of each element⁶. In this analogy, one can observe the proximity and distance between each particle and the impact relationship of one part with another, similar to family systems, where the interaction of each member is evident.

In this way, it is understood that the family nucleus will respond to the stress of the disease, necessitating an analysis of the importance of all its components for the development of a support and care network to effectively meet the demands. The reality of the pathology contributes to the strain on relationships and manifests obstacles in the relationships between family members⁹. At the same time, difficulties such as indifference and distancing from some family members are faced.

The configuration practiced by the family members when attending to their members promotes a discussion within the family context, and how care and illness are experienced by each individual⁸. However, according to the second category "External Support to the Family," healthcare providers and patients interact in the daily care routine, establishing connections often due to the extended treatment time, as seen in individuals with chronic kidney conditions, fostering connection and support.

Nursing care providers possess greater aptitude for forming bonds, given their proximity to patients and families, allowing them to perceive their needs. The experience of empathy contributes to the formation of the bond with the provider and therefore acknowledges the anxieties of the individual in need¹⁴. Accordingly, it is understood that interpersonal relationships promote effective and participatory care, and nursing care providers offer solicitous and interactive assistance, facilitating the quality of life for both the patient and the family nucleus.

In this regard, hemodialysis therapy significantly alters the routine of patients. Consequently, they are required to frequent dialysis units and engage with machines and professionals previously unknown to them. Sessions last approximately four hours and are conducted three or four times a week. This time allocated for treatment often induces anxiety during the therapeutic process¹⁵.

Hence, the reduction of social support contributes to an increased risk of mortality and, consequently, a lower acceptance of treatment, especially concerning the duration of sessions, weight gain, and psychological issues⁵.

Simultaneously, with the naturalization of the responsibility for caring for a family member, the caregiver prioritizes the needs of the patient over their own. This process extends beyond tasks and chores, encompassing the obligation to make oneself available to meet the demands of the other, minimizing one's own needs¹⁶. The caregiver, as a family member, shares in the pain and distress of the chronically ill patient in a continuous, intimate, and enduring manner.

The provision of care by a family member involves actions of great complexity, as its context generates various sensations and experiences. For some, receiving assistance from relatives during this phase instills a sense of commitment, alleviating feelings of abandonment in the face of adverse situations. Having someone as support in challenging scenarios allows individuals to feel supported, as the family unit should serve as the foundation for its members¹⁶.

Care assisted by a family member goes beyond an intervention based on the biomedical conception, where mechanical and prescribed plans exist. The caregiver provides comfort, affection, and attention, based on their subjective viewpoint, even in technical aspects. By offering affectionate assistance, caregivers engage in the acquisition of technical knowledge similar to that found in healthcare services, aiming to meet the demands of their care¹⁷.

In the final discourse, feelings of resentment, a sense of uselessness, and powerlessness were evident, as, under current conditions, the patient constantly required assistance to be led and wait for another person. A previous study similarly indicated that individuals may lose enthusiasm for achievements, presuming they no longer can offer anything to others¹⁸.

The category "Renunciation" highlighted aspects of the chronic kidney patient's routine, which is almost entirely focused on medical appointments, hemodialysis sessions, changes in daily routines, the impossibility of travel for leisure or work, or hindering the establishment of life goals. This restricts the places to be visited, keeping individuals within the domestic sphere, and bringing about a sense of limitation to their freedom in the daily lives of patients and their families. This detachment from an active and functional life alters their organization, reducing autonomy, and impacting beyond physical exhaustion and emotional destabilization¹⁵.

Previous study findings confirm that family members are predominantly responsible for the care of an ailing relative. They are characterized as individuals without specific training, unpaid, contributing to the absence of a profession, leisure time, or self-care, directly affecting the quality of life of caregivers and the care provided to the patient¹².

Therefore, recognizing these characteristics and understanding the care scenario and interaction with a support network from the perspective of those providing care is necessary, as these particularities differ according to various contexts. It is also known that hemodialysis is essential for the individual's well-being; however, it imposes numerous restrictions. Consequently, it instills, in the patient, a perception, often negative, discouraging adherence to treatment and leading to neglect. Therefore, there exists a relationship of "life and death," where life is sustained by the therapy that confines them¹⁵.

Limitations of the study

The study has limitations in both the methodology employed and the geographical scope of the data collection, thereby restricting the generalizability of the results. However, it has potential for innovation due to the scarcity of literature pertaining to the scientific approach of the themes addressed, particularly from the perspective of family members. Additionally, it explores the family-patient dyad within the context of their significant obstacles and/or issues, contributing to the novelty of the research landscape.

CONCLUSION

The experience of patients with chronic illness, especially those with kidney diseases, is marked by daily restrictions, leading to changes in living habits. The meaning each individual assigns to the period of their treatment, as well as the understanding of family members regarding this moment, is unique, however, permeated with challenges and expectations.

The results reflect on the care needs that both the patient and the family have in their restructuring amid the care requirements. Consequently, healthcare services must develop strategies to expand or enhance support for patients and their families.

The professional bond must take into account the discourses or warnings issued by patients and family members, as they are responsible for their care and should be part of their support network for the promotion of health and life. Patients and their families often need to (re)encounter themselves and (re)discover themselves, in order to live in their own way with the health challenge because they continue to possess their life stories. It is the entirety of individuals that nursing cares for.

In conclusion, the study contributes to the recognition of chronic kidney patients and their families who face daily sacrifices including the deprivation of leisure, personal relationships, and their way of "being in the world." Therefore, it emphasizes the need to understand the pathways of care needs with the proposition of new knowledge, especially to expand or enhance support for patients and their families.

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