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ORIGINAL ARTICLE

FAMILY PERCEPTIONS OF CARE WITH PATIENTS IN RENAL DIALYSIS PERCEPÇÕES DOS FAMILIARES FRENTE AO CUIDADO COM PACIENTE EM DIÁLISE RENAL PERCEPCIONES DE LOS MIEMBROS DE LA FAMILIA FRENTE A LOS CUIDADOS CON PACIENTE EN DIÁLISIS RENAL

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ABSTRACT

Objective: to investigate the perception of family members regarding the care of patients with chronic renal failure on hemodialysis. **Method:** exploratory and descriptive study, with qualitative approach. Eight family caregivers of patients with chronic renal failure on hemodialysis were interviewed. The data was submitted to the Thematic Analysis technique. **Results:** three categories emerged that expose caring from the family caregiver's focus, the difficulties faced by intercurrents and actions taken, degree of knowledge and lack of orientations, adaptations and feelings emerged from caring. **Conclusion:** family members adapt quickly to the new living conditions, overcome limitations, and gain knowledge about care. Caregivers need to look at caregivers as they are also affected. **Descriptors:** Renal Dialysis; Caregivers; Nursing.

RESUMO

Objetivo: investigar a percepção dos familiares frente ao cuidado de pacientes com insuficiência renal crônica em tratamento hemodialítico. **Método:** estudo exploratório e descritivo, com abordagem qualitativa. Foram entrevistados oito familiares cuidadores de pacientes com insuficiência renal crônica em tratamento hemodialítico. Os dados foram submetidos à técnica de Análise Temática. **Resultados:** emergiram três categorias que expõem o cuidar a partir do foco do cuidador familiar, as dificuldades diante de intercorrências e ações realizadas, grau de conhecimento e carências de orientações, adaptações e sentimentos emergidos do cuidar. **Conclusão:** os familiares adaptam-se rapidamente diante da nova condição de vida, vencem limitações e ganham conhecimentos acerca do cuidado. É necessário um olhar das equipes de saúde sobre os cuidadores, pois estes têm também sua saúde afetada. **Descritores:** Diálise Renal; Cuidadores; Enfermagem.

RESUMEN

Objetivo: investigar la percepción de los miembros de la familia frente a la atención de pacientes con insuficiencia renal crónica en tratamiento de hemodiálisis. **Método:** estudio descriptivo, y exploratorio con un enfoque cualitativo. Fueron entrevistados ocho familiares cuidadores de pacientes con insuficiencia renal crónica en tratamiento de hemodiálisis. Los datos fueron sometidos a la técnica de Análisis Temático. **Resultados:** surgieron tres clases que exponen el cuidar desde del foco de cuidador familiar, las dificultades que enfrentan las complicaciones y las medidas adoptadas, grado de conocimiento y falta de directrices, ajustes y sentimientos emergidos del cuidado. **Conclusión:** los familiares se adaptan rápidamente frente a la nueva condición de vida, vencen limitaciones y ganan conocimientos sobre el cuidado. Es necesaria una mirada de los equipos de salud sobre los cuidadores, pues estos tienen también su salud afectada. **Descriptores:** Diálisis Renal; Cuidadores; Enfermería.

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INTRODUCTION

Chronic Kidney Failure (CKF) is a condition that requires hemodialysis support and is characterized by gradual and irreversible loss of renal function, causing various signs and symptoms resulting from the inability of the body to maintain its homeostasis. The course of treatment, often leads to hospitalization in Intensive Care Units (ICU), for gradual stabilization of the clinical picture.¹

Hemodialysis or renal dialysis is a treatment that performs the renal function when the kidneys cease to be functional, allowing the removal of toxins and excess fluid from the body.²

The treatment of hemodialysis is considered an extremely invasive procedure for a patient, who demands continuous and direct full time in-hospital and in-home care. Hemodialysis is considered a high cost, physical and psychosocial therapy for patients and their families. The Brazilian Society of Nephrology (SBN) conducted a census in 2013 and found that 50,961 people were treated in nephrology units, corresponding to 25.35% of the Brazilian population in the same year.²⁻³

Renal disease and its treatment have repercussions throughout the life aspect of the patient and their family members who follow this process, characterized by life changes, uncertainties, limitations and fears. It is important to clarify that these changes are present, since the patient on renal dialysis coexists with situations imposed by the treatment, such as changes in eating habits, continuous venous access and dependence on a machine, changing their family and social lifestyle.⁴⁻⁵

Nursing assumes a role of interaction with the patient, in the search for clarifications about illness, and provide counseling in self care and especially in the efficacy of fluid management. Self-care developed by the team enables the patient to maintain life, health and well-being.⁶ In this way, family members take care of themselves, learning to seek resources that facilitate the same in the environment and for the people with whom they coexist, with Intention to adapt to the complex processes required in this dialytic treatment.⁷ Currently, Nursing has remitted its care to the family as a unit of care, since when a family member gets sick the rest of the family will also get sick or at least suffer some Impact that will influence the dynamics of its operation.⁷⁻⁸

The interest in investigating this issue is justified by the fact that chronic renal patients perform life-long outpatient

treatment, with the family being the basis of this process. However, the care provided by the Nursing team is almost always intended only for the patient, making the patients Family/ family caregiver (s) assume a supporting role in this context.

OBJECTIVE

- To investigate the perception of family members regarding the care of patients with chronic renal failure on hemodialysis.

MÉTHOD

Exploratory, descriptive study, with a qualitative approach. It was carried out in a city in the northwest RS / Brazil, where family caregivers of patients undergoing hemodialysis were enrolled. The participants of this study were found from the Family Health Strategy teams, following the inclusion criteria: to accept to participate in the research and to be a familiar caregiver of patients in hemodialysis therapy for a time superior to three months. Summarizing eight familiar caregivers who presented all the criteria, they are identified in the study by the letter F (family) followed by sequential Arabic numbers according to the order of realization.⁹

The instrument used in the research was an interview with semi-structured script, containing questions about the profile of participants and 14 open-ended questions. The interviews were recorded in audio and transcribed in full, performed at the caregiver's home in a private environment. The data collection period, was from August to September 2015. For the analysis of the data, the thematic analysis, proposed by Minayo, consisted of three stages: pre-analysis, material exploration and treatment and interpretation of the results Obtained.¹⁰

All ethical precepts have been contemplated. Resolution 466/12 was respected, and the study was approved by the Human Research Ethics Committee, of the Federal University of Santa Maria, under the number CAAE 46741415.1.0000.5346 and opinion number 1,149,199, on July 14, 2015.

RESULTS

The family caregivers investigated were composed of five women (62.5%) and three men (37.5%), and the mean age of the participants was 47 years. In relation to the degree of kinship, five were spouses (62.5%); Two were children (25%); and a daughter-in-law (12.5%). Five of them were unemployed at the time of the interview; and three

Lima LR de, Cosentino SF, Santos AM dos et al.

Family perceptions of care with patients...

participants, besides caregivers, had the following professions: pharmacy clerk, teacher and general service assistant. All patients with CKF dialed on average four years ago, the most recent being treated eight months ago and the oldest 10 years ago, five were female (62.5%) and three male (37.5%); Five (two women and three men), in addition to CKF, were also carriers of Diabetes mellitus. Seven dialysate in clinic and only one of them dialyses in a hospital nephrology unit three times a week.

Three thematic categories emerged, in this study, based on the methodological framework of analysis: perception of family caregivers in relation to care: patient and family adaptations to the disease and feelings emerged from caring.

α **Category 1 - Perception of family caregivers in relation to care**

In view of the diagnosis of CKF and the need for continuous and prolonged treatment, that will keep the patient generally compromised in three shifts per week, the patient, after hemodialysis at his home may present interurrences or signs and symptoms that will require prompt action of his caregiver To reverse the clinical picture that presents itself.

In speeches, family caregivers demonstrate a certain mastery of the post-dialytic interurrences that occur at home. When questioned about complications, upon arriving at the residence, soon after the end of the hemodialysis, the interviewees reported that:

Sometimes it gets bad, says that it hurts the head and they get nauseous, from there it goes straight for bed. (F4)

This, already arrived several times vomiting, with nausea, headache, in the beginning it was thus, had to rescue him here. (F6)

Of the relatives interviewed, four of them demonstrated a domain of the most frequent interurrences that patients with CRF are affected after the hemodialysis session. This is evidenced in their speeches, when they demonstrate to know how to intervene to help their sick family member, In episodes of hypotension.

First thing, I leave the pillow on the couch for her to lie down on ... She lifts her legs, and looks like she's getting better, she sits down, she gets up, and she gets better. (F5)

Usually it was under low pressure, I lay it on the bed, I raise my feet and legs and control the pressure with a digital device that I have at home. (F8)

These reports make it clear how caregivers dominate the main symptoms, such as

hypotension, not requiring immediate care immediately, but rather by solving and assisting the family member / patient with effectiveness at home.

Another speech that emerged from the interviewees is that they seek to learn about the pathology, signs and symptoms, as well as to know about the medications used by the patient with CRF to understand and be able to have better care for their relatives.

No, until I have no difficulties. I've been sucking, I've been learning, I've started from scratch in terms of care ... And I went checking how it had to be until I found a way to take care of, to control her blood pressure and glucose. (F2)

Regarding the information, the caregivers report receiving guidance from the health team at the beginning of the treatment. The professionals cited by the interviewees, are mostly, doctors, but some family members highlight the nurse as the one who keeps guiding them over time. In the following speeches it is observed that the means that the Nursing team has used to meet this demand:

Usually, they pass on to her, right! As she goes with the transportation of the city hall there is no way we are always talking to them, so, they always go to her. (F4)

When I need something, they call me to explain. If they do not call me there, they will send me a note to explain to me when a medication changes or something like that. When they need something to communicate, they send for me, or they just send me a note. (F6)

The interviewees also expressed the importance of being communicated / informed about the clinical picture. In the following statements, the family's concern about care and the need for more guidance. It is understood, it is also understood that there is still a lack of information to be supplied by the health team.

Look, this, for those who take care, to receive information is always good! It had to be even as a requirement of the person who is attending to call the responsible, caretaker, familiar to pass the instructions, because, in this part were few times I had conversations with the doctor, but so to have been called, told to have to go there Were few times. (F2)

It was good, right! We know more, to be inside everything to be able to do things at home. (F5)

At first I was a bit nervous about all this, especially, with the fistula care, because I did not know how to deal with it all. (F8)

⌘ **Category 2 - Family caregiver and family adaptations to the disease**

In the face of all the changes already mentioned regarding the family routine, there is a movement of carer and family adaptations to the disease. The following statements show how these family members have been trying to manage the chronic kidney disease of their family member and faced the changes in their families.

I leave some 'crucible' and leave the phone, I leave just to do something about her or something I need home and then return. I make all the arrangements of house management, which she can not accomplish I am performing. (F2)

As time passed, she went to see that she was having a crisis, had some happenings and she did not know how to act. I said: What is it to do? What do you need? And I noticed that she was not able to clarify, but due to her own illness, that's why I went to take action ... That's why I had to interact in all aspects with her, from there I said: Oh no, now it's me ! You cannot leave it! And I went checking for glucose control, pressure control, what could, what was within the reach of those who care to perform, but provided it is always in accordance with the prescriptions of the doctor, never inventing something that does not match what is prescribed. (F2)

There is an organization of the whole family around the sick family member. The following allocutions present the adaptations of these family caregivers to provide assistance to the patient:

I take care of her straight. When I cannot, there are my sisters who are with her, so it's me and my sisters, she's never alone. (F4)

After he became ill, it was a turnaround in family life, medications, schedules, food and, especially psychologically, because every day we know of patients who suffer poorly during hemodialysis and some who have had cardiac arrest and even died. (F8)

⌘ **Category 3 - Feelings and concerns emerged from caring**

In caring for, supporting and helping his family member in hemodialysis treatment, the family caregiver is modified in the way they live and in the reorganization of the family structure, with repercussions in several areas such as social, financial, psychological, health and others. In the allocutions below this is emphasized:

It is very worrying, because we know that the body often goes undoing, complicating. We know this, it's not easy! (F1)

We're always worried! It is pretty hard! I already had to do a treatment right, gave

me depression, I cried for anything! It's complicated because you end up getting sick together. (F7)

In the same perspective, in the following lines, the familiar caregivers demonstrate the burden of responsibility that ends up being overwhelming when faced with a family that was previously independent and confronted with the new reality of being a caregiver.

I went to take action and now I know it's me [...] I only feel sad that she has this disease, but as for me to help her I feel very well, I like to be useful to her! (F2)

To help her is not difficult, just a matter of concern[...] Seeing her badly the way she stayed for us is complicated. Feeling scared to lose her, right! It's complicated! Are we always worried about her health, how is she? (F4)

I take care of everything, food, salt, water, everything I eat has liquid, but here at home I take it in control. 'Round and a half' we discussed. It can take one or two mates (chimarrão), and if I let it, because when it takes too much water, it affects her breathing. Talking is hard, sleeping or sleeping. (F5)

Sometimes, the familiar caregiver does not have the physical conditions to take care of the family member who is ill, reporting the difficulties they encounter in caring:

I'm already accustomed to caring, only when I get sick what's the problem, because I do not have the strength to lift it. Yesterday, he fell out of bed and I had to call the neighbor to help me [...] I have to be always around, I can not go restful. (F6)

DISCUSSION

CKF is a progressive disease and, once patients and their families undergo sudden changes in their routine, physical and psychological changes they need to be adapted as stress-generating factors. The family often ends up taking responsibility for care and adhering to the new lifestyle.¹¹

Regarding the variables found in the study, the health / disease process interconnects the family in their routine, the family members play a fundamental role in adherence and treatment care. The study pointed out that the woman appears more as a caregiver.

The predominance of female caregivers in our society is due to a vision of the society itself about the woman, who constitutes as a caregiver. She is the, par excellence, keeper of care, because throughout her life she cares for the whole family. This care can be taken as a result of the condition of conjugality, religious beliefs and for carrying with it the responsibility of obligation. However, it was observed that a portion of men assumed the

Lima LR de, Cosentino SF, Santos AM dos et al.

Family perceptions of care with patients...

role of caregiver in an integral manner, with no impairment in care.¹¹⁻³

Family members, for the most part, provide comprehensive care to patients. In relation to the degree of kinship, it is perceived, together with another study realized that, the nuclear family does not always present itself as a reference of care for the patient, in this case, having the help of the daughter-in-law.¹¹

The perception of the family caregivers about the post-dialytic interurrences and their actions taken regarding the signs and symptoms presented in the domicile, have revealed mastery and perform specified care for each change. In the literature, there are two categories of adverse reactions: the least serious and the most serious. The least serious are: nausea, vomiting, headache, cramps, hypotension, bruising and small bleeding at puncture sites. These are actions that the family member, after a training can resolve in their residence. The most serious, but rarely frequent after termination of hemodialysis are: severe hypotension, cardiac changes such as arrhythmias, gas embolism, angina in the chest, which can exceptionally put the patient's life at risk. It was noticed in the interviewees' statements that the most frequent reactions are the least serious.¹⁴

There are few therapies that do not cause any adverse effects to the patient. Although the treatment has a beneficial effect on health, it interferes with the natural functioning of the organism, causing some symptoms. Hemodialysis is responsible for clinical manifestations in patients, who start at the dialysis session until some moments at home. One study showed that hypotension, nausea, vomiting, headache, low back pain are present in a large percentage, as it was seen in this work through the lines.¹⁴⁻⁵

These manifestations are common in hemodialysis patients. It is up to the health team to maintain a clear and resolute communication between the family caregiver, empowering the patient to be prepared to meet the needs of the patient. The development of specific hemodialysis, care such as the use of medications, diet and fluid restriction, seek satisfactory results to keep treatment stable. In order to have a greater adherence among patients with CKF, it is necessary for nurses to use guidelines to patients and their families so that within their limitations, they have a better quality of life.¹⁶

The health professionals need to create a bond with the caregiver and the patient to evaluate the family dynamics around the

treatment, in order to try to approach the reality of these subjects. Through this link, it becomes easier to elaborate a specific care plan for such patients, adapting care to the patients' habits, preferences and socioeconomic status.¹³

The concern about caring for the family member can sometimes lead to pathologies for the caregiver, thus, evidencing the importance of the health service. Through educational actions promoted by the professionals in the Dialysis Clinics or Family Health Strategy, Should be given to the family caregiver, taking greater care and building a specific care plan for this public.¹⁷

The act of caring is a means that brings significant modifications and wear to the health of the caregiver subject, and can lead to the condition of chronicity, passing from caregiver to the person to be cared for. The caregivers / relatives' suffering is visible in relation to the present disease, although in this investigation it has not been scaled, but observed empirically. These face new challenges such as: fear, pain, stress, impotence, sadness and even physical fatigue.¹⁷

The act of caring can lead to a high degree of anxiety and distress, generating, after a period of time aggression with the family member who becomes ill or ends up becoming the caregiver himself, whether it is an emotional or physiological illness. This shows how important the work is to be done Together with the relatives of patients on hemodialysis therapy aimed at alleviating the impact of chronic kidney disease in caregivers.¹⁸

Authors discuss the difficulty of maintaining an effective treatment by health professionals, due to the lack of attention to patients at home, such as diet, venous access and hygiene. In another investigation, nurses stated that when the patient is well cared for at the health facility and at home, the success of hemodialysis, treatment results in a better quality of life and a sense of well-being.²

The results of this research highlight that it is relevant that communication among all involved is increasingly present in front of this therapy so important to maintain life. It was noticed that each caregiver sought to find the best way to adapt, the new routine and the tasks. The family plays a role of protection and socialization and as support in coping with the difficulties arising from the disease.^{1,19}

Caregiving requires a continual effort at the cognitive, emotional and physical levels, often unrecognized and inadequately rewarded. Since this caregiver needs to

absent himself from work, he will make changes on a personal and social level, also interfering in family relationships. Corroborating with study authors report how difficult is the trajectory of the carrier of CRI, constantly changing their quality of life in all social, physical and psychological aspects.²⁰⁻¹

The dynamics of this work make it possible for society, health teams and authorities to take action so that these patients, as well as their families, can be fully assisted and that they can enjoy a decent quality of life. It is important to emphasize that more studies can be directed to this theme, since the work developed with family caregivers should instill the professionals and the community to integrate them into society and help in their adaptation.

CONCLUSION

Differently from the initial impression regarding the orientation and care of the professional nurses towards the family caregivers, according to the interviewees, these professionals have sought to supply the needs of instruction / guidance, clarifying doubts and seeking to include the relative in the context of care. There is still a lack of guidelines to be met by health professionals, in order to achieve greater adherence to treatment.

Faced with the changes imposed by the IRC, patients and families adapt quickly, organizing themselves in terms of the flow of care, often giving up their time and self-care to provide patient care. Each patient may have one or more family caregivers. These however, end up suffering from such changes, the feelings mentioned by the interviewees showed this.

It is necessary to have a specific look from the health team, especially from the nurses to the family caregiver, because the caregiver carries out the care and also needs to be taken care of. Organizing frequent encounters, with the purpose of informing and reassuring about the treatment, are extremely important so that both the patient and the caregiver have a better quality of life, reducing the overload of care.

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Lima LR de, Cosentino SF, Santos AM dos et al.

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