

SOCIAL SUPPORT OF FAMILY CAREGIVERS OF CHRONIC RENAL PATIENTS ON HEMODIALYSIS

APOIO SOCIAL PERCEBIDO POR CUIDADORES FAMILIARES DE PACIENTES RENAI CRÔNICOS EM HEMODIÁLISE

APOYO SOCIAL PERCIBIDO POR LOS CUIDADORES FAMILIARES DE PACIENTES RENALES CRÓNICOS EN HEMODIÁLISIS

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ABSTRACT

Objective: to describe the profile of family caregivers accompanying chronic renal patients at the hemodialysis service and to measure perceived social support. **Method:** cross-sectional, descriptive study, with convenience sampling. A sociodemographic and health status questionnaire and the scale of the Medical Outcomes Study were applied to 16 caregivers of patients with chronic kidney disease on hemodialysis who remained during the session. **Results:** 93.8% of the caregivers were female, with an average age of 45.7 years, married, living with pain and having some health problem, being on treatment and feel overwhelmed in caring. It was verified that the dimension of the scale with the highest average was the affective, followed by the material. The worst evaluation refers to the emotional dimension. **Conclusion:** knowing the family caregivers and evaluating the perceived social support contributes to propose activities that strengthen and enhance their quality of life and, consequently, the patients.

Keywords: Caregivers; Renal Dialysis; Social Support; Family Nursing.

RESUMO

Objetivo: descrever o perfil de cuidadores familiares que acompanham pacientes renais crônicos ao serviço de hemodiálise e mensurar o apoio social percebido. **Método:** estudo transversal, descritivo, com amostragem por conveniência. Aplicou-se questionário sociodemográfico e de condições de saúde e a escala do Medical Outcomes Study, a 16 cuidadores de pacientes com doença renal crônica em hemodiálise que permaneciam durante a sessão. **Resultados:** constatou-se que 93,8% dos cuidadores são do sexo feminino, com média de idade de 45,7 anos, casadas, que convivem com dor e possuem algum problema de saúde, estando em tratamento e, mesmo assim, não se sentem sobrecarregadas em cuidar. Verificou-se que a dimensão da escala com a maior média foi a afetiva, seguida da material. A pior avaliação referiu-se à dimensão emocional. **Conclusão:** conhecer os cuidadores familiares e avaliar o apoio social percebido contribui para propor atividades que os fortaleçam e potencializem sua qualidade de vida e, por consequência, a dos pacientes.

Palavras-chave: Cuidadores; Dialise Renal; Apoio Social; Enfermagem Familiar.

RESUMEN

Objetivo: describir el perfil de los cuidadores familiares que acompañan a pacientes renales crónicos al servicio de hemodiálisis y medir el apoyo social percibido. **Método:** estudio transversal descriptivo, con muestreo por conveniencia. Se realizó una encuesta de evaluación sociodemográfica y de condiciones de salud y se utilizó la escala del Medical Outcomes Study, con 16 cuidadores de pacientes con enfermedad renal crónica en hemodiálisis que permanecían durante la sesión. **Resultados:** se constató que el 93,8% de los cuidadores era del sexo femenino, con edad promedio de 45,7 años, casados, con dolor y problemas de salud, en tratamiento y, aun así, que no se sentían sobrecargados por tener que cuidar a alguien. Se verificó que la dimensión de la escala con la mayor media fue la afectiva, seguida de la material. La peor evaluación se refería a la dimensión emocional. **Conclusión:** conocer a los cuidadores familiares y evaluar el apoyo social percibido ayudar a proponer actividades que los fortalezcan y potencien su calidad de vida y, por consiguiente, la de los pacientes.

Palabras clave: Cuidadores; Hemodiálisis; Apoyo Social; Enfermería de la Familia.

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INTRODUCTION

In recent years, there has been an increase related to the number of people diagnosed with chronic renal failure (CRF) in Brazil, and consequently, a high rate of patients undergoing renal replacement therapy.¹ These conditions have affected a significant part of the Brazilian population and it was estimated in a survey conducted in the Brazilian dialysis centers that there were 122,825 thousand people with CRF in Brazil in 2016. These data show an increase of 31.5 thousand cases in the last five years, with an average of 6.3% per year, when compared to the estimates for 2011, whose data revealed 91,314 thousand people affected by CRF.¹

In developing countries of Europe and Asia, there is a constant annual increase in the prevalence rate identified, although since the mid-2000s the incidence rate of patients in renal replacement therapy has tended to stabilize or has a discrete growth. In the United States, the prevalence rate increased by around 3% per year between 2008 and 2013.²

Thus, the substitutive renal therapies emerge as a therapeutic possibility against the clinical evolution of chronic kidney disease (CKD), which in later stages it causes irreversible loss of renal function. Hemodialysis (HD) is a treatment option that allows the blood to be pumped from a venous access of the patient to a hemodialysis machine, in which the blood is filtered and purified, being free of toxins and accumulated substances as a result of CRF.³

Hemodialysis is an important procedure for the maintenance of the life of patients with CKD. However, it can be a debilitating experience, which causes physical repercussions and emotional disorders, significantly affecting the quality of life of people on hemodialysis. It may also hinder the development of daily life activities, compromising self-care and impairing social and leisure activities, causing the need for support from another person in the routine of care imposed by the treatment.³⁻⁵

Hemodynamic therapy associated with CKD progression may lead to different levels of patient dependence, culminating in the need for caring, involvement and caregiver availability. The care function is usually assumed by a family member, coming from the nuclear family - consisting of spouses, parents, and children or the extended family, which is the family of close relatives with whom the person lives and maintains bonds of affection and affinity. Also, they can have the help of the extended family, which includes the relationships between grandparents and grandchildren, uncles and nephews, and among friends, in which the bonds of affinity and affectivity stand out.⁶

When care is offered by someone in the family, studies reveal that this caregiver is usually female whose predominant bond is the spouse, daughter or child of the patient or even a daughter-in-law or son-in-law.⁶ Caring brings series of demands for which the family caregiver (re) organizes with the intention of contemplating the different spheres of care, and the existence of social support is a facilitator for the planning and ex-

ecution of care actions, influencing on the well-being of the caregiver and, consequently, on their quality of life.⁷

Social support is having to deal with adverse situations. It is considered the resource available by other people in situations of need and can be measured by the individual perception of each person, according to the level to which the interpersonal relationships correspond to the particular functions.⁸

The family is an integral part of the social network of the chronic renal patient, especially his primary caregiver. Health workers can also be included as a complementary part of this network, as they provide specific information about illness and care with treatment, as well as enable the caregiver to manage home-based care.⁹

In a bibliographic search in the Latin American and Caribbean Literature in Health Sciences (LILACS) and Medical Literature Analysis and Retrieval System Online (MEDLINE) databases, a shortage of productions related to the social support of caregivers of chronic renal patients on hemodialysis was identified. Localized social support studies were mostly related to chronic diseases such as cancer.^{10,11} It was also observed that studies with patients on hemodialysis¹² did not address or extend to their caregivers.

It is considered that social support helps in coping with problems, strengthening the caregiver's strengths and reducing the negative effects in the task of caring, favoring health, well-being, and quality of life. Thus, it is understood that studies addressing this issue, from the perspective of the family caregiver, can broaden the knowledge about this specific context and direct the nursing care. Thus, the purpose of this study is to describe the profile of family caregivers of the chronic renal patients at the hemodialysis service and to measure perceived social support.

METHODOLOGY

This is a cross-sectional, descriptive study performed with 16 family caregivers of patients undergoing hemodialysis in a renal clinic in the interior of Rio Grande do Sul, Brazil. The selection criteria were to be a family caregiver of a hemodialysis patient, to remain in the hemodialysis room or waiting room during the session at least once during the data collection period, and to be 18 years old or older.

Data were collected from May to October 2016, and all the caregivers who met the above criteria were invited. There was a refusal to attend. A sociodemographic and health condition questionnaire was used and the Medical Outcomes Study (MOS) scale, in the Brazilian version, developed by Sherbourne and Stewart in 1991, translated and validated in Brazil in 2005⁸. The scale is composed of 19 items answered by the Likert five-point scale and divided into four factors (social interaction, emotional/information support, material and affective support). For each domain, there are five options for answers,

graduated as follows: 1 = never, 2 = rarely, 3 = sometimes, 4 = usually and 5 = always, and the respondent should opt for a single option. The sum of the points of each dimension was divided by the maximum score and multiplied by 100, obtaining the value reached in each of the dimensions.¹³

Data were collected during hemodialysis sessions. Initially, the caregiver was approached, showing the objectives of the study and inviting him to participate. After accepted, the Consent Form was read and later signed in two copies. Afterward, the data collection was started by the questionnaire and then the scale of the Medical Outcomes Study was performed.

For the processing of the information and creation of the database, the Microsoft Office Excel was used with double independent typing. After checking and correcting errors and inconsistencies in typing, data analysis was performed using Statistical Package For Social Sciences (SPSS) software version 15.0.

A descriptive analysis of the variables was performed to describe the variables, using absolute frequency (N) and relative frequency (%) for the categorical variables. The central tendency (mean) measures were used for the numerical variables and the results of the MOS scale scores.

Ethical precepts were observed in accordance with Resolution N° 466 of December 12, 2012, of the National Health Council.¹⁴ This study, was submitted to the *Comitê de Ética em Pesquisa of the Universidade Federal de Santa Maria (CEP/UFMS)* and approved under opinion N° 1,610,996.

RESULTS

The sample studied was composed of 16 family caregivers of patients with CRF who underwent hemodialysis treatment and who were waiting in the service during the session, for the well-being of patients or for coming from other cities exclusively to accompany him as a result of dependence. In the sample, most of the participants were female (93.8%), with a mean age of 45.07 (± 12.71) years old, minimum 22 years old and maximum of 64 years old, married, wife or children, Catholic religion, with complete primary education, who could read and write (Table 1).

Table 2 shows that most caregivers currently have paid work or are housewives. In the main paid occupation, the caregivers cited commercial salesman, domestic services, nursing technique, companion and caregiver, these activities carried out concomitantly with the care provided to the family member who underwent hemodialysis. As for the current employment, most of them cited being a paid work, revealing the double day of activity developed. When analyzed the occupation that the caregivers practiced in most of their life, it is observed that most developed domestic services (43.9%) and other different activities, such as teacher, farmer, nursing technician, commercial salesperson, and caregiver.

Table 1 - Distribution of characterization variables of family caregivers of patients on hemodialysis. Santa Maria, RS, 2017 (n=16)

Variables	f	%
Gender		
Female	15	93.8
Male	1	6.2
Marital status		
Married	9	56.4
Single	5	31.2
Separate/divorced	2	12.4
Level of kinship		
Children	4	25.0
Husband/spouse	4	25.0
Father/mother	3	18.8
Brother/sister	2	12.4
Others	3	18.8
Religion		
Catholic	10	62.4
Evangelic/protestant	4	25.0
Umbanda	1	6.3
Without religion	1	6.3
Education level*		
IES	4	25.0
CES	5	31.2
IHS	1	6.3
CHS	5	31.2
CG	1	6.3
Know how to read		
No	8	50.0
Yes	8	50.0
Know how to write		
Only the name	1	6.3
Yes	15	93.7

*Education level: IES (incomplete elementary school), CES (complete elementary school), IHS (incomplete high school), CHS (complete high school), CG (complete graduate).
Source: research data.

Table 2 - Distribution of variables related to the working conditions of family caregivers of hemodialysis patients. Santa Maria, RS, 2017 (n=16)

Variables	f	%
He has currently paid work		
Yes, exercising activity	5	31.2
No, unemployed	3	18.8
No, housewife	5	31.2
Other	3	18.8

Continued...

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Table 2 - Distribution of variables related to the working conditions of family caregivers of hemodialysis patients. Santa Maria, RS, 2017 (n=16)

Variables	f	%
Principal paid occupation		
Companion	1	6.3
Caregiver	1	6.3
Domestic services	3	18.5
Nursing Technician	1	6.3
Commercial seller	2	12.6
No current occupation	8	50.0
Occupation in which they worked most of their professional life		
Farmer	1	6.3
Caregiver	1	6.3
Domestic services	7	43.9
Hospital services	1	6.3
Teacher	1	6.3
Nursing Technician	1	6.3
Commercial seller	1	6.3
No occupation	3	18.3
Labor link		
Employee with salary	6	37.5
Employee who only receives commission	1	6.3
Self-Employed	2	12.5
No link	7	43.8

Source: research data.

Regarding the results presented in Table 03, it is verified that half of the caregivers referred to do some health treatment, being mentioned chronic asthma, depression, cancer, herniated disc, hypertension, diabetes, rheumatism, arthritis and complications in the thyroid. Regarding health problems, 68.8% of caregivers reported that they did not take medication for depression or analgesic. Concerning pain, 63% of the participants responded positively, indicating pain in the joints, legs, head, spine, arms, gastric, lumbar, gluteal and cramp regions. In the intensity of pain, four of the 10 caregivers who reported pain had intensity almost unbearable. Concerning to feel overwhelmed by being a caregiver, 69% said they did not feel overwhelmed by the activity. Among the five who manifested overload, three reported feeling overwhelmed daily.

About the time of care, the average was 5.34 years, and one of the caregivers reported being in this role only a month ago and another 20 years ago. The average number of people residing in the household is 3.20 and the average monthly family income is around 2,500.00 reais (considering that the national minimum wage in force at the time of data collection was R\$ 937.00).

Table 3 - Distribution of health condition characteristics reported by family caregivers of hemodialysis patients. Santa Maria, RS, 2017 (n=16)

Variables	f	%
Health treatment		
No	8	50.0
Yes	8	50.0
Health problem		
No	5	31.2
Yes	11	68.8
Use of prescribed antidepressant medications		
No	13	81.3
Yes	3	18.8
Pain		
No	6	37.5
Yes	10	62.5
Intensity of pain		
Weak	2	14.2
Moderate	2	14.2
Intense	2	14.2
Unbearable	4	28.7
Does not apply	4	28.7
Overload		
No	11	68.8
Yes	5	31.3
Overload frequency		
Often	2	40.0
Always	3	60.0

Source: research data.

Evaluating the results presented in Table 04, it can be verified that the social support dimension with the highest average in caregivers was the affective (90.00), which is related to the perception of having whom to love, to have those who show love and affection, embracing and making oneself feel loved, followed by the material dimension (82.50), which refers to the help received when one needs to stay in bed or go to the doctor, in the preparation of meals and in daily tasks.

Table 4 - Descriptive analysis of the scores of social support dimensions perceived by family caregivers of hemodialysis patients. Santa Maria, RS, 2017

Dimension	Mean	Standard Deviation	Median	Minimum	Maximum
Material	82.50	24.08	90	20	100
Affective	90.00	19.01	100	26.67	100
Emotional	63.75	30.52	67.5	20	100
Information	65.31	28.43	60	20	100
Social interaction	66.56	30.70	67.5	20	100

Source: research data.

The scores of the social interaction dimension (66.56) include having fun, distracting, relaxing and doing nice things. The information dimension (65.31) includes having good advice, suggestions for dealing with problems and help with information, and presenting intermediate results. The worst evaluation refers to the emotional dimension (63.75), which is related to having someone to listen to, trust, talk about problems and share concerns.

Thus, when considering the highest score relative to the affective dimension, and the lowest score related to the emotional dimension, it can be verified that although family caregivers perceive that they have who to love and who loves them, this relationship is not recognized as good to share concerns and problems, which may reveal that care for participants in this study is a solitary activity.

DISCUSSION

Considering the obtained results, we confirm that these studies corroborate studies that addressed the profile of family caregivers of people dependent on chronic diseases, which is similar to caregivers of renal patients, especially as they are predominantly women, wives or daughters, married, who develop another activity concomitant to care.^{6,9,10,12-16}

Regarding paid work activities carried out by family caregivers, the findings show that most of them are currently engaged in paid work or perform activities at home, which explains the double journey of activity performed. These characteristics reinforce as a consensus in the literature: the woman is, historically, the caregiver of the members of her family and society. Culturally, it is expected that these attributions will be assumed by women.¹⁶

The reality of taking care of the family member and also of other work activities may be related to the development of health problems for the caregiver, the onset of pain, overload, the use of antidepressant drugs or analgesics, since the accumulation of functions exposes them to physical, emotional, and social workloads.¹⁷ Also, a study¹⁷ that aimed to evaluate the effect of educational programs on home care for patients with CRF on hemodialysis makes relevant scores by showing that knowledge and adequate learning of the conditions involved in this caring process may contribute to significantly improve the conditions of caregivers, influencing and modifying their quality of life and care.

Another relevant fact relates to the pains of intense intensity by the participants, who in contrast they deny feeling overwhelmed, which may be related to the affective or family bond that they maintain with the patient and contributes to the performance of the function in a compensatory way. This data corroborates a study¹⁸ that aimed to analyze the association between the dimensions of social support and the profile of fam-

ily caregivers of patients with dependence, which concluded that pain and overload do not have a significant statistical relationship with social support. However, these data are important so it can be understood how social support is offered to this population.

Also, although caregivers mostly have health problems and use antidepressant medications, it is important to point out that care is perceived by the individual as a feeling of accomplishment, bringing satisfaction of well-being, which contributes to the quality of life of the family caregiver and the reduction of overload.^{18,19}

In this research, the caregivers had a mean affective and material score above 82%, which indicates strong social support, showing more perception of the manifestations of love, affection, and cooperation in daily tasks, when there is a need for rest. In the evaluation of the emotional dimensions, information, and positive social interaction, mean scores were below 64%, indicating that caregivers in these evaluations perceived less social support when having someone to trust and talk about problems, seek advice or information and get distracted.

Considering that family caregivers are "hidden patients"²⁰ who may have physical and mental disorders resulting from the activity developed, a systematic review study²⁰ aimed to evaluate the quality of life and its associated factors among the family caregivers of patients undergoing hemodialysis. The findings enabled to conclude that the quality of life of family caregivers is low when compared to the general population, and there is a direct relationship between the quality of life of family caregivers and the quality of life of the patients.

In the associated factors identified as relevant to quality of life, there is the perceived social support, besides aspects such as age, gender, perceived care burden, understanding of disease limitations, adaptation strategies, relationship with the spouse and, also, with the person cared. In this sense, they emphasize that careful attention by the health system and professionals, aimed at promoting and improving the quality of life of caregivers, resulting in benefits for the patient.²⁰

Regarding the social support to family caregivers, a study²¹ with caregivers of dependent elderly showed that the perceived support comes from formal sources, such as basic health units and members of the family health strategy teams, especially community health agents, and informal sources from their families, especially their children. The support mentioned by the caregivers included the emotional support offered by the family when participating in the care activities and the financial support related to the help in acquiring medicines and other materials necessary for care. These supports cover the affective and material dimensions, respectively, according to the MOS scale, being the highest scores among the dimensions perceived by the study participants.

The difficulties faced by caregivers of people with chronic health problems have been explored in the literature.^{22,23} It is

observed that issues related to the context of financial, physical and emotional overload arising from care, lack of training²⁴ and other personal demands, family and work of the caregiver reveal that this task can lead to illness.

In this sense, a study²⁴ that aimed to assess the burden of care in caregivers of hemodialysis patients found that more than two-thirds of the participants presented moderate to severe levels of overload, related to disappointment, isolation, and failure due to lack of support, training, and experience.²⁴ Also, another study²³ conducted with family caregivers of people with chronic kidney disease identified that the prevalence of depressive symptoms was 46%, with a positive correlation between care time and depression.

Considering this perspective, it is perceived that feeling supported in the affective, material, emotional, positive social interaction and information dimensions constitutes a factor of protection for the health of the family caregiver, contributing to their self-esteem, valorization and strengthening them.

CONCLUSION

Knowledge of the characteristics of family caregivers, with attention to the singularities and the way they accompany the patient together with the possibility of evaluating the social support perceived by them contributes to the planning of nursing care and proposes activities that include caregivers, especially those who remain waiting in the waiting room while the patient is undergoing hemodialysis.

Providing information and clarification about care and CKD, offering qualified listening space, sharing of feelings, health education activities for self-care and other initiatives may be effective to promote appreciation and recognition of the caregiver for the availability in caring, in their mental health and in the quality of life and, consequently, in the patients' quality of life.

As limitations of the study, we highlight the sample the sample that due to the number of participants and considering the caregivers who were waiting for the hemodialysis session were highlighted as limitations of the study, restricting the possibility of generalizing the results to other caregivers. It is suggested that further studies be conducted with a larger sample, including caregivers of patients with different levels of dependence, and to analyze the associations between the dimensions of the Medical Outcomes Study scale and the characteristics of the family caregivers.

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