Original Article

Quality of life of family caregivers of patients under hemodialysis

Qualidade de vida do cuidador familiar de paciente em hemodiálise

Calidad de vida de cuidadores familiares de pacientes en hemodiálisis

Viviane Rodrigues Jardim[1] https://orcid.org/0000-0002-8593-2119
Ilka Afonso Reis[1] https://orcid.org/0000-0001-7199-8590
Samantha Vieira Alves Amaral[1] https://orcid/0000-0003-1481-5318
Heloisa de Carvalho Torres[1] https://orcid.org/0000-0001-5174-3937

How to cite:
Jardim VR, Reis IA, Amaral SV, Torres HC. Quality of life of family caregivers of patients under hemodialysis. Acta Paul Enferm. 2023;36:eAPE00372.

DOI
http://dx.doi.org/10.37689/acta-ape/2023AO003722

Abstract

Objective: To analyze the quality of life of family caregivers of patients under hemodialysis and the existence of an association with their sociodemographic and clinics characteristics.

Methods: This is a cross-sectional study conducted with 75 family caregivers in two hemodialysis centers. Caregivers' quality of life was measured using the World Health Organization Quality of Life – BREF instrument, and its association with sociodemographic characteristics was assessed using the Kruskal-Wallis test (significance level equal to 5%).

Results: Most family caregivers were women (84%), spouses (41.3%), children (38.7%), housewives (38.7%) and had a family income of one to three minimum wages (85.4 %). The variable working outside the home had a positive influence on overall quality of life (p=0.014), psychological domains (p=0.009) and social relationships ($p \leq 0.001$). Being male (p=0.016), not having diseases (p=0.002) and not using medications (p=0.007) positively interfered with the physical domain. The absence of financial help from other people and/or family members had a negative influence on the social relationships (p=0.050) and environment (p=0.001) domains.

Conclusion: Male family caregivers, or those who work outside the home or receive financial help from other people and/or family members had better quality of life levels. On the other hand, clinical conditions such as using a drug or having diseases have negatively influenced quality of life levels.

Resumo

Objetivo: Analisar a qualidade de vida do cuidador familiar do paciente em hemodiálise e a existência de associação com suas características clínicas e sociodemográficas.

Métodos: Estudo transversal, realizado com 75 cuidadores familiares em dois centros de diálise. A qualidade de vida do cuidador foi medida por meio do instrumento *World Health Organization Quality of Life – BREF*, e sua associação com as características sociodemográficas foi avaliada pelo teste de Kruskal-Wallis (nível de significância igual a 5%).

Resultados: A maioria dos cuidadores familiares era mulher (84%), cônjuge (41,3%), filho (38,7%), do lar (38,7%) e possuía renda familiar de um a três salários mínimos (85,4%). A variável trabalhar fora de casa teve influência positiva na qualidade de vida geral (p=0,014), nos domínios psicológicos (p=0,009) e nas relações sociais ($p \leq 0,001$). Ser do sexo masculino (p=0,016), não ter doenças (p=0,002) e não usar medicamentos (p=0,007) interferiram positivamente no domínio físico. A ausência de ajuda financeira de outras pessoas e/ou familiares influenciou de forma negativa nos domínios das relações sociais (p=0,050) e meio ambiente (p=0,001).

Keywords
Quality of life; Caregivers; Renal dialysis; Surveys and questionnaires

Descritores
Qualidade de vida; Cuidadores; Diálise renal; Inquéritos e questionários

Descriptores
Calidad de vida; Cuidadores; Diálisis renal; Encuestas y cuestionarios

Submitted
February 22, 2022

Accepted
October 24, 2022

Corresponding author
Heloisa de Carvalho Torres
E-mail: heloisa.ufmg@gmail.com

Associate Editor (Peer review process):
Bartira de Aguiar Roza
(https://orcid.org/0000-0002-6445-6846)
Escola Paulista de Enfermagem, Universidade Federal de São Paulo, São Paulo, SP, Brazil

---

[1] Universidade Federal de Minas Gerais, Belo Horizonte, MG, Brazil.

Conflicts of interest: nothing to declare.

Conclusão: O cuidador familiar do sexo masculino, ou que trabalha fora de casa ou recebe ajuda financeira de outras pessoas e/ou familiares apresentaram melhores níveis de qualidade de vida. Em contrapartida, as condições clínicas tais como fazer uso de algum medicamento ou ter doenças influenciaram de forma negativa nos níveis de qualidade de vida.

Resumen

Objetivo: Analizar la calidad de vida de los cuidadores familiares de pacientes en hemodiálisis y la existencia de asociación con las características demográficas y clínicas.

Métodos: Estudio transversal, realizado con 75 cuidadores familiares en dos centros de diálisis. La calidad de vida de los cuidadores fue medida a través del instrumento *World Health Organization Quality of Life – BREF,* y su relación con las características sociodemográficas fue evaluada mediante la prueba de Kruskal-Wallis (nivel de significación igual a 5 %).

Resultados: La mayoría de los cuidadores familiares era mujer (84 %), cónyuge (41,3 %), hijo (38,7 %), del hogar (38,7 %) y poseía ingresos familiares de uno a tres salarios mínimos (85,4 %). La variable trabajar fuera de casa tuvo influencia positiva en la calidad de vida general (p=0,014), en los dominios psicológicos (p=0,009) y en las relaciones sociales (p≤0,001). Ser de sexo masculino (p=0,016), no tener enfermedades (p=0,002) y no usar medicamentos (p=0,007) interfirieron positivamente en el dominio físico. La ausencia de ayuda financiera de otras personas o familiares influyó de manera negativa en los dominios de las relaciones sociales (p=0,050) y del medio ambiente (p=0,001).

Conclusión: Los cuidadores familiares de sexo masculino, o que trabajan fuera de casa o reciben ayuda financiera de otras personas o familiares presentaron mejores niveles de calidad de vida. En contraste, las condiciones clínicas, tales como hacer uso de algún medicamento o padecer enfermedades, influyeron de forma negativa en los niveles de calidad de vida.

Introduction

The number of patients with end-stage chronic kidney disease associated with hemodialysis treatment has increased more and more in Brazil. It is estimated that more than 130,000 people are on chronic hemodialysis, with hemodialysis being the method adopted for 92% of patients with end-stage renal disease.(1) Hemodialysis is a necessary procedure for maintaining patients' life, which depends on a machine to survive.(2,3) Chronic hemodialysis kidney disease can generate some type of sequel or deficiency, which results in different patient dependence levels, in addition to family involvement in the care provided.(2,4)

In this regard, the care provided by a family member and the management of treatment of patients under hemodialysis imply responsibilities regarding dietary needs, clinical consultations, psychosocial issues and trips to the hemodialysis clinic, in addition to frequent clinical changes that require skills and technical capacity from family caregivers.(5-7) It is noted that family caregivers actively involved in the care provided to patients are more likely to depressive symptoms, anxiety, fatigue, social isolation, relationship tensions, financial difficulties and stress, generating their mental and physical illness, which affects family caregivers' quality of life (QoL).(6,8-10)

Study indicate that the average QoL score of caregivers was at low levels and sociodemographic variables such as age, average hours of care and age of patients indirectly influenced QoL, while income and education level directly influenced caregivers' QoL.(11) Another study reveals that, when assessing QoL perception by a group of caregivers, physical, spiritual and social aspects were not affected, while psychological aspects had a more negative perception on the part of these caregivers.(12)

However, the perception of caregivers' QoL is little explored in the national and international literature considering the cultural context and values they experience, in addition to their own sociodemographic factors, which can also interfere negatively or positively in their QoL.(9-14) Knowing the factors influencing QoL can more assertively direct intervention actions by health professionals.

This study aimed to analyze the QoL of family caregivers of patients under hemodialysis and the existence of an association with their sociodemographic characteristics and those related to care.

Methods

This is a cross-sectional study conducted with 75 family caregivers of patients under hemodialysis at the hemodialysis outpatient clinics of *Santa Casa* and *Hospital das Clínicas* in the city of Belo Horizonte (MG), between September and December 2020. After searching the database of these outpatient clinics, 415 patients under hemodialysis were listed. Figure 1 describes how eligible caregivers were identified from database search. The researcher used an interview script to help identify, among the 306 patients who answered the first call, those who needed a family caregiver to help with day-to-day activities. Family caregivers of a patient under hemodialysis, with at least 3 months as a caregiver, aged over 18 years and residing in the same household as patients, were included. Family caregivers presenting inability to communicate or difficulty in responding to the questionnaire were excluded. The second call has already been applied to the survey questionnaires. Considering the participant gathering method, the sample is of convenience.

Considering comparisons of two groups regarding the study response variables (QoL levels) via non-parametric tests, a minimum power of 75%, significance level of 5% and an effect size of 0.50, each comparison group must have at least 38 individuals, totaling a minimum sample size of 76 individuals. The calculations were done in GPower version 3.1.9.7.

The instrument for collecting sociodemographic data was divided into two questionnaires. The first, with questions regarding the profile of each patient under hemodialysis, contained the variables age, gender, marital status, occupation, education, time under hemodialysis and time since diagnosis of type 2 diabetes mellitus. The second questionnaire had questions regarding each caregiver's profile (age, kinship, sex, marital status, occupation, education level, family income), caregiver behavioral data considering the care provided (time who took care of a person under hemodialysis, how many hours were dedicated to caring, how many times a week a person underwent hemodialysis, if they received help from other people and/or family members) and caregivers' clinical characteristics (if they had any disease, if they used any medication and how many times they had sought the physician in the last 12 months).

To measure QoL levels, the World Health Organization Quality of Life (BREF) (WHOQOL-BREF) was used, consisting of 26 questions, two questions on overall QoL and health: How would you assess your QoL? How satisfied are you with your health? The remaining 24 questions represented each of the 24 facets that made up the original instrument and were distributed as follows: physical domain (seven questions), psychological domain (six questions), social relationships domain (three questions) and environment domain (eight ques-

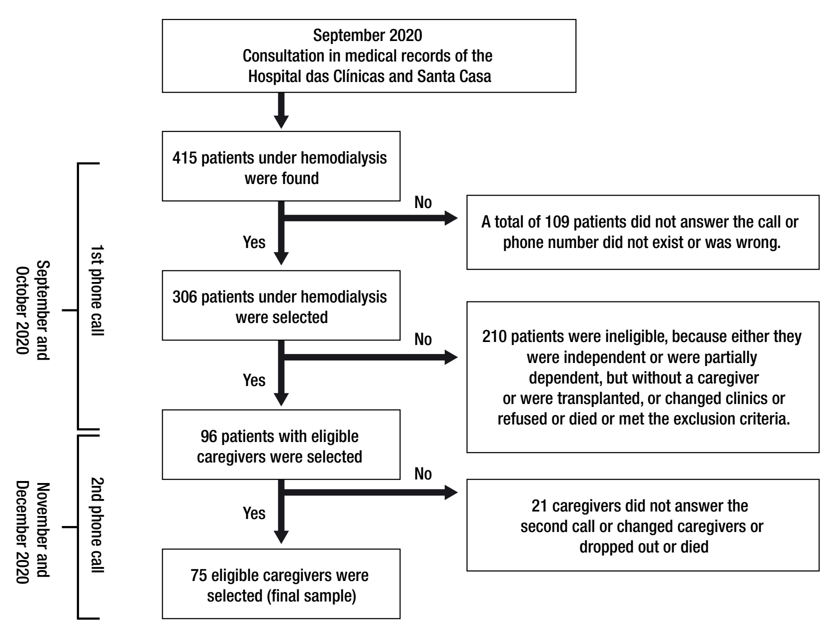

Figure 1. Flowchart of family caregiver gathering for research

tions). Response options were based on the five-point Likert scale, ranging from "very bad" (1) to "very good" (5); from "very dissatisfied" (1) to "very satisfied" (5); from "not at all" (1) to "very possible" (5); and from "never" (1) to "forever" (5). The score of questions three, four and 26 should be reversed, i.e., the lowest score was considered the best answer. The domains' scores range from seven to 35 points for the physical domain, between six and 30 points for the psychological domain, between three and 15 points for social relationships, and between eight and 45 points for the environment domain. The total WHOQOL-BREF varies between 26 and 130 points, adding the results of the domains with the two independent questions about QoL and overall health perception. For questions one and two, about overall perception of QoL and health, respectively, analysis of results was based on the following values: needs improvement (from 1 to 2.9); fair (3 to 3.9); good (4 to 4.9); and very good (5). A higher score indicates better QoL. Regarding the application of the WHOQOL-BREF, Brazilian version, internal consistency was assessed by Cronbach's alpha coefficient, obtaining 0.77 for the domains, 0.91 for the 26 questions, 0.84 for the physical domain, 0.79 for the psychological domain, 0.69 for the social relationships domain and 0.71 for the environment domain.(15)

The instruments were applied by Google Form, via telephone call, in a reserved place and taking into account the confidentiality of interviewees' answers.

To assess the internal consistency of WHOQOL-BREF results, Cronbach's alpha coefficient (α) was used. Alpha values between 0.70 and 0.95 indicate acceptable internal consistency,(16) although some authors indicate that values above 0.60 are still considered acceptable.(17) To compare groups with respect to QoL levels in each domain, the Kruskal-Wallis test was used. All analyses used a 95% confidence level for interval estimates and a significance level of 5% for hypothesis tests.

In relation to research biases, a possible source of bias would be to select occasional caregivers, who, because they do not have a very close bond with patients, could have a lower burden. However, the inclusion criterion tried to control this bias, as caregivers should have been performing this role for 3 months or more and should reside in the same household as the patient.

As for the aspect of dependence of analysis methods on assumptions about the probability data distribution, we chose to use nonparametric hypothesis testing in the comparison of groups because some groups were small in size to allow an adequate assessment of assumptions about data distribution.

The collected data were analyzed in the R statistical programming environment.

This study complied with the ethical standards in research involving Human Beings expressed in Resolution 466/2012 of the Ministry of Health,(18) being approved by the Research Ethics Committees of *Hospital das Clínicas*, through Protocol 3,797,321/2020 (CAAE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration) 15772719.2.0000.5149), and *Santa Casa de Misericórdia*-BH, by Protocol 4,189,289/2020 (CAAE 15772719.2.3001.5138). Participants were informed about the study and its confidentiality. After acceptance, all informed the Informed Consent Form (ICF).

Results

Seventy-five family caregivers participated in the study. Regarding the sociodemographic characteristics of patients under hemodialysis, most were male (43; 57.3%). The mean age was 61 years (standard deviation of 17.0), 38 (50.7%) were married and most were retired (55; 73.3%). About education, 26 (34.7%) studied up to elementary school, 18 (24.0%) completed high school and 7 (9.3%) did not know how to inform it. More than half (42; 56%) had been on hemodialysis for more than 5 years. The presence of other comorbidities was also verified: 86.7% had systemic arterial hypertension; 48% had diabetes mellitus; 34.7% reported having glomerulonephritis; and 48% had some other comorbidity. Of the participants, 28 (37.3%) had been diagnosed with diabetes for more than 10 years. Table 1 shows family caregivers' sociodemographic characteristics.

Table 1. Description of family caregivers' sociodemographic characteristics (n=75)

Variables	Family caregiver
Age, years	50.0±13.7
Kinship	
Spouse	31(41.3)
Child > 18 years old	29(38.7)
Sibling	4(5.3)
Grandson/granddaughter	1(1.3)
Son in law/daughter in law	3(4.0)
Parent	7(9.3)
Sex	
Female	63(84.0)
Male	12(16.0)
Marital status	
Married	42(56.0)
Single	17(22.7)
Widow	2(2.7)
Stable union	8(10.7)
Divorced	6(8.0)
Occupation	
Employed	8(10.7)
Unemployed	18(24.0)
Retired	13(17.3)
Housewife/househusband	29(38.7)
Self-employed	7(9.3)
Care benefit (LOAS)	-(-)
Pensioner	-(-)
Education	
Illiterate	2(2.7)
Elementary school up to 4 years	14(18.7)
Elementary school 5 to 8 years	23(30.7)
High school	27(36.0)
Higher education	9(12.0)
Not informed	-(-)
Family income, minimum wage	
Less than 1	2(2.7)
1-2	35(46.7)
2-3	29(38.7)
3-4	6(8.0)
More than 4	3(4.0)

Results expressed as ± standard deviation or n (%); Minimum wage in force in 2020: (about US$190.00); LOAS: Organic Law of Social Assistance

As for the behavioral characteristics of family caregivers in the face of the care provided, 41 (54.7%) cared for more than 5 years, and 17 (22.7%), for 3 to 4 years, and 50 (66.6%) dedicated more than 8 hours a day to care for patients under hemodialysis. Most of the 63 caregivers (84%) had no financial aid from another person or family member; 49 (65.3%) had a chronic disease; 46 (61.3%) were using some medication; 20 (26.7%) had looked for a physician in the last 12 months at least once, and the same number looked for two to three times and 17 (22.7%) looked for a physician four times or more. Cronbach's alpha coefficient for the 26 questions was 0.90 and, considering the domains separately, it was 0.83 for the physical domain, 0.71 for the psychological domain, 0.64 for the social relationships domain and 0.70 for the environment domain, showing acceptable internal consistency. The social relationships domain had only three questions, which may justify its lower alpha value than the other domains. The mean and standard deviation of caregivers' overall perception of QoL and health was 3.3 ± 1 points. The mean QoL score in the physical domain was 24.5, in the psychological domain, 20.6, in the environment domain, 25.2, and in the social relationships domain, 10.7.

There was a positive and significant relationship between the variable working outside the home and caregivers' overall QoL (p=0.014), the psychological (p=0.009) and social relationships domains (p<0.001). Males showed a positive influence on the physical domain (p=0.016). The variable receives financial help from another person/family member showed a positive relationship with the social relationships (p=0.050) and the environment (p=0.001) domains. The variables present disease and use of medications had a negative and significant influence on the physical domain, with p=0.002 and p=0.007, respectively (Table 2). As for presence of diabetes mellitus, systemic arterial hypertension and glomerulonephritis in patients, no significant association was found between these variables and QoL and overall health perception, nor with the WHOQOL-BREF domains. Regarding the other variables, no statistically significant association was found with caregivers' QoL levels, so these variables were not presented in Table 2.

Discussion

The present study aimed to analyze the sociodemographic characteristics of family caregivers and their influence on the perception of individuals' well-being, considering the physical, psychological, social relationships and environment in which they are in-

Table 2. Assessment of the association between sociodemographic variables of family caregivers and the WHOQOL-BREF domains that presented statistically significant values in at least one of the domains (n=75)

Variables/categories		Physical domain (7 to 35 points)			Psychological domain (6 to 30 points)			Social relationships (3 to 15 points)			Environment (8 to 45 points)		
	n	Mean	SE	p-value*	Mean	SE	p-value*	Mean	SE	p-value*	Mean	SE	p-value*
Sex													
Female	63	23.9	0.7	0.016†	20.3	0.5	0.252	10.8	0.3	0.437	24.9	0.6	0.153
Male	12	28	1.3		22	0.9		10.2	0.6		27	0.9	
Occupation													
Work outside home	15	27.1	1.4	0.066	22.9	0.8	0.009†	12.5	0.4	<0.001†	27.1	1.3	0.122
Do not work outside home	60	23.9	0.7		20	0.5		10.2	0.3		24.7	0.6	
Caregiver behavioral data considering the care provided													
Do they receive financial help from other people and/or family members?													
Yes	12	26.2	1.2	0.224	22.3	0.8	0.126	11.8	0.5	0.050†	28.7	0.7	0.001*
No	63	24.2	0.7		20.3	0.5		10.5	0.3		24.5	0.6	
Have any disease													
Yes	49	23.2	0.7	0.002†	20.3	0.5	0.209	10.6	0.3	0.488	25.6	0.6	0.243
No	26	27.1	1		21.2	0.9		10.9	0.4		24.5	0.9	
Do they use a drug for chronic use?													
Yes	46	23.3	0.7	0.007†	20.5	0.6	0.654	10.8	0.3	0.825	25.8	0.6	0.131
No	29	26.6	1.1		20.7	0.9		10.5	0.5		24.2	0.9	

SE: standard error; Minimum wage in force in 2020: R$ 1,045.00 (about US$190.00); *Kruskal-Wallis test; †values with statistical relevance

serted. The findings corroborate the literature and show changes in QoL levels, being more noticeable in the domains that encompass physical, mental, emotional and social health.(19-23)

The analysis of sociodemographic variables showed that, for patients under hemodialysis, the mean age was 61 years. Most of them were male, married, retired, with an education level of up to 8 years of study, undergoing hemodialysis for more than 5 years and had comorbidities (systemic arterial hypertension and diabetes mellitus). These findings corroborate several studies.(1,24,25)

The sociodemographic profile of family caregivers found in the study showed that the majority were female. The most frequent kinship degrees were those of wife and daughter. It is known that both, wife and daughter, are the ones who care the most due to closer blood ties and the greater degree of commitment.(23,12,26) As for the level of education, 36% of caregivers completed high school (12 years of study), corroborating a study developed in the United States.(9) Most family caregivers were unemployed or were housewives (housewives). Family income was between one and three minimum wages, most of which was represented by the income of patients under hemodialysis (64 of the 75 patients participating in the research received a salary through some social transfer: pension, retirement or social benefits). A study shows that more than 80% of family caregivers have low to medium economic status. Added to this reality, the act of caring generates financial burdens and some caregivers still have another dependent entity in need of care.(26)

Considering the sociodemographic characteristics of sex and family income, women with low family income were observed taking care, in addition to patients, of other entities under their responsibility. This reality presents a vulnerable individual, who suffers socioeconomic losses to perform the role of caregivers. In European Union countries, as well as in Canada, informal/family caregivers are seen as a vital element of the health system in the care of dependent people and their rights are recognized through policies that range from financial support and flexible working hours to technological innovations that improve competence and the ability to care.(27) In Brazil, there seems to be no social security policy or social support that includes family caregivers.

The mean score of caregivers' overall perception of QoL was moderate. For caregivers interviewed in this study, the variable receiving financial help from other people and/or family members had a positive impact on the social relationship and environment domains. This finding reinforces the importance of financial support for caregivers' safety, directly reflecting on their QoL. This direct relationship between the economic situation and cultural development at the level of family caregivers' QoL has been described in other studies.(11,24) Caregivers who work outside the home showed better results in overall QoL and in the psychological and social relationships domains, which may be related to the desire to maintain goals, expectations and position in life.(13) Studies show lower QoL levels in caregivers who work outside the home, whose care routine affects work commitments, causing delays, requests for time off, changes in work hours.(9,26)

When analyzing sex and the impact of this variable on family caregivers' QoL, males had a positive influence in the physical domain, giving higher values of QoL in relation to females. A study developed in Iran found no influence of sex on caregivers' level of QoL; however, others found males to be a factor related to the decrease in physical health.(11,20) It is important to emphasize that QoL perception by individuals can present a significant difference, according to their individual characteristics, such as sex, age, education level, occupation and income.(28)

Regarding caregivers' health condition, more than half had some chronic disease and were on continuous medication. Such variables had a negative influence on QoL levels of family caregivers in terms of the physical domain. A study developed in India showed that the presence of chronic diseases influenced the mean overall and physical health.(28) A study in Brazil showed that half of family caregivers reported having some health treatment, reporting the presence of various chronic diseases (hypertension, diabetes, asthma, depression, etc.) with pain complaint present in more than half of interviewees, requiring medication use in some cases.(29)

Chronic conditions, such as systemic arterial hypertension, type 2 diabetes mellitus, and glomerulonephritis, are the main causes of chronic kidney disease;(1) however, in this study, they did not influence caregivers' QoL.

Sociodemographic and behavioral characteristics can affect caregivers' QoL, such as financial status, physical health and working conditions and which, when confronted with social determinants, evidenced the vulnerability of these caregivers with a high risk of illness, both physical and mental.(30) Studies have detected the presence of signs of depression in 30% of family caregivers of older patients, in addition to being more likely to have psychopathology, attend medical appointments more frequently, and have worse health conditions than the general population.(29,31)

The limitations of the results of this research are related to its cross-sectional design, which does not allow establishing an association between cause and effect. Moreover, carrying out convenience sampling, due to the restricted access to the population of family caregivers due to the pandemic moment, may limit the extension of the results to the family caregivers' universe. However, the results found were supported by international and national literature. These results mostly corroborate findings from different regions of the world, exposing a real problem that is increasingly evident in the entire population, which is the increase in individuals with chronic kidney disease under hemodialysis who become dependent on the care of another person, especially their family members.

Identifying factors that influence of family caregivers' QoL can contribute to the implementation of coping strategies to improve the well-being of family caregivers of patients under hemodialysis, in addition to the recognition, through public policies, of improving competence and ability to care.

Conclusion

The present study showed that male family caregivers, or those who work outside the home or receive financial help from other people and/or family members, had better QoL levels. On the other hand, family caregivers' clinical conditions, such as taking medication or having diseases, had a negative influence on QoL levels.

Acknowledgments

The researchers thank the hemodialysis centers of *Hospital das Clínicas* and *Santa Casa* of Belo Horizonte and patients and caregivers who participated in the research. This study was funded by the Brazilian National Council for Scientific and Technological Development (CNPq - *Conselho Nacional de Desenvolvimento Científico e Tecnológico*) - Process 303250/2019-4.

Collaborations

Jardim VR, Reis IA, Amaral SVA and Torres HC contributed to project design, data analysis and interpretation, article writing, relevant critical review of the intellectual content and approval of the final version to be published.

References

1. Neves PD, Sesso RC, Thomé FS, Lugon JR, Nasicmento MM. Brazilian Dialysis Census: analysis of data from the 2009-2018 decade. J Bras Nefrol. 2020;42(2):191–200.
2. Cruz TH, Girardon-Perlini NM, Beuter M, Coppetti LC, Dalmolin A, Piccin C. Apoio social percebido por cuidadores familiares de pacientes renais crônicos em hemodiálise. Rev Min Enferm. 2018;22:e1119.
3. Ventura J, Cargnin MC, Santos KS, Getelina CO, Rotoli A, Paula SF. Pacientes em tratamento hemodialítico: percepção acerca das mudanças e limitações da doença e tratamento. Rev Pesqui Cuid Fundam. 2018;10(4):926–31.
4. León Zamora Y, Ávila Sánchez M, Enríquez C. Calidad de vida de los cuidadores principales de pacientes en hemodiálisis. Medicentro (Villa Clara). 2020;24(2):422–9.
5. Shah KK, Murtagh FE, McGeechan K, Crail SM, Burns A, Morton RL. Quality of life among caregivers of people with end-stage kidney disease managed with dialysis or comprehensive conservative care. BMC Nephrol. 2020;21(1):160.
6. Shukri M, Mustofai MA, Md Yasin MA, Tuan Hadi TS. Burden, quality of life, anxiety, and depressive symptoms among caregivers of hemodialysis patients: the role of social support. Int J Psychiatry Med. 2020;55(6):397–407.
7. Hreńczuk M, Koziel W, Małkowski P. Health problems and restrictions of chronic haemodialysis patients. Gen Int Med Clin Innov. 2019;4(1):1–5.
8. Coitinho D, Benetti ER, Ubessi LD, Barbosa DA, Kirchner RM, Guido LA, et al. Intercorrências em hemodiálise e avaliação da saúde de pacientes renais crônicos. Av Enferm. 2015;33(3):362–71.
9. Starks SA, Graff JC, Wicks MN. Factors associated with quality of life of family caregivers of dialysis recipients. West J Nurs Res. 2020;42(3):177–86.
10. Alnazly E. Coping strategies and socio-demographic characteristics among Jordanian caregivers of patients receiving hemodialysis. Saudi J Kidney Dis Transpl. 2016;27(1):101–6.
11. Farzi S, Farzi S, Moladoost A, Ehsani M, Shahriari M, Moieni M. Caring burden and quality of life of family caregivers in patients undergoing hemodialysis: a descriptive-analytic study. Int J Community Based Nurs Midwifery. 2019;7(2):88–96.
12. Romero Massa E, Bohórquez Moreno C, Castro Muñoz K. Calidad de vida y sobrecarga percibida por cuidadores familiares de pacientes con enfermedad renal crónica, Cartagena (Colombia). Arch Med (Oviedo). 2018;18(1):105–13.
13. The World Health Organization quality of life assessment (WHOQOL): position paperfrom the World Health Organization. Soc Sci Med. 1995;41(10):1403–9.
14. Seidl EM, Zannon CM. Qualidade de vida e saúde: aspectos conceituais e metodológicos. Cad Saude Publica. 2004;20(2):580–8.
15. Fleck MP, Louzada S, Xavier M, Chachamovich E, Vieira G, Santos L, et al. Aplicação da versão em português do instrumento abreviado de avaliação da qualidade de vida "WHOQOL-bref". Rev Saude Publica. 2000;34(2):178–83.
16. Bland JM, Altman DG. Cronbach's alpha. BMJ. 1997;314(7080):572.
17. Taber KS. The Use of Cronbach's Alpha When Developing and Reporting Research Instruments in Science Education. Res Sci Educ. 2018;48(6):1273–96.
18. Brasil. Ministério da Saúde. Conselho Nacional de Saúde (CNS). Resolução Nº 466, de 12 de dezembro de 2012. Diretrizes e normas regulamentadoras sobre pesquisa envolvendo seres humanos. Brasília (DF): CNS; 2012 [citado 2021 Out 8]. Disponível em: https://conselho.saude.gov.br/resolucoes/2012/Reso466.pdf
19. Tavakol M, Dennick R. Making sense of Cronbach's alpha. Int J Med Educ. 2011;2:53–5.
20. Nagarathnam M, Sivakumar V, Latheef SA. Burden, coping mechanisms, and quality of life among caregivers of hemodialysis and peritoneal dialysis undergoing and renal transplant patients. Indian J Psychiatry. 2019;61(4):380–8.
21. Sajadi SA, Ebadi A, Moradian ST. Quality of life among family caregivers of patients on hemodialysis and its relevant factors: a systematic review. Int J Community Based Nurs Midwifery. 2017;5(3):206–18. Review.
22. Gilbertson EL, Krishnasamy R, Foote C, Kennard AL, Jardine MJ, Gray NA. Burden of care and quality of life among caregivers for adults receiving maintenance dialysis: a systematic review. Am J Kidney Dis. 2019;73(3):332–43. Review.
23. Ghane G, Farahani MA, Seyedfatemi N, Haghani H. The effect of supportive educative program on the quality of life in family caregivers of hemodialysis patients. J Educ Health Promot. 2017;6(1):80.
24. Jafari H, Ebrahimi A, Aghaei A, Khatony A. The relationship between care burden and quality of life in caregivers of hemodialysis patients. BMC Nephrol. 2018;19(1):321.
25. El-Habashi AF, El-Agroudy AE, Jaradat A, Alnasser ZH, Almajrafi HH, Alharbi RH, et al. Quality of life and its determinants among hemodialysis patients: a single-center study. Saudi J Kidney Dis Transpl. 2020;31(2):460–72.
26. Celik G, Annagur BB, Yılmaz M, Demir T, Kara F. Are sleep and life quality of family caregivers affected as much as those of hemodialysis patients? Gen Hosp Psychiatry. 2012;34(5):518–24.
27. Minayo MC. Cuidar de quem cuida de idosos dependentes: por uma política necessária e urgente. Cien Saude Colet. 2021;26(1):7–15.

28. Nagarathnam M, Latheef SA, Sivakumar V. Factors influencing scales of burden, coping mechanisms, and quality of life in caregivers of hemodialysis patients in Andhra Pradesh, India. Indian J Palliat Care. 2021;27(1):62–7.

29. Belasco A, Barbosa D, Bettencourt AR, Diccini S, Sesso R. Quality of life of family caregivers of elderly patients on hemodialysis and peritoneal dialysis. Am J Kidney Dis. 2006;48(6):955–63.

30. Geib LT. Determinantes sociais da saúde do idoso. Cien Saude Colet. 2012;17(1):123–33.

31. Adejumo OA, Iyawe IO, Akinbodewa AA, Abolarin OS, Alli EO. Burden, psychological well-being and quality of life of caregivers of end stage renal disease patients. Ghana Med J. 2019;53(3):190–6.