REFACS

Mental status of caregivers of elderly people on renal dialysis

Estado mental dos cuidadores de idosos em hemodiálise

Estado mental de los cuidadores de ancianos en diálisis renal

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This study aims to characterize the sociodemographic, economical and clinical aspects and analyze the mental state of caregivers of elderly people on renal dialysis. The cross-section, descriptive, quantitative study was conducted in 2017, on a dialysis treatment unity with 91 elderly patients. Of these, 80.22% were family members, 68.13% were women, 45.05% had more than eight years of education, 71.43% did not have arterial hypertension, and they had an average age of 50.37 years and mean time in renal dialysis and care for the elderly by the caregiver of 36.60±39.65 and 72.70±109.50 months, respectively. Three categorial variables significantly influenced the caregivers' mental state scores: type of caregiver, level of education and occurrence of arterial hypertension. The variable coefficient was 17.56%, with a minimum score of 10.0 points and a maximum score of 29.0% points. Mental state was influenced by the type of caregiver, level of education and occurrence of arterial hypertension.
Descriptors: Aged; Caregivers; Renal dialysis; Hemodialysis units, Hospital.

O objetivo foi caracterizar os aspectos sociodemográficos, econômicos e clínicos e analisar o estado mental dos cuidadores de idosos em hemodiálise. Estudo transversal, descritivo, quantitativo, realizado em 2017 na unidade de tratamento dialítico com 91 cuidadores de pacientes idosos. Destes, 80,22% eram de familiares, 68,13% mulheres, 45,05% com mais de oito anos de estudo, 71,43% não portadores de hipertensão arterial, com média de idade de 50,37 anos, tempo médio em hemodiálise e de cuidado do idoso pelo cuidador de 36,60±39,65 e 72,70±109,50 meses, respectivamente. Três variáveis categóricas influenciaram significativamente os escores do estado mental dos cuidadores: tipo de cuidador, escolaridade e ocorrência de hipertensão arterial. O coeficiente de variação foi de 17,56% com escore mínimo de 10,0 pontos e máximo de 29,0 pontos. O estado mental foi influenciado pelo tipo de cuidador, a escolaridade e a presença de hipertensão arterial.
Descritores: Idoso; Cuidadores; Diálise renal; Unidades hospitalares de hemodiálise.

El objetivo fue caracterizar los aspectos sociodemográficos, económicos y clínicos y analizar el estado mental de los cuidadores de los ancianos en hemodiálisis. Estudio transversal, descriptivo y cuantitativo realizado en 2017 en la unidad de tratamiento de diálisis con 91 cuidadores de pacientes ancianos. De ellos, el 80,22% eran familiares, el 68,13% mujeres, el 45,05% con más de ocho años de estudio, el 71,43% sin hipertensión, con una edad media de 50,37 años, una media de tiempo en hemodiálisis y cuidado de ancianos por parte del cuidador de 36,60 ± 39,65 y 72,70 ± 109,50 meses, respectivamente. Tres variables categóricas influyeron significativamente en las puntuaciones del estado mental de los cuidadores: el tipo de cuidador, la escolaridad y la aparición de hipertensión. El coeficiente de variación fue del 17,56% con una puntuación mínima de 10,0 puntos y una máxima de 29,0 puntos. El estado mental se vio influenciado por el tipo de cuidador, la escolaridad y la presencia de hipertensión.
Descritores: Anciano; Cuidadores; Diálisis renal; Unidades de hemodiálisis en hospital.

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INTRODUCTION

Due to the aging of the world's population and the subsequent epidemiological transition, there was a sharp increase in the prevalence of elderly patients with end-stage renal disease (ESRD), especially among those ≥ 80 years old, who receive treatment with or without renal replacement therapy (RRT).

The incidence of hemodialysis (HD) among the elderly population has increased in recent decades, both in Brazil and worldwide[1]. In Brazil, epidemiological data is scarce, but it is known that, among the more than 120 thousand dialysis patients in the country in 2016, about 11% were 75 years old or more[2]. In 2018, data from the Ministry of Health shows that 39.5% of the elderly population have some chronic disease and almost 30% have two or more. It will take just over two decades for Brazil to be considered an old country in 2032, when 32.5 million of the more than 226 million Brazilians citizens will be elderly[3]. Even though life expectancy gets longer, it also gets associated with chronic degenerative diseases. Consequently, the increase in diseases, such as hypertension, arthritis, heart disease and diabetes affect the individual's functional capacity[4].

In association with this situation, there was an increase in cases of terminal chronic kidney disease (TCKD), since they are related to the aging of the population. Its main causes are diabetes mellitus (DM) and systemic arterial hypertension (SAH). TCKD is the final stage of impaired renal function, and it causes various signs and symptoms due to the inability of the kidneys to contribute to maintenance of the body's homeostasis. The intensity of signs and symptoms of chronic end-stage renal disease depends on the degree of renal impairment and the association with other comorbidities[5].

The partial replacement treatments for renal function are: dialysis, hemodialysis, continuous ambulatory peritoneal dialysis (CAPD) and kidney transplantation. These treatments preserve the patient's life, without, however, curing them of end-stage renal disease. Hemodialysis, which promotes extracorporeal filtration of blood with the help of a machine, is the most used treatment today. Normally, this treatment consists of three weekly sessions, sessions lasting between three (3) to five (5) hours, depending on the patient's condition[5].

Chronic end-stage renal disease and hemodialysis treatment impair the patient's quality of life, as they have certain biopsychosocial negative effects[5]. The implications do not fall only on the elderly patients, but also on their families, the community and the healthcare system, which needed to review criteria and models to assess the health of elderly people[6].

The quality of life of elderly people with chronic diseases suffers with functional disability, which is described as the difficulty of performing everyday tasks without assistance, and that compromises independence necessary for living life in a community. The degree of dependence on activities of daily living (ADLs), such as bathing and getting dressed, and on instrumental activities of daily living (IADLs), for example, transportation, washing and ironing clothes, make the elderly person dependent on a caregiver to assist in these functions[7].

According to a study with elderly people assisted in the Family Health Strategy (Estratégia de Saúde da Família), approximately 25% had some issue in performing IADLs and 12% had issues in ADLs[8]. Family members who act as caregivers end up going through problems after the elderly person receives their diagnosis. Whoever decides to care for a person with TCKD may suffer from a variety of negative physical, psychological, social and financial consequences, which can challenge their ability to remain a caregiver. The informal caregiver who cares for a family member with a chronic disease suffers consequences on their family relationships in the affective, social and financial dimensions[9].

Power relations can directly impact the relationship of care between family member caregivers and the elderly person with chronic disease. The concept of self-care proves to be relevant for the maintenance and balance of interpersonal relationships between the elderly person and the family caregiver. It is common for family caregivers to be burdened by adding

care activities to their personal routines with no support for family members in most cases[10]. It is also common for them to nor receive adequate preparation to provide health care (knowledge, skills and abilities).

The harmful effects come from functional disabilities of the elderly person (physical, cognitive or behavioral), in addition to the constant need for attention and vigilance. The consequences of overload, both occupational and emotional, on the life of the caregiver and their family are physical, financial, psychological and social[9].

Hemodialysis causes changes that negatively impact the quality of life of both patients and their families, causing functional and physical impairment of the individual, decreasing their social interaction, making them lose their autonomy and making them depending on the help of third parties to carry out various activities everyday and, for elderly people, this dependence is even greater.

Once an individual undergoes hemodialysis, there are influences in their psychological state. The disease's repercussions go beyond physical symptoms, as they generate emotional disturbances, such as: anxiety, depression, a decrease on self-esteem, among other mental disorders. Thus, the present study aims to characterize the sociodemographic, economic and clinical aspects and analyze the mental state of caregivers of elderly patients on hemodialysis.

METHOD

This is a cross-sectional study with a descriptive, quantitative analytical design with correlation between variables. The research was carried out in a teaching hospital, which provides services in different medical specialties. The hospital provides care for private patients, insured patients and patients from the Unified Health System (*Sistema Único de Saúde - SUS*). This hospital is considered a reference center in town and region, and it also cares for patients from other Brazilian states. The nephrology service is located on the ground floor, so access is easier for outpatients. It consists of hemodialysis room, peritoneal dialysis, CAPD room, emergency room, area for collection of tests, doctors' offices, kitchen, meeting room, reception, and others.

Caregivers who accompanied the elderly patients during treatment were included on this study, since the majority of patients did not have anyone with them. Those who did not accept to participate and those who withdrew from the study were excluded from the study.

Sampling was intentional non-probabilistic, a choice made by convenience. This study was carried out in the dialysis treatment unit of a teaching hospital with caregivers of elderly patients on hemodialysis, aged 60 years or more who were accompanying them during sessions of hemodialysis. Data were collected through interviews, in the sector's waiting room, using Mini-Mental State Examination (MMSE)[11] and a questionnaire on sociodemographic data. The amount of time used for collection was 4 months, between May and August of 2017.

We investigated sociodemographic characteristics, such as age, sex, racial group, origin, marital status, education, occupation, origin of income, who they live with, type of housing, religion, length of treatment of the patient and follow-up, illnesses of the caregiver and treatment and type of caregiver.

We used MMSE as instrument, alongside a questionnaire about mental state. The MMSE questionnaire is used internationally and it was developed as a way to clinically assess the mental state of symptons of dementia[12,13] in a standardized, simplified, reduced and rapid way. It consists of 30 questions that assess the impairment of cognitive functions; making it possible to diagnose dementia and monitors the responde to treatment. It is separated into temporal orientation, spatial orientation, immediate and evocative memory, calculations, naming, repetition, execution of commands, reading, writing and visual-motor skills. It is a generic instrument for assessing cognitive status. It is translated, suitable and validated for the Portuguese language, easy to administer and understand[12,13].

Data were subjected to descriptive statistical analysis of categorical and continuous variables related to sample characterization. The t-test for independent samples was used to compare the caregivers' mental status scores in relation to categorical variables with up to two levels of response and analysis of variance test with Tukey's post-hoc multiple comparison test to compare the scores of the caregivers' mental status in relation to categorical variables with more than two levels of response.

We applied Spearman's correlation test to observe the correlation between caregivers' mental status scores and continuous variables. All analyzes were obtained using the Minitab 17 software (Minitab Inc.). The result will be considered significant when $p < 0.05$.

Before starting the research, all participants were informed about the study, their right to not participate, and were assured that their healthcare assistance would not be affected if they did not accept to participate, nor by the answers provided, if they did. Anonymity and confidentiality were ensured. Those who agreed to participate signed the Post-Informed Consent Form. This study was submitted to and approved by the Research Ethics Committee of Faculdade de Medicina de São José do Rio Preto, and were filled under the number 2,040,777.

RESULTS

Of the 198 elderly people on hemodialysis, 91 caregivers participated in the study, as most of the elderly patients did not have caregivers. The caregivers evaluated were family members (80.22%), female (68.13%), white (48.35%), from an urban area (93.41%), from cities in the region where the study took place(81.32%) (Table 1).

Caregivers were married (56.04%), had more than 8 years of education (41; 45.05%), performed domestic work (37; 43.02%), financially independent (41.86%) . They live with family (60.44%), owned a home (83.52%), Catholic (60.47%) and took part on social activities (62.64%) (Table 1).

Of the caregivers who participated, 71.43% did not have hypertension (SAH) and 84.62% were under drug treatment. Most of them did not have Diabetes Mellitus (DM) (91.21%) and, of those who did have it, six (75%) used medications. Most of them did not have any other type of health issue (54.95%) (Table 1).

The average age of caregivers was 50.37 ± 15.55 years and a median of 50.5 years. The coefficient of variation (CV) of this distribution was 30.8%. The minimum age observed was 18 years and the maximum was 85 years. The mean time of SAH was 7.07 ± 7.02 years and median of 5.00 years. The coefficient of variation (CV) was 99.3% (Table 1).

The mean time of treatment of the patient with CKD was 36.60 ± 39.65 months and a median of 24.00 months. The coefficient of variation (CV) was 108.33%. The minimum treatment time for the patient was 0.5 months and the maximum was 204 months. The average time care for patient by the caregiver was 72.70 ± 109.50 months and a median of 27.00 months. The variation coefficient (CV) was 150.70%. The minimum time of care for the patient performed by the caregiver was 0.03 months (1 day) and the maximum 480 months (Table 1).

The average score of the caregivers' mental status (N = 91) was 23.80 ± 4.18, with a median of 25.00 points. The variation coefficient was 17.56% with a minimum score of 10.0 points and a maximum score of 29.0 points. Some categorical variables were analyzed in order to verify the comparison of caregivers' mental status scores (Table 1).

Table 1 shows that three categorical variables were significant on the caregivers' mental state scores assessed in the study, since all P-values were less than 0.05. The variables of gender, origin, social activities, occurrence of DM in the caregiver, other health issues in the caregiver and religion were not significant in the mental state scores, as the P-values were higher than the significance level adopted for the test (P> 0.05).

At first, the type of caregiver significantly influenced the caregivers' mental state scores, assuming that the scores are significantly higher for hired or family member caregivers (Table 1).

The caregivers educational level also significantly influenced the caregivers' mental state scores, assuming that caregivers with more than eight years of education had significantly higher scores than other caregivers. It was also possible to assume that illiterate caregivers had the lowest scores among the evaluated caregivers (Table 1).

The occurrence of SAH in the caregiver was also a major factor to demonstrate significant differences in the caregivers' mental status scores, assuming that caregivers with SAH had significantly higher mental state scores compared to other caregivers (Table 1).

Table 1: Caregivers' mental state scores according to some categorical variables - São José do Rio Preto, SP, Brazil, 2017.

Categorical variables	n	Mean standard deviation (±)	Median	P-Value[1]
Type od caregiver				
Acquaintance	6	18.17±6.31 b	17.50	
Hired	12	23.33±3.20 a	24.00	**0.002[2]**
Family member	73	24.34±3.81 a	25.00	
Gender				
Female	62	23.91±4.42	25.00	
Male	29	23.55±3.67	25.00	0.679
Origin				
Rural area	6	21.67±4.41	21.00	
Urban area	85	23.95±4.15	25.00	0.273
Level of education				
Illiterate	5	13.60±3.91 c	13.00	
1 to 4 years of education	27	22.77±4.10 b	23.00	
5 to 8 years of education	18	23.05±2.96 b	23.00	**<0.001[2]**
More than 8 years of education	41	26.04±1.98 a	26.00	
Social activities				
No	34	24.61±3.66	25.00	
Yes	57	23.31±4.41	24.00	0.134
Caregiver has SAH				
No	65	23.23±4.28	24.00	
Yes	26	25.23±3.60	26.00	**0.028**
Caregiver has MD				
No	83	23.91±4.12	25.00	
Yes	8	22.63±4.90	23.50	0.494
Caregiver has other health issues				
No	50	23.86±4.15	25.00	
Yes	41	23.73±4.26	25.00	0.885
Religion				
Catholic	52	24.44±26.00	26.00	
Spiritist	5	26.60±3.36	28.00	
Evangelical	23	22.47±3.68	23.00	0.080[2]
Other	6	22.00±5.76	24.00	

[1] PP-value for the t-test for independent samples at P<0.05 [2]. P-value referring to the Analysis of Variance test with post-hoc Tukey test at P<0.05. Different letters in the samr column indicate significant differences at P<0.05.

The results in Table 2 show that there was no statistically significant correlation between the caregivers' mental state scores and the continuous variables analyzed, since the p-values were greater than 0.05. Therefore, there is no correlation between any of the continuous variables in the highest or lowest score for the mental state of the caregivers.

Table 2. Spearman's correlation coefficients (P-value) for the correlation between caregivers' mental state scores and continuous variables - São José do Rio Preto, SP, Brazil, 2017.

Continuous variables	*Mental healt score*
Age	-0.022 (p=0,834)
Length of pacient's treatment (months)	0.015 (p=0,885)
Lenght of dedication of the caregiver to patient (months)	0.118 (p=0,267)

DISCUSSION

This study showed that women and married women accounted for more than 50% of caregivers, indicating the historical role of providers of family care assigned to them, especially regarding their husband, father and children[10,14]. Research shows that informality is predominant among caregivers, and among these, most are family members, with some degree of kinship[15,16]. In this study, a group of "acquaintance" caregivers (6.6%) was identified among informal caregivers (6.6%), most of whom were neighbors, without family or employment ties. This data is not specified in other studies, but included in the group of informal caregivers[17,18].

Most patients were from urban areas. A study carried out in the countryside of the state of São Paulo, in 2017, showed that caregivers in rural areas had better health conditions as a whole[19]. The low level of education may be a consequence of elderly people having lived at a time when the countryside concentrated most of the Brazilian population, education was catered for men and/or people with more favorable socioeconomic conditions. The elderly currently population living in urban areas shows that men are married or with partners, while women were widows. Most elderly people live with other people, are able to read and write and have primary education[20].

Most caregivers had eight or more years of education and an average age of around 50 years[21], that is, an economically active population with an relevant level of education. This may reflect the growing demands of the formal job market and the financial Brazil is currently in, leading many trained people with a high level of education to dedicate themselves to domestic and caregiver work[22].

The increasing aging of the population and the high prevalence of comorbidities among elderly people may require greater training by caregivers[23,24]. A study carried out in Vitória da Conquista, in the state of Bahia, showed that the prevalence of female caregivers, daughters, married, with low education, in which they performed the task of caregiver for more than 10 years. As for the overload, family caregivers had a severe overload level. We can say that the task of being a caregiver has a great impact on the physical, social, emotional and economic well-being of the caregiver and the whole family[14].

However, the MMSE averages of the elderly caregivers in this study showed a decrease in all levels of education, indicating impairment in mental health regardless of the level of study. The reduced time to maintain a social life and to care physical and psychologically to oneself is reflected in the mental health of the caregivers, that is, in the compromise of quality of life of the caregivers that gets lost in the background[18,25].

Caregivers' health is associated with overloads that compromise quality of life, cause anxiety, depressive symptoms and, in cases of high tension, higher mortality[18]. Biopsychosocial overload affects more than 80% of caregivers and influences the onset or worsening of diseases[10,16,17]. However, caregivers stated that they did not have SAH (71.43%) and, in addition to that, those who suffered with the condition had higher mental health scores.

The burden falls mostly on the family member caregiver. The physical effort of needing to assist in ADLs and IADLs is associated with the emotional issue of often having the "obligation to take care" or the "commitment", as stated by a family member in a study conducted in Juiz de Fora, in the state of Minas Gerais[25]. There is also the financial issue, due to not being able to conciliate a job to the responsibility of being a caregiver, lack of cooperation from other relatives, high cost of medicines, diapers, and other reasons[17,26,27].

This study, however, does not show a difference in cognitive deficit between family members and hired caregivers, but in does regarding "acquaintances". These, in addition to not having a family affective bond that would provide a feeling of affection and love to balance with stress and tiredness, suffer the financial burden of care, thus presenting the lowest mental health scores[25].

The prognosis of elderly people in need of care does not predict many positive changes regarding the current situation, since they mostly suffer from chronic diseases[15]. In addition,

patients with CKD have a worse quality of life and often go through social exclusion, due to the higher prevalence of cognitive impairment and morbidity and mortality in relation to individuals of the same age, increasing the burden of care[21-28].

The evolution of CKD leads to renal replacement therapy and, particularly, hemodialysis in the elderly person may indicate a greater impairment of functionality. Thus, greater dependence, both social and economic as well as emotional, which leads approximately 90% of patients to depression related to affection, understanding and motivation provided by their caregiver[10,21,24,29]. This relationship, however, in the present study, did not show any correlation with the mental health scores of the caregivers, being at odds with a survey conducted with caregivers of elderly people in Ribeirão Preto, in which the dependence of the elderly is a risk factor for overload caregiver[14].

CONCLUSION

Mental status was influenced by the type of caregiver, education and the presence of SAH. What influenced the mental state of these caregivers was their educational levels. In addition to this, it was possible to perceive that illiterate caregivers had the lowest scores among the evaluated caregivers.

The occurrence of SAH in the caregiver was also a major factor to show significant differences in the caregivers' mental status scores, showing that caregivers with SAH had significantly higher mental status scores compared to other caregivers.

The study's limitations were intentional non-probabilistic convenience sampling. In this type of sampling, sample calculation was not performed, which reduced the sample size, as the population was not available to be drawn. The main gap was the caregiver's lack of information regarding hemodialysis.

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