



PERCEIVED STRESS OF FAMILY MEMBERS OF CHRONIC KIDNEY PATIENTS ON HEMODIALYSIS TREATMENT

ESTRESSE PERCEBIDO DE FAMILIARES DE RENAIIS CRÔNICOS EM TRATAMENTO HEMODIALÍTICO

ESTRÉS NOTADO DE FAMILIARES DE RENALES CRÓNICOS EN TRATAMIENTO HEMODIÁLITICO

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ABSTRACT

Objective: to evaluate the perceived stress of family members of chronic renal patients on hemodialysis treatment. **Method:** a descriptive, cross-sectional study with a quantitative approach, performed with 52 family members in a city of Northwestern Rio Grande do Sul. The data were collected using the Perceived Stress Scale and a characterization form, and then analyzed by the software *Statistical Package for the Social Sciences*. **Results:** the items with the highest average in the scale were: felt nervous or stressed; been angered because of things that were outside of your control; been upset because of something that happened unexpectedly; and felt that you were unable to control the important things in your life. **Conclusion:** the relatives of chronic renal patients experienced stressful situations that may be related to dispensing care to the sick member and the physical and emotional burden faced by them. **Descriptors:** Psychological Stress; Family; Chronic Kidney Disease; Nursing.

RESUMO

Objetivo: avaliar o estresse percebido de familiares de renais crônicos em tratamento hemodialítico. **Método:** estudo descritivo, transversal, com abordagem quantitativa, realizado com 52 familiares de um município do Noroeste do Rio Grande do Sul. Os dados foram coletados por meio da Escala de Estresse Percebido e formulário de caracterização, analisados pelo software *Statistical Package for the Social Sciences*. **Resultados:** os itens da escala de maiores médias foram: esteve nervoso ou estressado; esteve bravo por coisas que estiveram fora de seu controle; ficou aborrecido com algo que aconteceu inesperadamente; e sentiu que foi incapaz de controlar coisas importantes na sua vida. **Conclusão:** os familiares dos renais crônicos vivenciaram situações estressoras, que podem estar relacionadas com as ações de cuidado dispensadas e com sobrecarga física e emocional enfrentada por eles. **Descritores:** Estresse Psicológico; Família; Doença Renal Crônica; Enfermagem.

RESUMEN

Objetivo: evaluar el estrés notado de familiares de renales crónicos en tratamiento hemodialítico. **Método:** estudio descriptivo, transversal, con enfoque cuantitativo, realizado con 52 familiares de un municipio del Noroeste de Rio Grande do Sul. Los datos fueron recogidos por medio de la Escala de Estrés Percibido y formulario de caracterización, analizadas por el software *Statistical Package for the Social Sciences*. **Resultados:** los items de la escala de mayores medias fueron: estuvo nervioso o estresado; estuvo enojado por cosas que estuvieron fuera de su control; se incomodó con algo que aconteció inesperadamente; y sintió que fue incapaz de controlar cosas importantes en su vida. **Conclusión:** los familiares de los renales crónicos viven situaciones estresantes, que pueden estar relacionadas con las acciones de cuidado dispensadas y con sobrecarga física y emocional enfrentada por ellos. **Descritores:** Estrés Psicológico; Família; Enfermedad Renal Crónica; Enfermería.

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INTRODUCTION

Chronic Kidney Disease (CKD) is a public health problem and is defined by a slow, progressive and irreversible loss of the kidney function.¹ Globally, it is estimated that about 1.5 million people are receiving hemodialysis treatment, among them 100,397 in Brazil and 12,286 in the state of Rio Grande do Sul.¹

Renal Replacement Therapy (RRT) includes Hemodialysis (HD), Continuous Ambulatory Peritoneal Dialysis (CAPD), Intermittent Peritoneal Dialysis (IPD), Automated Peritoneal Dialysis (APD) and renal transplant.² Regarding the hemodialysis treatment, it conveys a number of negative consequences to the patient, both physical and psychological, being among them social isolation, movement and physical activity hardships, loss of autonomy, changes in body image and feeling of impending death³; in addition, there are the adverse effects of the hemodialysis treatment, such as catheter obstruction, accidental removal of the needle, improper operation of the hemodialysis machine, hair-like fiber disruption, allergic process to blood products, fall from height and error in medication administration.⁴

The patient on hemodialysis needs to go to the nephrology clinic three times a week and stay there for three to four hours for the dialysis, a fact that can trigger physical and mental discomfort.⁵ Moreover, he is vulnerable to harms, symptoms related to the disease and the treatment, as well as to stress. These situations experienced by chronic kidney patients can change the family structure because, also, they can be perceived by the family as stressful.

Stress was defined according to the Interactionist Model, which considers the individual subjectivity as a determinant of the severity of the stressor, as any event that demands from the external or internal environment that taxes or exceeds the adaptability of an individual or social system.⁶ In this context, all demands and complications involving the hemodialysis treatment can be assessed by the patients and his family as stressful situations as long as they exceed their capacity of adaptation.

The discovery of a chronic disease diagnosis triggers changes throughout the family context, so that all members in a greater or lesser degree are affected by the new situation.⁷ These changes affect the daily life of the family members because the hemodialysis demands require their time, care and monitoring of the chronic kidney patient, which can lead to physical and emotional

exhaustion. This reflects the importance and the need for family members to receive adequate support so that they feel prepared and strengthened to act in this process.

Besides the patient, the family also suffers as a result of the kidney disease and the changes needed in their daily life. Results of a study conducted with 22 family members of patients admitted to an Intensive Care Unit (ICU) showed that the majority of the participants were in the middle or late stage of stress⁸, which indicates the importance of providing nursing care also to the families, in different health care settings.

Given the complexity involved in the hemodialysis treatment and its consequences, the patient needs support, and the family is a major source of support.⁹ It consists of an experience exchange system among its members so that a situation influences the whole, that is, the fact that one of its members is sick influences the whole family.¹⁰ Therefore, the family member may suffer the resulting stress of living with the patient, given the complexity of the disease, the care it requires, combined with the anguish caused by the possibility of terminally life.⁹

Thus, in view of the impact of the diagnosis of CKD and the need for hemodialysis, it is relevant to assess the perceived stress of the family members of chronic renal patients undergoing hemodialysis, in order to contribute with the health professionals by expanding the understanding of this stress with the purpose of mitigating it.

OBJECTIVE

- Assess the perceived stress of family members of chronic renal patients undergoing hemodialysis.

METHOD

A cross-sectional descriptive study with a quantitative approach developed in a Renal Unit of a hospital size IV in a city of Northwestern Rio Grande do Sul.

The study included 52 relatives of chronic renal failure patients on hemodialysis who met the inclusion criteria, which are: being a family member of a chronic renal patient undergoing hemodialysis treatment in the said unit and being 18 years or older. Family members with difficulty in understanding and answering the questions contained in the data collection instruments were excluded.

Data collection was conducted in May and June 2014, with the following instruments: Sociodemographic form for family members and Perceived Stress Scale (PSS-10)¹¹

The sociodemographic form included the following variables: age, sex, marital status, religion, children, education level, monthly income, profession, occupation, relationship-affinity, lifestyle, physical activity and leisure. The PSS-10 measures the degree to which situations in life are assessed as stressful and comprises ten items of multiple choice regarding the frequency that the person perceives certain situations ¹¹ The answer options range from 1 to 5, as follows: 1 = never; 2 = almost never; 3 = sometimes; 4 = fairly often and 5 = very often.

Data analysis was performed by using descriptive statistics and the statistical software Statistical Package for Social Sciences (SPSS) version 17.0. Joint frequency distributions were built, and it was observed simultaneously two study variables, i.e., the variable representations in the cross-tables, in

order to identify more clearly the relationship between them.

It was observed all ethical precepts involving research with human beings, according to the Ministry of Health Resolution No. 466 of December 2012, that establishes research parameters with humans. The research project was evaluated by the Ethics Committee and approved under Embodied Opinion No. 427.613/2014.

RESULTS

The study included 52 family members of chronic renal patients on hemodialysis treatment. In the Table 1, the sociodemographic characteristics of the participants are shown.

Table 1. Sociodemographic characteristics of the family members of chronic renal patients on hemodialysis treatment, Ijuí, Rio Grande do Sul, in 2015.

Characteristics	Female n (%)	Male n (%)	Total n (%)
Age			
Less than 29 years old	8 (15.4)	3 (5.8)	11 (21.2)
30 --- 39 years old	6 (11.5)	1 (1.9)	7 (13.5)
40 --- 49 years old	4 (7.7)	3 (5.8)	7 (13.5)
50 --- 59 years old	12 (23.1)	1 (1.9)	13 (25.0)
Over 60 years old	8 (15.4)	6 (11.5)	14 (26.9)
Marital status			
Married/Partner	27 (51.9)	9 (17.3)	36 (69.2)
Single	7 (13.5)	5 (9.6)	12 (23.1)
Divorced/Separated	1 (1.9)	-	1 (1.9)
Widow	3 (5.8)	-	3 (5.8)
Children			
Yes	30 (57.7)	10 (19.2)	40 (76.9)
No	8 (15.4)	4 (7.7)	12 (23.1)
Number of children			
One	9 (22.5)	3 (7.5)	12 (30.0)
Two	8 (20.0)	3 (7.5)	11 (27.5)
Three	9 (22.5)	-	9 (22.5)
Four or more	4 (10.0)	4 (10.0)	8 (20.0)
Education level			
Elementary School	21 (40.4)	9 (17.3)	30 (57.7)
High School	16 (30.8)	4 (7.7)	20 (38.5)
Graduate	1 (1.9)	1 (1.9)	2 (3.8)
Kinship degree			
Son/daughter	12 (23.1)	3 (5.8)	15 (28.8)
Husband/wife	11 (21.1)	5 (9.6)	16 (30.7)
Brother/sister	2 (3.8)	1 (1.9)	3 (5.8)
Mother/father	2 (3.8)	-	2 (3.8)
Daughter-in-law/son-in-law	1 (1.9)	2 (3.8)	3 (5.8)
Uncle/Aunt	1 (1.9)	-	1 (1.9)
Other	7 (13.4)	2 (3.8)	9 (17.2)
Total	38 (73.1)	14 (26.9)	52 (100)

According to the data presented in the Table 1, it was found that 73.1% of the family members were female, 51.9% over 50 years old, 69.2% were married or living with a partner, 76.9% had children and 57.7% attended elementary school. As for the degree of kinship of the participants with the chronic renal patients on hemodialysis treatment, it

was showed that the highest percentages were daughters (23.1%) and spouses (21.1%).

Sequentially, in the Table 2, it was described the participants' life habits. It was found that 28.8% of women said they exercise, and 37.3% informed that they had a healthy diet.

Table 2. Lifestyle of the family members of chronic patients on hemodialysis treatment, Ijuí, Rio Grande do Sul, in 2015.

Lifestyles	Female n (%)	Male n (%)	Total n (%)
Physical exercise	14.4	14.4	14.4
Healthy eating	14.4	14.4	14.4
Other:	14.4	14.4	1950.

In the Table 3, it is shown the descriptive measures of the perceived stress with the

mean, the standard deviation and the coefficient of variation of each item.

Table 3. Descriptive measures of the Perceived Stress Scale (PSS - 10), Ijuí, Rio Grande do Sul, 2015.

Frequency (considering the last 30 days)	Average	SD	CV (%)
1. Been upset because of something that happened unexpectedly	14.4	14.4	14.4
2. Felt that you were unable to control the important things in your life	14.4	1.06	14.4
3. Felt nervous and stressed	1950.	14.4	14.4
4. Felt confident about your ability to handle your personal problems	0,79	14.4	1950.
5. Felt that things were going your way	14.4	1.11	14.4
6. Found that you could not cope with all the things that you had to do	14.4	1.20	14.4
7. Been able to control irritations in your life	1.17	14.4	1.72
8. Felt that you were on top of things	1.50	1.18	78
9. Been angered because of things that were outside of your control	14.4	14.4	14.4
10. Felt difficulties were piling up so high that you could not overcome them	14.4	14.4	14.4

SD = Standard Deviation; CV = Coefficient of Variation.

Scores: 0 = never; 1 = almost never; 2 = sometimes; 3 = infrequent; 4 = fairly often; 5 = very often.

Scores reverse: questions 4, 5, 7 and 8.

DISCUSSION

As for the characteristics of the family members of the chronic renal patients on hemodialysis treatment, it was found that the majority (73.1%) were female, a result that is in line with other studies.^{8,12} This shows that women still occupy more often the caregiver role than men and this data may be related to the availability of time and willingness to take on the tasks inherent in caring for a sick person.¹²

Furthermore, it is known that the chronic kidney patient needs a balanced nutrition with low levels of sodium, which requires care in preparing the meals, a task which is often delegated to women. It is inferred that there is an overload of activities of family caregivers, because besides caring for chronic renal patients, they have other duties, performing double or even triple shifts, which can influence the perception of stress.

As for the age of the family members, it was found that the majority were below 60 years of age. It is considered that the study participants were in their productive phase, and the demands of caring for a family member can interfere with their daily lives. Noteworthy is, on one hand, that the younger the caregiver the more affected is the quality of his psychological life, because care activities cause stress and emotional overload, as well as social-recreational deprivation.¹² However, on the other hand, the more elderly

were the caregiver, the more experience and resilience they had to face this situation.¹²

Regarding marital status, 69.2% of the participants were married. Having a companion to share feelings, difficulties and everyday tasks can help ease the physical and emotional burden and the triggering of stress. In this sense, a study conducted with 40 family caregivers of elderly patients with chronic diseases points out that having a partner brings benefits to the caregivers, for example, emotional support and fewer feelings of loneliness.¹² Similarly, having children may represent a support network, which make it easier to cope with stress.

As for education, 57.7% of the family members only attended elementary school. It is noteworthy that this aspect should always be taken into account when planning educational strategies¹³, as this condition can interfere with processing the information received, trigger anxiety and distress because they do not understand the disease process and the care needs. A low level of education have an influence on the aid, care and quality of attention and may represent a barrier in the health education.¹² In this sense, it is emphasized the need for nurses to know the family members of chronic kidney patients in order to guide them properly.

As for the descriptive measures of the items in the PSS-10, it was found that the highest averages were that of the items 3 (felt nervous or stressed), 9 (been angered because of things that were outside of your control), 1

(been upset because of something that happened unexpectedly) and 2 (felt that you were unable to control the important things in your life). Given these high averages, it is held that the family members of chronic renal patients experienced stressful situations, which may be related to dispensing care and the physical and emotional burden faced by them. This shows the relevance of health professionals, especially the nurses, to be alert to the family members' symptoms of anxiety and stress in order to make their daily life less stressful.

It was observed a gap in the production of knowledge about stress in the families of chronic renal patients on hemodialysis treatment, which led to the discussion of these results with studies conducted with family members of patients with chronic diseases, elderly and patients in the ICU. In a study that evaluated stress and coping in 110 caregivers, the results showed that providing care to a sick family member impacts the intensity of the stress.¹⁴ This result also refers to the care that must be dispensed to the family members, in order to instrumentalize them for caring the sick family member and to encourage them to use effective coping strategies.

In a study of 53 families of patients hospitalized in an ICU, it was showed that hospitalization is considered by the family as a stressful event.¹⁵ In this context, it is known that often a chronic kidney patient also needs hospitalization, which may increase the overload because it is a condition permeated of stressors, both for the patient and their families.

In a qualitative research with six family caregivers of patients with Chronic Obstructive Pulmonary Disease (COPD), it was found that caring for a sick person causes stress in everyday family dynamics leading to physical, mental and emotional complications to the caregiver, loss of freedom and/or overloaded spouses.¹⁶ Also in relation to stress, in a study with ten caregivers, it was concluded that it is necessary to recognize that family caregivers need guidance and, above all, care, in order to minimize the stress that they experienced.¹⁷ These actions of support, appreciation and recognition of the family caregiver are essential for him/her to feel equally cared.

In a survey of 50 caregivers of patients with schizophrenia and 50 caregivers of patients with major depression, it was shown the need to plan specific interventions for each group of caregivers.¹⁸ This result converges with the importance of individualizing the care

provided to the family members, regardless of the pathology of the patients and the health care site, in order to reduce the burden and the stress of the family. The findings in a study that evaluated the quality of life and the presence of burden in drug addicts caregivers confirmed the impairment of the quality of life and the high overload of care, which highlight the need of emotional support for the caregivers.¹⁹

Based on these results, combined with the referenced authors' positions, it is thought that the nurse, because he/she is in direct contact with the patient, the family and other members of the multidisciplinary team, is responsible for guiding the patient and his family about the disease, its implications and limitations. Furthermore, the treatment plan, the technical aspects of hemodialysis process and the possible physical and emotional problems that the patient may show should be informed. Knowing the patient's family provides subsidies to direct it, answer their questions and ease their feelings about the disease and the treatment of their family member.²⁰

It is considered that the nurse, when attending a chronic kidney patient, should include the family in order to guide it properly through a clear, simple and objective approach. It is highlighted that the possible effects that arises from the change in the family dynamics and the difficulties in handling the situation in the family relational framework also deserves special attention from the nurses.²¹ Therefore, allowing the family involvement as a protagonist and a partner in the process of caring for the patient and in the decision making is an important strategy in order it may develop skills and security to care for the patient.²¹

Moreover, it is important to explain the diagnosis and prognosis of the disease to them, because both subjects - the patient and the family - need to have a better preparation and support to adequately address the chronic kidney disease and reduce stressors.

FINAL REMARKS

The findings of this study made it possible to know the family members of CKD patients on hemodialysis treatment and to evaluate the perceived stress by means of a validated instrument. Knowing the profile of the family members is important for nurses, regardless of their area, because it promotes the development of actions directed at caring for these individuals who often give up their personal, professional and social life to take care of their loved one.

As for the perceived stress, it was found that the items with the highest averages were “felt nervous or stressed, been angered because of things that were outside of your control, been upset because of something that happened unexpectedly and felt that you were unable to control the important things in your life”. Given these high averages, it is pointed out that the family members of chronic renal patients experienced stressful situations, which may be related to dispensing care to the sick person and the physical and emotional burden faced by them.

The nurse in a renal unit maintains a close relationship that easily leads to the creation of bonds with the patients and their families. This is positive and promotes a personalized care, as well as the development of strategies that lead both the patients and their family members to cope better with the disease.

One of the limitations of this research is the scarcity of studies that addresses this subject, which shows a gap to be filled. Thus, this study may contribute to extend the knowledge in this area and to the development of further studies with different approaches.

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