

Health-related quality of life of patients receiving hemodialysis therapy

Qualidade de vida relacionada à saúde de pacientes em terapêutica hemodialítica

Calidad de vida relacionada con la salud de pacientes en terapia de hemodiálisis

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Renal insufficiency; Renal dialysis; Patient compliance; Quality of life

Descritores

Insuficiência renal crônica; Diálise renal; Cooperação do paciente; Qualidade de vida

Descriptores

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Abstract**Objective:** To identify and measure factors associated with health-related quality of life of patients on hemodialysis with chronic kidney disease, and to analyze the association of health-related quality of life and adherence to the therapeutic hemodialysis regimen.**Methods:** Cross-sectional study with 258 patients on hemodialysis therapy. Health-related quality of life was assessed using the Kidney Disease Quality of Life Short Form questionnaire. We analyzed the specific components of chronic kidney disease, and the physical and mental components summary. The analysis of non-adherence to the hemodialysis regimen was based on the indicators of the study, The Dialysis Outcomes and Practice Patterns Study. The Mann Whitney and Kruskal Wallis tests were used for the analysis.**Results:** White female subjects, under 60 years of age, who were of a low socioeconomic level, required an accompanying person during hemodialysis therapy for less than 5 years, were prescribed ten or more medications, had low serum levels of albumin and hemoglobin, and did not adhere to fluid restriction and hemodialysis therapy experienced a lower health-related quality of life.**Conclusion:** The assessment of health-related quality of life in patients on hemodialysis was associated with sociodemographic, clinical, and therapeutic characteristics. The monitoring of these parameters, as well as the attempts to achieve recommended standards, will be able to support clinical practice, improve the planning of care, and improve several aspects of the lives of the patients.**Resumo****Objetivo:** identificar e mensurar fatores associados à qualidade de vida relacionada à saúde de pacientes renais crônicos em hemodiálise e analisar a associação da qualidade de vida relacionada à saúde e a adesão ao regime terapêutico hemodialítico.**Métodos:** Estudo transversal com 258 pacientes em terapia hemodialítica. Avaliou-se a qualidade de vida relacionada à saúde através do questionário *Kidney Disease Quality of Life Short Form*. Foram analisados os componentes específicos da doença renal crônica e os componentes sumarizados físico e mental. A análise da não adesão ao regime terapêutico hemodialítico teve como base os indicadores do estudo *The Dialysis Outcomes and Practice Patterns Study*. Utilizaram-se, para a análise os testes de Mann Whitney e Kruskal Wallis.**Resultados:** Indivíduos do sexo feminino, com menos de 60 anos, brancos, baixo nível socioeconômico, que necessitam de acompanhante, em terapia hemodialítica por menos de 5 anos, que possuem prescrição medicamentosa com dez ou mais fármacos, com baixos níveis séricos de albumina e hemoglobina e que não aderiram à restrição hídrica e à terapia apresentaram piora na qualidade de vida relacionada à saúde.**Conclusão:** A avaliação da qualidade de vida relacionada à saúde dos pacientes em hemodiálise apresentou associação com as características sociodemográficas, clínicas e terapêutica. A monitoração desses parâmetros, bem como a busca do alcance dos padrões recomendáveis poderão subsidiar a prática clínica, aprimorar o planejamento assistencial e trazer melhorias em diversos aspectos da vida dos pacientes.**Resumen****Objetivo:** Identificar y medir factores asociados a la calidad de vida relacionada con la salud de pacientes renales crónicos en hemodiálisis y analizar la conexión entre la calidad de vida relacionada con la salud y la adhesión al régimen terapéutico de hemodiálisis.**Métodos:** Estudio transversal con 258 pacientes en terapia de hemodiálisis. Se analizó la calidad de vida relacionada con la salud mediante el cuestionario *Kidney Disease Quality of Life Short Form*. Fueron estudiados los componentes específicos de la enfermedad renal crónica y los componentes resumidos físicos y mentales. El análisis de no adhesión al régimen terapéutico de hemodiálisis utilizó como base los indicadores del estudio *The Dialysis Outcomes and Practice Patterns Study*. Para el análisis, se utilizaron las pruebas de Mann Whitney y Kruskal Wallis.**Resultados:** Individuos de sexo femenino, de menos de 60 años, blancos, de nivel socioeconómico bajo, que necesitan acompañante, en terapia de hemodiálisis por menos de 5 años, que tienen prescripción de medicamentos de diez o más fármacos, con niveles bajos de albúmina y hemoglobina en sangre y que no tuvieron adhesión a la restricción hídrica y a la terapia presentaron un deterioro en la calidad de vida relacionada con la salud.**Conclusión:** El análisis de la calidad de vida relacionada con la salud de los pacientes en hemodiálisis presentó conexión con las características sociodemográficas, clínicas y terapéuticas. El monitoreo de estos parámetros, así como la búsqueda por alcanzar los estándares recomendables, podrán respaldar la práctica clínica, mejorar la planificación asistencial y ofrecer mejoras en varios aspectos de la vida de los pacientes.**Corresponding author**Cláudio Vitorino Pereira
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Introduction

Chronic kidney disease (CKD) has a prominent role in the epidemiological transition, due to its prevalence and costs involved in its treatment, as well as the high morbidity and mortality rate. When at its most advanced stage, renal replacement therapy (RRT) is necessary.⁽¹⁾ Currently, hemodialysis, peritoneal dialysis, and renal transplant are available therapies.⁽²⁾

According to the census of the Brazilian Society of Nephrology, the prevalence of patients on dialysis is in the range of 544 per million people (pmp), with an annual incidence rate for cases of 180 pmp. It is estimated that 111,303 individuals require dialysis treatment each year, of which approximately 92.8% receive hemodialysis.⁽³⁾

The advancement of hemodialysis therapy enabled the prolonging of life of patients with terminal CKD.⁽²⁾ However, the dynamics of these therapies can inflict psychosocial barriers on patients, due to the weekly time spent in treatment, increased family dependence, anxiety, and fatigue following the sessions.⁽⁴⁾

The impact of hemodialysis on patients' daily lives has motivated the development of research to evaluate health-related quality of life (HRQoL),⁽⁵⁾ which centers on the ability to live without disease or to overcome difficulties related to conditions of status or morbidity.⁽⁶⁾ The hemodialysis therapy regimen comprehends changes in daily life, such as commuting to dialysis centers, food restrictions, as well as changes in family life.⁽⁷⁾ Such changes are related to treatment characteristics, which include hemodialysis sessions, medication regimen, and control of food and fluids.⁽⁸⁾ Conditions associated with CKD are detrimental to the health of these patients. The average hospitalization per year is approximately 15 days, and the self-reported HRQoL is lower than that of the general population.⁽²⁾

Hemodialysis patients often report lack of energy, muscle weakness, feelings of discouragement, fatigue, and cramps. Such repercussions lead to a decrease in the HRQoL due to the limitation on daily activities - because of their health

condition - and work - because of physical problems - causing frustration and interference in patients' lives.⁽⁹⁾

The reactions founded in patients' daily lives demonstrate the relevance of knowing aspects related to the HRQoL of patients on hemodialysis, as well as their association with adherence to therapy, in order to guide planning and health interventions.

The present study aims to identify and measure factors associated with the HRQoL of patients with chronic kidney disease on hemodialysis, and to analyze the association between HRQoL and adherence to the therapeutic hemodialysis regimen.

Methods

This was a cross-sectional, census-based study that included patients, after analyzing inclusion and exclusion criteria, who received hemodialysis therapy in a university hospital and two private hemodialysis clinics, in agreement with the Unified Health System. This was a macro-regional health assistance center located in the southeast region of Brazil, in the state of Minas Gerais. These three centers are responsible for all outpatient hemodialysis services in the municipality, and serve as references for care for 37 cities in the region.⁽¹⁰⁾

The data were collected by the principal investigator, by means of an interview and questionnaire administration, for sociodemographic and HRQoL analysis, while the evaluation of adherence was performed using the Nefrodata software and patient records from February to May of 2017. All dialysis centers that served as research sites used the Nefrodata Software, which provided uniformity for data collection.

The study included individuals aged 18 years or over, who were on hemodialysis for a minimum of three months, and who demonstrated ability to understand and provide information about their health condition using the Short Assessment of Health Literacy for Portuguese-speaking Adults (SAHLPA), on which a score of 14 or more points is considered satisfactory.⁽¹¹⁾ Hospitalized patients,

or those who had a hospitalization during the month prior to data collection, were excluded from the study.

Among the 482 patients receiving hemodialysis at the centers, 224 were excluded. Of these, 56 were under treatment for less than three months, 41 were hospitalized during the data collection period or in the previous month, 11 refused to participate in the study, and 116 presented poor health literacy. The final sample consisted of 258 participants.

The standards for evaluation of non-adherence to the hemodialysis regimen were based on the indicators established by The Dialysis Outcomes and Practice Patterns Study (DOPPS), which are: fluid restriction (interdialytic gain > 5.7% of dry weight), dietary restriction (serum potassium level > 6 mEq/l or phosphorus > 7.5 mg/dl), medication regimen (serum level of phosphorus content > 7.5 mg/dl), and hemodialysis therapy (non-attendance and/or decrease treatment time > 10 minutes in one or more sessions during the analysis period).⁽¹²⁾

In order to evaluate the HRQoL, the Kidney Disease Quality of Life Short Form (KDQOL-SF) questionnaire, validated in Brazil, was administered during the hemodialysis sessions. It is an instrument that is applicable to patients who are undergoing some type of dialysis program, which includes generic and specific aspects of the patient's health, CKD, effects of CKD on daily life, and satisfaction with treatment. The instrument is composed of 24 questions, totaling 80 multiple-choice items. For the evaluation, a score ranging from zero to 100 is adopted, in which 100 is the best classification of the evaluation of the patient's HRQoL, and zero is the worst.⁽¹³⁾ The criteria for assessing family income were based on the indicators established by the Brazilian Association of Research Companies (ABEP).⁽¹⁴⁾

Descriptive statistical analysis techniques were used, such as absolute and relative frequency, mean, median, standard deviation, interquartile range, and maximum and minimum values. The distribution profile of the quantitative variables was obtained

using the Kolmogorov-Smirnov test. Because these were variables with non-parametric distribution, the data were analyzed using the Mann Whitney and Kruskal Wallis tests. The results were considered significant when $p < 0.05$. We chose to evaluate the association of the variables with the specific components of CKD and the Physical Component Summary (PCS) and Mental Component Summary (MCS) that constitute the questionnaire. Data were analyzed using the Statistical Package for Social Sciences (SPSS), version 15.

The present study was approved by the Ethics and Research Committee of the University Hospital of the Federal University of Juiz de Fora - MG., opinion number 1,709,611. After agreeing to participate in the research, the participants signed the Terms of Free and Informed Consent.

Results

The main sociodemographic, clinical, and health characteristics of the 258 individuals interviewed are shown in Table 1. In the sample, 59.7% were female; 53.9% had non-white skin color; and the mean education level was 8.28 (SD=3.86) years. Among the participants, 92.2% were beneficiaries of social security; only 4.7% of the individuals were actively working during the data collection period.

Regarding access to the health services, 57.0% did not have a private health plan, and the SUS was responsible for the payment of 82.6% of the dialysis treatments. The majority of patients, 51.2%, did not have conservative nephrology treatment (Table 1).

Regarding the clinical variables, the most frequent underlying disease was systemic arterial hypertension, with 39.5% of the cases. The mean number of prescribed medications was 10.5 (SD=3.2). Among the participants, 65.1% presented albumin levels < 4 g/dl, and 53.1% had hemoglobin levels < 11 g/dl.

Table 2 presents the values of mean, standard deviation, median, interquartile range and minimum and maximum values of the KDQOL-SF

Table 1. Sociodemographic characteristics, patient access to the health service and clinic

Sociodemographic	
Sex	
Male n (%)	104(40.3)
Female n (%)	154(59.7)
Age – μ (\pm SD)	56.8(\pm 14.5)
Level of education – μ (\pm SD)	8. 28(\pm 3.86)
Marital status	
Single n (%)	122(47.3)
Stable union n (%)	136(52.7)
Skin color	
White n (%)	119(46.1)
Non-white n (%)	139(53.9)
Occupation	
Beneficiaries of social security n (%)	238(92.2)
Active worker n (%)	12(4.7)
Others n (%)	8(3.1)
Access to health services	
Private health plan	
Yes n (%)	111(43)
No n (%)	147(57)
Treatment payment	
SUS n (%)	213(82.6)
Private health plan n (%)	45(17.4)
Previous renal replacement therapy	
Peritoneal dialysis n (%)	18(7.0)
Renal transplant n (%)	17(6.6)
None n (%)	223(86.4)
Clinics	
Primary disease	
Arterial hypertension n (%)	102(39.5)
Diabetes mellitus n (%)	46(17.8)
Nephropathies n (%)	51(19.8)
Lupus n (%)	8(3.1)
Indeterminate n (%)	35(13.6)
Others n (%)	16(6.2)
Vascular access	
Arteriovenous fistula n (%)	193(74.8)
Long-term catheter n (%)	46(17.8)
Short-term catheter n (%)	19(7.4)
Kt/V	
< 1.2	104(40.3)
\geq 1.2	154(59.7)
Albumin	
< 4 g/dl n (%)	168(65.1)
\geq 4 g/dl n (%)	90(34.9)
Hemoglobin	
< 11 g/dl n (%)	137(53.1)
\geq 11 g/dl n (%)	121(46.9)
Number of medications μ (\pm SD)	10.5(3.2)

Mean - μ ; Standard deviation – SD

dimensions, with the PCS and MCS. In the specific part of the questionnaire, the lowest median score was obtained in the work status dimension: 0.00 (IQ=50.00). The worst score for generic components was obtained on role-physical 25 (IQ=75). The PCS presented a median of 35.75 (IQ=20.10), while the MCS was 57.64 (IQ=12.28) (Table 2).

Table 2. Dimensions of Kidney Disease and Quality of Life - Short Form of patients on hemodialysis

Dimension	Mean	SD	Median	IQ	Minimum	Maximum
Specifics						
Symptoms	77.62	17.25	83.33	22.92	25.00	100.00
Effects of CKD	63.29	25.04	62.50	37.50	0.00	100.00
Burden of CKD	53.90	32.15	50.00	50.00	0.00	100.00
Work status	20.35	28.97	0.00	50.00	0.00	100.00
Cognitive function	94.16	12.76	100.00	6.67	6.67	100.00
Quality of social interaction	87.52	17.09	93.33	20.00	6.67	100.00
Sexual function	83.25	31.69	100.00	21.87	0.00	100.00
Sleep	79.70	22.76	88.75	29.37	25.00	100.00
Social support	89.53	22.93	100.00	0.00	33.33	100.00
Dialysis staff encouragement	91.28	23.58	100.00	0.00	0.00	100.00
Patient satisfaction	96.45	12.62	100.00	0.00	0.00	100.00
Generics (SF – 36)						
Global health	71.24	22.04	80.00	30.00	0.00	100.00
Physical functioning	57.21	34.28	60.00	65.00	0.00	100.00
Physical role	38.28	36.98	25.00	75.00	0.00	100.00
Pain	61.02	39.74	70.00	80.00	0.00	100.00
General health	58.84	24.81	60.00	40.00	0.00	100.00
Emotional well being	80.48	20.59	88.00	25.00	4.00	100.00
Emotional role	80.88	33.21	100.00	33.33	0.00	100.00
Social functioning	78.83	31.51	100.00	50.00	0.00	100.00
Energy	68.22	25.09	70.00	40.00	0.00	100.00
Physical component	36.01	11.89	35.75	20.10	14.6	60.00
Mental component	55.47	9.60	57.64	12.28	19.84	72.01

Table 3 presents the median, interquartile range and the association between the variables related to HRQoL and the specific dimensions of KDQOL-SF, PCS and MCS. The dimensions of cognitive function, social support, staff encouragement, sexual function, and patient satisfaction with treatment were not statistically significant, and data are not presented.

The relevant aspect for the HRQoL of the hemodialysis patients is adherence to the therapeutic regimen: individuals classified as adherent to fluid restrictions presented fewer symptoms ($p<0.001$), lower CKD effect ($p=0.032$), and higher PCS score ($p=0.041$). Patient's adherence to the therapy showed a lower CKD load ($p=0.025$), higher social interaction ($p=0.003$), and better sleep pattern ($p=0.010$). Aspects related to adherence to dietary and medication regimens were not statistically significant (Table 3).

Discussion

The patient profile is similar to that found in national and international studies, which have as populations adult individuals receiving hemodialysis treatment.⁽¹⁵⁻¹⁷⁾ The data collected support the important role of SUS as the main funding agency for hemodialysis, even in cases where individuals have private health plans. According to data from the Brazilian Society of Nephrology, 84% of hemodialysis treatments are funded by the SUS.⁽³⁾ Such disparity encumbers the health system, due to the high cost of treatment.

Female patients showed greater CKD-related symptoms and less social interaction. It is also worth noting that HRQoL has been lower among women on hemodialysis.^(18,19) This fact can be credited to a greater exposure to physical and mental stress caused by the role of women in society,¹⁸⁾ in addition to life history and the lowest social support.¹⁹⁾ The age variable was associated with work status, PCS and social interaction. Elderly individuals have a better adaptation to the changes imposed by hemodialysis therapy, so they can preserve social relationships.²⁰⁾ This is not observed when the physical component is analyzed, as, in addition to the impact established by the treatment, a physiological decline related to aging occurs, which can potentiate functional limitations.⁽¹⁵⁾

The changes established by hemodialysis therapy have repercussions on the social and economic life of the patients, because of the characteristics of the treatment regimen, which mainly include dialysis sessions three times a week, lasting four hours each session.⁽²¹⁾ The scores obtained in the work dimension included the lowest scores of analysis in the present study. The maintenance of employment was associated with a better evaluation of HRQoL, and a lower perception of commitment to daily activities as a result of therapy, in Chinese patients.⁽²²⁾

Attending hemodialysis sessions was associated with a higher prevalence of symptoms, worsening effects of the CKD load, and lower scores on the PCS score. The need for companionship demon-

strates limitations imposed by the disease that result in the reduction of autonomy.⁽²²⁾

A longer time in hemodialysis improves the self-management of the health condition. Individuals in therapy for less than five years, in Japan, presented poorer results related to the physical, emotional, social domains, and the perception of the disease.⁽²⁰⁾

The evaluation of nutritional status in hemodialysis is fundamental for quality care. Hypoalbuminemia was associated with greater symptomatology and CKD load. Serum albumin level is an important marker for nutritional status.⁽²³⁾ Malnourished patients present poorer overall health dimensions, with a decrease in physical and mental aspects, and a higher prevalence of symptoms.^(23, 24)

Anemia worsens the HRQoL of hemodialysis patients. A low serum hemoglobin level has been independently associated with decreased MCS, low social and emotional function, worsening of physical function, and limitation in work and daily activities.⁽²³⁾ The adjustment of anemia through the use of erythropoietin has improved HRQoL of these patients.⁽²⁵⁾

The number of prescribed medications is an independent predictor of lower scores on the physical dimensions of the HRQoL of patients in hemodialysis.⁽²⁶⁾ These individuals have, on average, four comorbidities associated with CKD,⁽²⁾ resulting in a higher medication load.⁽²⁷⁾

Poor adherence to hemodialysis therapy may lead to worsening of health status and compromise the efficacy of treatment. Individuals who did not adhere to fluid restrictions presented greater symptoms, increased CKD effect, and decreased MCS. Fluid overload is associated with increased mortality, elevated blood pressure, cardiac events, and poorer outcomes in hemodialysis.⁽²⁸⁾ Patients not adherent to hemodialysis therapy have demonstrated an increase in CKD load, compromised social interaction, and impaired sleep patterns. Depressive symptoms and pain have independently been associated with omission and shortening of hemodialysis sessions, which, in turn, are related to the need for more

emergency care and hospitalizations, as well as to an increase in mortality.⁽²⁹⁾

The complexity of hemodialysis therapy and the multiplicity of factors associated with HRQoL require specialized multidisciplinary care. The nurse is essential for qualified, safe and individualized care in this scenario. Standardized nursing care can provide for adequate follow-up, assessment, planning, and interventions in order to enable improved adaptation and treatment comprehension, better results, minimization of risks, and more autonomy, which result in the improvement of HRQoL.⁽³⁰⁾

Conclusion

The results of the present study highlight factors associated with the HRQoL of patients on hemodialysis. White individuals of less than 60 years of age, with a low socioeconomic level, who required a companion, had undergone hemodialysis therapy for a period of less than five years, and who were prescribed ten or more medications showed the poorest scores in the HRQoL assessment. The presence of modifiable factors - such as low serum levels of albumin and hemoglobin, and non-adherence to fluid restriction and hemodialysis therapy - are also associated with worsening of HRQoL. Therefore, special attention to such characteristics is paramount for the staff within dialysis centers, so that the therapeutic plan will be appropriate to the individual needs of these patients. Monitoring of these parameters, as well seeking to achieve recommended standards, and adherence to treatment, can improve the patients' lives in several aspects. The evaluation of HRQoL in patients on hemodialysis, and its association with therapeutic adherence, are important indicators of health; the findings of this study may support clinical practice, improve planning of care, and motivate the development of new research, since studies analyzing these associations are insufficient. The limits of the results of this study are related to the transversal design that does not allow a causal relationship to be established.

Collaborations

Pereira CV and Leite ICG contributed to the design of the study, analysis and interpretation of the data, article writing, critical review of the intellectual content, and approval of the final version to be published.

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