

Prospective analysis of the impact of Chronic Kidney Disease on patients and caregivers

Análise prospectiva do impacto da Doença Renal Crônica em pacientes e cuidadores

Análisis prospectivo del impacto de la Enfermedad Renal Crónica en pacientes y cuidadores

Beatriz dos Santos Pereira¹, Filomena Maria Kirchmaier²,
Neimar da Silva Fernandes³, Lucas Fernandes Suassuna⁴,
Natália Maria da Silva Fernandes⁵

1. Psychologist. PhD. Graduation in Medicine, Faculdade de Ciências Médicas de Três Rios. Três Rios-RJ, Brazil. Orcid: <https://orcid.org/0000-0003-2394-930X>

2. Nurse. Specialist. Universidade Federal de Juiz de Fora. Juiz de Fora-MG, Brazil. Orcid: <https://orcid.org/0000-0001-6368-5658>

3. Graduated in Mathematics. Faculdade de Medicina da Universidade Federal de Juiz de Fora. Juiz de Fora-MG, Brazil. Orcid: <https://orcid.org/0000-0002-1198-6827>

4. Undergraduate student, Faculdade de Medicina da Universidade Federal de Juiz de Fora. Juiz de Fora-MG, Brazil. Orcid: <https://orcid.org/0000-0001-7327-692X>

5. MD, PhD. Faculdade de Medicina da Universidade Federal de Juiz de Fora. Juiz de Fora-MG, Brazil. Orcid: <https://orcid.org/0000-0001-8728-7937>

Resumo

Introdução. A doença renal crônica (DRC) apresenta alta incidência, prevalência e morbimortalidade na população mundial, impactando negativamente nos aspectos biopsicossociais dos pacientes e cuidadores familiares. **Objetivo.** Avaliar a associação entre a saúde mental de cuidadores e pacientes com DRC em terapia dialítica. **Método.** Estudo de coorte prospectivo, a amostra incluiu pacientes com DRC em diálise no Hospital Universitário da Universidade Federal de Juiz de Fora (UFJF) e seus cuidadores familiares no período de 2015 a 2019. Os instrumentos utilizados para coleta de dados foram um questionário sociodemográfico (dados retirados dos prontuários), a Escala de Percepção de Suporte Social (EPSS), a Escala Hospitalar de Ansiedade e Depressão (HADS), o Inventário de Sintomas de Estresse de Lipp (LISS), os Questionário de Qualidade de Vida SF-36 (SF-36), o Pictograma de Fadiga. **Resultados.** A maioria dos pacientes estava em hemodiálise há mais de 4 anos e era do sexo feminino, de meia-idade e negra. A maioria dos cuidadores era do sexo feminino, de meia-idade e branca. Os participantes de ambos os grupos eram predominantemente casados e com baixa escolaridade. Os níveis gerais de saúde mental e qualidade de vida (QV) foram semelhantes entre pacientes e cuidadores. **Conclusão.** A saúde mental dos pacientes e seus cuidadores familiares foi afetada de forma semelhante e negativa pela DRC; portanto, o tratamento e as medidas interdisciplinares de atenção à saúde mental são urgentes para essa população.

Unitermos. Doença renal crônica; Saúde mental; Qualidade de vida; Cuidadores familiares

Abstract

Introduction. Chronic kidney disease (CKD) has a high incidence, prevalence and morbidity and mortality among the world population, negatively impacting the biopsychosocial aspects of patients and family caregivers. **Objective.** To evaluate the association between the mental health of caregivers and CKD patients on dialysis. **Method.** A prospective cohort study, the sample included patients with CKD on dialysis at the University Hospital of the Federal University of Juiz de Fora (UFJF) and their family caregivers from 2015 to 2019. The instruments used for data collection were a sociodemographic questionnaire, the Perceived Social Support Scale (EPSS), the Hospital Anxiety and Depression Scale (HADS), the Lipp

Stress Symptom Inventory (LISS), the SF-36 Quality of Life Questionnaire (SF-36), the Fatigue Pictogram. **Results.** Most patients were on haemodialysis for more than 4 years and were female, middle-aged, and black. Most caregivers were female, middle-aged and white. The participants in both groups predominantly married people with low levels of education. The general levels of mental health and quality of life (QoL) between patients and caregivers were similar. **Conclusion.** The mental health of patients and their family caregivers was similarly and negatively affected by CKD; therefore, treatment and interdisciplinary mental health care measures are urgent for this population.

Keywords. Chronic kidney disease; Mental health; Quality of life; Family caregivers

Resumen

Introducción. La enfermedad renal crónica (ERC) presenta una alta incidencia, prevalencia y morbimortalidad entre la población mundial, impactando negativamente en los aspectos biopsicosociales de los pacientes y familiares cuidadores. **Objetivo.** Evaluar la asociación entre la salud mental de los cuidadores y los pacientes con ERC. **Método.** Estudio de cohorte prospectivo, la muestra incluyó pacientes con ERC en diálisis en el Hospital Universitario de la Universidad Federal de Juiz de Fora (UFJF) y sus cuidadores familiares de 2015 a 2019. Los instrumentos utilizados para la recolección de datos fueron un cuestionario sociodemográfico, la Escala de Apoyo Social Percibido (EPSS), la Escala de Ansiedad y Depresión Hospitalaria (HADS), el Inventario de Síntomas de Estrés de Lipp (LISS), el Cuestionario de Calidad de Vida SF-36 (SF-36), el Pictograma de Fatiga. **Resultados.** La mayoría de los pacientes llevaban más de 4 años en hemodiálisis y eran mujeres, de mediana edad y de raza negra. La mayoría de los cuidadores eran mujeres, de mediana edad y blancas. Los participantes en ambos os grupos son predominantemente personas casadas con bajos niveles de educación. Los niveles generales de salud mental y calidad de vida (QoL) entre pacientes y cuidadores fueron similares. **Conclusión.** La salud mental de los pacientes y sus familiares cuidadores se vio afectada de manera similar y negativa por la ERC; por lo tanto, el tratamiento y las medidas interdisciplinarias de atención en salud mental son urgentes para esta población.

Palabras clave. Enfermedad renal crónica; Salud mental; Calidad de vida; Cuidadores familiares

Research developed at Universidade Federal de Juiz de Fora. Juiz de Fora-MG. Brazil.

Conflict of interest: no

Received in: 09/07/2023

Accepted in: 10/30/2023

Corresponding address: Natalia MS Fernandes. Universidade Federal de Juiz de Fora (UFJF). Rua Eugênio do Nascimento s/n. Bairro Dom Bosco. Juiz de Fora-MG, Brazil. Email: nataliafernandes02@gmail.com

INTRODUCTION

Chronic kidney disease (CKD), which consists of progressive and irreversible damage to the kidneys¹, is currently considered a global public health challenge²⁻⁴ due to its high incidence and prevalence^{5,6} and the high financial cost of renal replacement therapies (RRTs), especially for public health systems⁷. In addition to costs, there is a human burden, as CKD is associated with high levels of morbidity, mortality and chronic disability^{8,9}.

CKD in the predialysis phase, especially when there is a need for RRT, causes significant changes in the lives of patients, for example, changes in eating patterns because of dietary restrictions, especially water restrictions. Physical capacity is limited, and very often, it is impossible for patients to maintain their work activities. Disruptions in relationships and reductions in social bonds are also common¹⁰. In this context, the impacts on the mental health and quality of life (QoL)¹¹⁻¹⁴ of patients who present depressive¹⁵⁻²⁰, anxiety^{21,22}, and stress²³ symptoms and physical and mental manifestations, for example, fatigue²⁴⁻²⁶, is notable. Clinical complications may also occur during treatment, and these complications are related to worse QoL and mental health conditions²⁷.

Patients with CKD, especially those with greater limitations, require assistance in treatment and activities of daily living, and for these patients, there is usually a family member who assumes the role of caregiver²⁸, i.e., responsible for providing care and directly involved in the CKD treatment or daily activities of the patient. Caregivers also suffer from various impacts on mental health^{29,30-33}, and among this group, high levels of anxiety, depression³⁴⁻³⁷, and stress and reductions in QoL are observed³⁸. The overlapping responsibilities of caregivers, who often add the care provided to the patient to their daily life and work routine, can lead to overload and symptoms of fatigue and can have impacts on the ability to perform daily activities. In addition, the various aspects of caregivers' mental health may worsen

over time and with the increase in the intensity of care provided³⁹.

CKD has a substantial impact on the mental health of patients and their caregivers, leading to the need for social support and comprehensive care for patients and caregivers so that researchers and clinicians can understand these various impacts and design strategies to improve the QoL of these patients⁴⁰. To our knowledge, there has been no evaluation of this complex context with regard to patients with CKD, but there have been studies that separately investigate aspects of mental health⁴¹⁻⁴⁹. The objective of evaluating the association between the mental health of caregivers and CKD patients on dialysis.

METHOD

Sample

This prospective cohort study was conducted at University Hospital of the Federal University of Juiz de Fora (HU/CAS – UFJF) in the city of Juiz de Fora during the period from 2015 to 2019. The RRT service of HU/UFJF follows the norms of Federal Collegiate Directive Resolution (RDC) number 11 of 2014, providing treatment through a multidisciplinary team of physicians, nurses, social workers, nutritionists and psychologists. As such, patients received psychological interventions, if needed, during the follow-up. The study design was observational, and no interventions other than those considered routine were performed.

The inclusion criteria were: aged over 18 years, of both sexes, and patients with CKD with a family caregiver, who had been on RRT for at least six months and who agreed to participate in the study by signing an informed consent form (ICF). Caregivers named by the patients were included. The noninclusion criteria were individuals who demonstrated difficulty in understanding the questionnaires and individuals whose medical records indicated severe cognitive impairment.

The study was reviewed by the Research Ethics Committee (CEP) of HU/UFJF and initiated after its approval under number 2,592,113, following the precepts of Resolution 196 of 1996 (MS, CNS 196/96).

Procedure

Variables analysed

The following patient-related variables were analysed: sociodemographic data (age, sex, race (self-declaration), income, education, marital status (according to IBGE) and religion). The following clinical data were analysed: CKD aetiology, comorbidities. These data were obtained from the medical records of the included patients.

The following caregiver-related data were analysed: sociodemographic data (age, sex, race (self-declaration), income, education, marital status (according to IBGE) and religion).

Psychological variables were analysed. The variables associated with the psychological assessment applied to

caregivers and patients are presented in Table 1. The surveys were administered to patients on haemodialysis (HD) during dialysis sessions. For patients treated with peritoneal dialysis (PD), the surveys were administered at the PD outpatient clinic when each patient arrived for their medical appointments. For caregivers, interviews took place at the outpatient clinic during patient consultations or when sitting in the waiting room.

Sociodemographic, clinical and psychological variables data were collected at baseline (T0) and four years later (T1) and clinical outcomes, death and loss to follow-up were collected at T1.

Table 1. Descriptive list of the psychological instruments used in this study.

Instrument	Characteristics	Recommended responsible
Sociodemographic questionnaire	Semistructured interview composed of questions about social and demographic aspects of the participant (prepared by the research team)	Psychologist, non-anonymous instrument.
Hospital Anxiety and Depression Scale (HADS)	14-item scale (7 for HADS-A and 7 for HADS-D) used to assess the presence of symptoms of anxiety and depression, scored using a Likert scale. Each item is scored from zero to three. The maximum score is 21 points for each scale. The cut-off point for the presence of symptoms is a score ≥ 9 ⁵⁰ .	Psychologist, non-anonymous instrument.
Perceived Social Support Scale (PSSS)	29-item instrument that evaluates the social support perceived by the respondent; each item is scored from 1 to 4. The scale evaluates social support in two dimensions: practical and emotional ⁵¹ .	Psychologist, non-anonymous instrument.
Fatigue Pictogram	Illustrated instrument for evaluating fatigue; two sets of figures are used to evaluate the intensity and impact of fatigue in usual activities. Two questions and figures are presented on an ordinal scale with five graduated and captioned illustrations that assess the intensity and impact of fatigue. This evaluation does not have a cut-off point for the diagnosis or classification of fatigue intensity, as it is easier for participants to interpret and provides information that can be interpreted in an ordinal way ⁵² .	Psychologist, non-anonymous instrument.
Lipp Stress Symptom Inventory (LSI)	A self-report instrument to identify the presence of stress symptoms, the type of symptoms (somatic or psychological predominance) and the stage (alertness, resistance, near exhaustion and exhaustion) ⁵³ .	Psychologist, anonymous instrument.
Quality of Life Questionnaire (SF-36)	Short version of the <i>Medical Outcomes Trust</i> questionnaire that assesses various domains of QoL. Scores range from 0 to 100, with scores closer to zero indicating poorer quality of life and scores closer to 100 indicating better quality of life ⁵⁴ .	Psychologist, non-anonymous instrument.

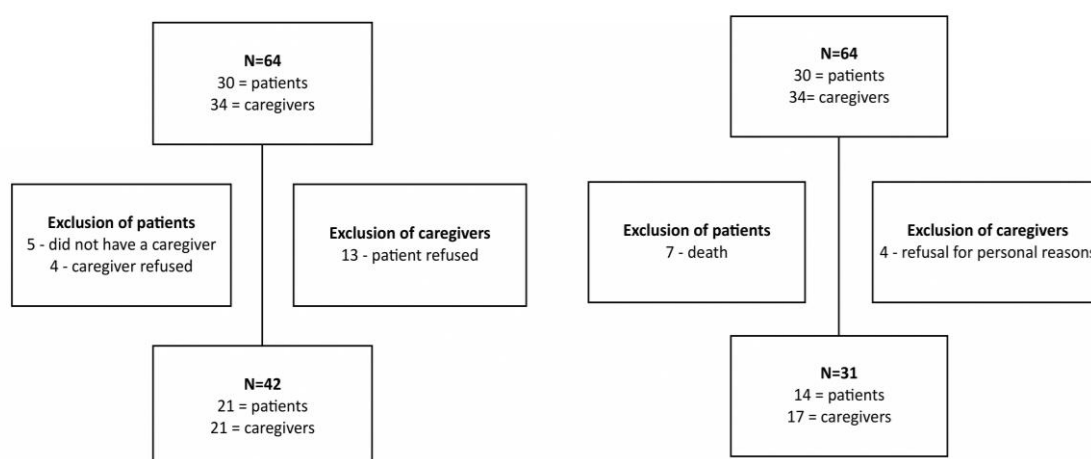
Statistical analysis

The sociodemographic data and questionnaire data are presented as the mean \pm standard deviation, median (interquartile range), percentage or frequency on the basis of the characteristics of the data. Subsequently, patients who were still being followed up and those who died were separated into two groups, and depression, quality of life, stress and fatigue and the clinical and laboratory variables of the patients at T0 were compared between the groups using paired Student's t test, the Wilcoxon test or the chi-square test. Subsequently, these same variables were compared between T0 and T1 for patients, between T0 and T1 for caregivers and between patients and caregivers at T1. A confidence interval of 95% was considered. The statistical software SPSS 17.0 was used for all analyses.

RESULTS

Convenience sampling was used to recruit patients receiving treatment at the RRT service of UH/UFJF. Over three shifts, patients were approached randomly and individually during treatment or while waiting for RRT and offered the opportunity to participate in the study. Figure 1 shows the study flowchart.

Figure 1. Study flowchart at T0 and T1.



The sociodemographic and clinical data of patients and caregivers (Table 2) indicated that most participants, both patients and caregivers, were female and middle-aged; the majority of patients were black, and the majority of caregivers were white (self-declaration); both groups had low education levels, with most participants having incomplete elementary school education and being married; the majority of patients were retired due to disability or were away from work with benefits; most caregivers maintained full-time and part-time work activities; the most prevalent comorbidity was systemic arterial hypertension (SAH), followed by diabetes mellitus (DM), and the most frequent cause of CKD was hypertensive nephrosclerosis; most patients were on HD for approximately 4 years; and all caregivers were family members.

Table 2. Sociodemographic and clinical data of the study population at T0 and T1.

	Patient T0 (N total=21)	Caregiver T0 (N total=21)	Patient T1 (N total=14)	Caregiver T1 (N total=17)
Female sex (%)	57.1	76.2	50	70.5
Age in years (mean±SD)	58.86±14.37	47.86±15.20	54.71±15.96	50.82±14.88
Race/Colour (%)	38.1	47.6	35.7	58.8
White	47.6	28.6	50.0	23.5
Black	14.3	23.8	14.3	17.6
Brown				
Education (%)				
Illiterate	9.5	0.0	0.0	0.0
Literate	4.8	0.0	7.1	0.0
Incomplete elementary school	52.4	38.1	42.8	41.1
1st degree complete	0.0	14.3	0.0	17.6
Incomplete high school	4.8	0.0	7.1	0.0
High school complete	19.0	33.3	28.5	29.4
3rd degree incomplete	0.0	0.0	0.0	0.0
3rd degree complete	9.5	14.3	14.2	11.7
Marital status (%)				
Single	23.8	19.0	21.4	17.6
Married/Stable union	47.6	80.9	42.8	82.3
Divorced	4.8	0.0	7.1	0.0
Widower	23.8	0.0	28.5	0.0
Working period (%)				
Part-time	31.6	15.8	0.0	5.88
Full-time			7.14	41.17
Retired with benefits	15.8	5.3	42.85	17.64
Retired due to length of service	47.4	15.8	21.42	11.76
Retired due to age	0.0	5.3	14.28	5.88
Retired due to disability	5.3	57.9	0.0	5.88
Aetiology of CKD (%)				
Hypertensive nephrosclerosis	52.4	Does not apply	50.0	Does not apply
Diabetic kidney disease	23.8		7.1	
Polycystic kidney disease	4.7		7.1	
Glomerulonephritis	9.5		28.5	
Other	9.6		7.1	
Comorbidities (%)				
Systemic arterial hypertension	100	Does not apply	100	Does not apply
Diabetes mellitus	66.7		71.4	
Peripheral vascular disease	9.5		71.4	
Stroke	9.5		7.14	
Heart disease	14.3		7.14	
Type of treatment (%)				
Haemodialysis	66.7	Does not apply	78.57	Does not apply
Peritoneal dialysis	33.3		21.42	
Duration of treatment in years (mean±SD)	4.57±4.49	Does not apply	3.2±6.2	Does not apply

At the second timepoint (T1), data related to religiosity were collected, and most patients declared that they were Catholic (71.4%, n=10), followed by Jehovah's Witnesses (14.2%, n=2), and evangelical (7.1%, n=1). Most caregivers declared that they were Catholic (52.9%, n=9), followed by evangelical (29.4%, n=5) and Jehovah's Witnesses (5.8%, n=1).

As seen in Table 3, when comparing T0 vs. T1 for the patients, there was a decrease in anxiety ($p=0.028$) and psychological symptoms of stress (0.001), and a tendency towards improvements in social aspects within the QoL score ($p=0.08$).

Table 3. Comparison of anxiety and depression, fatigue, stress and quality of life between patients at T0 (n=21) vs. T1 (n=14).

Scales	Mean \pm SD (T0)	Mean \pm SD (T1)	p
Hospital anxiety scale	7.42 \pm 5.35	5.14 \pm 4.38	0.028
Hospital depression scale	6.76 \pm 4.79	4.92 \pm 4.95	0.210
Practical social support	3.32 \pm 1.01	3.42 \pm 0.73	0.346
Emotional social support	3.35 \pm 1.30	3.50 \pm 0.80	0.508
How tired have you felt in the last week?	2.90 \pm 1.26	2.64 \pm 1.49	0.564
How much does the feeling of tiredness prevent you from doing what you want to do?	2.90 \pm 1.22	2.93 \pm 1.54	0.750
Stress phases	1.25 \pm 1.13	0.75 \pm 1.01	0.082
Physical symptoms	1.80 \pm 0.92	1.42 \pm 1.20	0.145
Psychological symptoms	2.38 \pm 1.02	0.95 \pm 1.02	0.001
Functional capacity	53.09 \pm 26.52	52.50 \pm 33.49	0.361
Limited by physical aspects	33.33 \pm 36.51	42.85 \pm 45.39	0.607
Pain	48.66 \pm 30.44	52.35 \pm 30.52	0.665
General health status	51.00 \pm 26.85	54.78 \pm 27.96	0.362
Vitality	58.80 \pm 28.36	56.42 \pm 25.37	0.413
Social aspects	60.71 \pm 32.42	72.32 \pm 34.38	0.080
Limited by emotional aspects	41.26 \pm 40.69	42.85 \pm 51.35	0.891
Mental health	66.47 \pm 25.18	58.28 \pm 24.03	0.193
Physical domain	36.36 \pm 8.96	39.04 \pm 9.80	0.551
Mental domain	45.65 \pm 12.07	44.31 \pm 13.18	0.638

Regarding caregivers (Table 4), when comparing T0 vs. T1, there was a decrease in anxiety ($p=0.017$), a trend towards an increase in emotional social support ($p=0.08$), a decrease in physical ($p=0.051$), and psychological stress

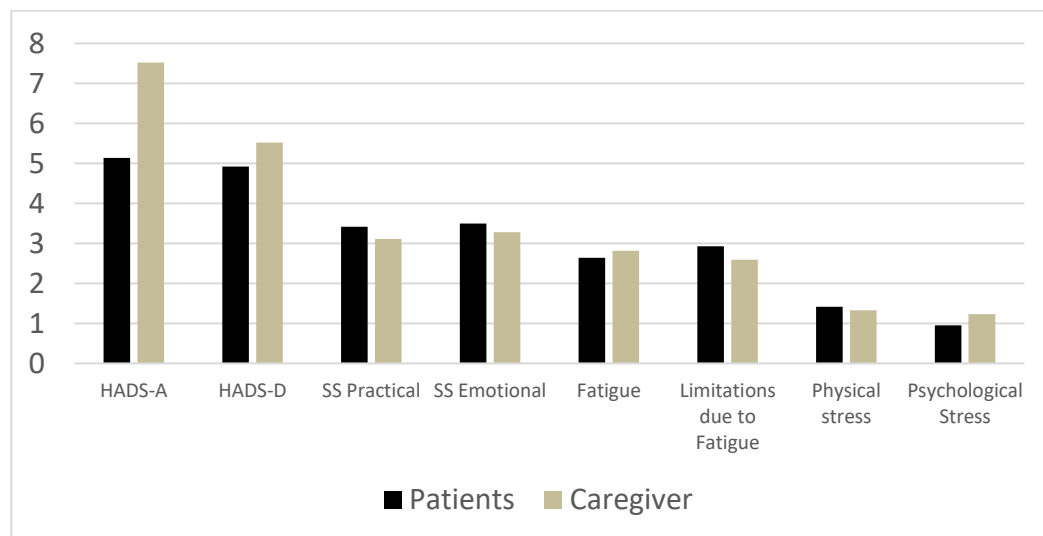
($p=0.02$) and a tendency towards an increase in vitality within the QoL score ($p=0.093$).

In Figures 2 and 3, after four years of follow-up (T1), patients and caregivers presented very similar scores without significant differences.

Table 4. Comparison of anxiety and depression, fatigue, stress and quality of life between caregivers at T0 (n=21) vs. T1 (n=17).

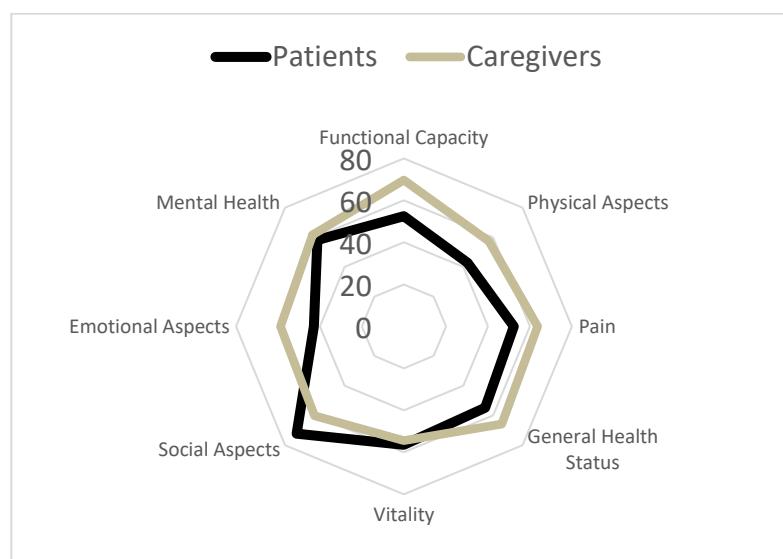
Scales	Mean±SD (T0)	Mean±SD (T1)	p
Hospital anxiety scale	8.71±3.84	7.52±4.44	0.017
Hospital depression scale	6.23±4.41	5.52±3.87	0.242
Practical social support	2.98±0.86	3.11± 0.72	0.909
Emotional social support	3.00±0.72	3.28± 0.83	0.087
How tired have you felt in the last week?	2.95±1.32	2.82±1.01	0.566
How much does the feeling of tiredness prevent you from doing what you want to do?			
	2.52±1.25	2.59±1.32	0.951
Stress phases	1.40±1.01	0.96±1.06	0.122
Physical symptoms	1.90±0.99	1.33±0.91	0.051
Psychological symptoms	2.04±0.74	1.23±1.13	0.028
Functional capacity	74.52±26.64	69.70±29.39	0.850
Limited by physical aspects	64.28±38.28	57.35±46.57	0.917
Pain	56.95±24.93	63.68±26.97	0.220
General health status	63.47±26.75	65.81±29.82	0.363
Vitality	44.52±27.29	54.41±18.69	0.093
Social aspects	63.69±32.33	60.29±31.01	0.968
Limited by emotional aspects			
	55.55±45.13	58.82±47.91	0.402
Mental health	57.33±24.11	61.64±19.34	0.120
Physical domain	46.29±10.29	45.30±12.26	0.379
Mental domain	40.09±15.10	43.60±12.00	0.278

Figure 2. Comparison between anxiety, depression, social support, fatigue and stress in patients and caregivers after four years of follow-up (T1).



T1: second stage of the study, after a 4-year follow-up, with the second stage of data collection; HADS-A: questions used to assess symptoms of anxiety in the Hospital Anxiety and Depression Scale; HADS-D: questions used to assess symptoms of depression in the Hospital Anxiety and Depression Scale; SS Practical: practical social support aspects of the Perceived Social Support Scale; SS Emotional: emotional social support aspects of the Perceived Social Support Scale; Fatigue: fatigue rated using the Fatigue Pictogram; Limitations due to Fatigue: limitations in daily activities caused by fatigue, as rated using the Fatigue Pictogram; Physical stress: physical component of stress assessed using the Lipp Stress Inventory; Psychological Stress: emotional component of stress assessed using the Lipp Stress Inventory.

Figure 3. Comparison of quality of life between patients and caregivers after four years of follow-up (T1).



T1: second stage of the study, after a 4-year follow-up, with the second stage of data collection; All other aspects described in the figure (functional capacity, physical aspects, pain, general health status, vitality, social aspects, emotional aspects and mental health) refer to the various aspects of quality of life that were assessed using the SF-36 quality of life questionnaire.

There were seven deaths during the follow-up period. Comparing survivors vs. deaths (Table 5), patients who had higher levels of physical symptoms of stress at T0 had lower mortality ($p=0.09$).

Table 5. Comparison of sociodemographic and clinical data, anxiety and depression, fatigue, stress and quality of life at T0 between patients who lived through the follow-up period and those who died (T test, chi-square).

Scale	Died N=7	Survived N=14	p value
Age (mean±SD)	67.14±4.06	54.71±15.98	0.08
Sex (male/female) (n)	2/5	7/7	0.32
CKD aetiology (n)			
Hypertensive nephrosclerosis	4	7	0.45
Diabetic nephropathy	1	1	
Polycystic kidney disease	1	1	
Chronic glomerulonephritis	1	4	
Other	0	1	
Comorbidities (n)			
Diabetes mellitus	3	4	0.13
Peripheral vascular disease	1	1	0.56
Stroke	1	1	0.56
Heart disease	2	5	0.24
Duration of dialysis (months)	31.67±32.73	25.30±18.89	0.67
HADS - Anxiety*	7.43±4.93	7.43±5.73	1.00
HADS - Depression**	7.42±3.50	6.42±5.41	0.50
EPSS - P ***	3.06±0.83	3.45±1.10	0.47
EPSS - E****	3.05±0.91	3.50±1.46	0.62
How tired have you felt in the last week?	3.14±1.34	2.79±1.25	0.48
How much does the feeling of tiredness prevent you from doing what you want to do?	3.14±0.90	2.79±1.36	0.55
ISSL***** - initial	0.71±0.48	0.50±0.51	0.36
ISSL-Phases	1.51±1.03	1.12±1.19	0.63
ISSL-Physical symptoms	1.28±1.11	2.07±0.73	0.09
ISSL-Psychological symptoms	2.57±1.13	2.28±0.99	0.30
SSRI-Symptom predominance	1.85±0.89	1.92±0.73	0.93
SF*****36-Functional capacity	43.57±21.35	57.85±28.26	0.27
SF36-Limited by physical aspects	21.42±26.72	39.28±40.08	0.37
SF36-Pain	54.57±35.95	45.71±28.30	0.59
SF36-General health status	54.00±26.43	49.50±27.92	0.85
SF36-Vitality	50.00±25.16	63.21±29.71	0.20
SF36-Social aspects	64.28±38.47	58.92±30.39	0.65
SF36-Limited due to emotional aspects	44.19±35.63	42.85±44.19	0.93
SF36-Mental health	63.42±25.86	68.00±25.68	0.45
SF36-Physical domain	34.95±9.22	37.06±9.35	0.88
SF36-Mental domain	44.97±11.86	45.99±12.60	0.82

* Hospital Anxiety and Depression Scale corresponding to the evaluation of anxiety symptoms; ** Hospital Anxiety and Depression Scale corresponding to the evaluation of depressive symptoms; *** Perceived Practical Social Support Scale. **** Perceived Social Emotional Support Scale; ***** Lipp Stress Symptom Inventory; ***** Quality of Life Questionnaire.

DISCUSSION

The results of this study indicated that the mental health of caregivers and patients was impacted by CKD and, notably, that the variables evaluated were not different between these two groups at the end of four years, indicating

overload resulting from the disease for both groups. The main limitation of our study is the decrease in the sample size; however, in prospective studies of populations with a mortality rate of approximately 20% per year, this decrease was expected⁵⁵. The most relevant aspect of the study is the broad assessment of the mental health of the patient-caregiver dyad.

The age range for patients in this study was similar to that for patients on dialysis in Brazil⁵⁶; however, the majority of patients in this study were female, a finding that is inconsistent with the literature, with most patients on dialysis being male. Additionally, in agreement to data from the Brazilian Society of Nephrology (SBN), most patients undergo HD as RRT⁵⁵. The socioeconomic profile also reflects the Brazilian reality, i.e., patients with low education levels and most without jobs (retired). The aetiologies of CKD and the most prevalent comorbidities identified herein are consistent with those observed in Brazil⁵⁵⁻⁵⁸. Regarding caregivers, the majority were women, a finding that is consistent with the literature, with close kinship and a significant percentage maintaining their work activities⁵⁹⁻⁶². While the majority of patients declared themselves black, the majority of caregivers declared themselves white. This data may be due to self-declaration of color and/or miscegenation that means that the caregiver and the patient do not have the same perception of skin color. We emphasize that it is about color and not race or ancestry.

Interestingly, in this study, for patients, there was a decrease in anxiety and psychological symptoms of stress over time as well as a tendency towards improvements in the social aspects of QoL. Regarding improvements in the aforementioned aspects and patients' ability to adapt, there are several factors that impact patient coping, such as patients' perception of their own disease⁶³, beliefs, emotions and behaviours⁶³, coping style⁶⁴, religious coping⁶⁵, and spirituality⁶⁶. A previous study showed that lower psychological resilience, lower education and greater cognitive distortions are factors associated with depression and anxiety in patients with CKD⁶⁷. Other recent studies have indicated that patients go through several phases of adaptation, that the resilience potential of patients is related to perceived stress⁶⁸ and that perceived stress, general QoL and QoL subcomponents are related to the resilience profile of patients with CKD⁶⁹. Thus, interdisciplinary teams should develop specific interventions to build resilience in patients with CKD, aiming to facilitate their adaptation to treatment and positively impact their lives in general. It is essential to fully recognize the emotional demands of patients⁷⁰. A space for listening⁷¹ and psychological reception for each patient should be ensured.

For the caregivers, after four years, there was also a decrease in anxiety, a tendency towards an increase in emotional social support, a decrease in physical and psychological stress and a trend towards an increase in vitality within QoL.

Several factors are associated with the presence of anxiety and depression in caregivers, including close kinship with the patient, increasing age of the caregiver, low education level, being retired, having children and poor financial conditions⁷². Most of these risk factors were present in the profile of the participants in this study. The decrease in the levels of anxiety and stress in the caregivers in this study may reflect a coping strategy for adapting to conditions of care. The increase in emotional social support in caregivers reinforces that the role of caregiver is often assumed by a family member; however, care is not limited to that person. Informal support networks include other family members as well as friends, neighbours and people from the community who are linked to the patient⁷³⁻⁷⁵. The support offered can be objective, practical or instrumental depending on the task, such as helping with medication, monitoring appointments and procedures, and providing financial aid. Support can also be emotional, addressing emotional aspects of the patient in times of crisis. Thus, there are several ways of expressing support that relate to the health of the patient attended⁷⁵. This better social support may foster caregivers' greater adaptation to the care required.

Interestingly, after four years, there were no statistically significant differences between patients and caregivers, with no overall improvement in patients and a worsening of scores for caregivers. Our research shows that caregivers, despite all the impacts suffered, maintain daily

activities and their formal employment, beyond patient care, suggesting overload. Caregiver burden in the context of nephrology, especially in dialysis treatment⁷⁶.

The mental health of caregivers impacts patient support⁷⁷, and this support is related to adherence to treatment⁷⁸ and patient health outcomes⁷⁹.

Assessing the conditions associated with mortality, only age was a predictor in the bivariate analysis, a finding that is expected in studies evaluating survival. Although the small sample size makes this analysis difficult to interpret. This finding is not corroborated by study that reported that QoL was an independent predictor of mortality in PD patients⁸⁰. Additionally, a recent review indicated that several studies associate mental health and mortality in patients with CKD on RRT⁸¹.

Despite the difficult prognosis, social and family support offered to patients is essential for maintaining their health and clinical care. Multidisciplinary teams in nephrology must determine and, if needed, intervene in the social and family support network of patients with CKD to improve the care offered to patients and promote positive impacts on their physical and mental health and QoL, with the expectation of positive effects leading to greater survival⁵⁰.

This context highlights the need for mental health diagnosis and interventions for patients with CKD and their family caregivers in the prevention of illness and promotion of health, quality of life and well-being⁸², encompassing various health factors such as the provision of adequate

social, economic, physical and psychological support for this population^{83,84}. Psychological interventions are strongly indicated for this population^{85,86}.

CONCLUSION

The evaluation of mental health beyond QOL score, with a broader assessment of this complex context, that is, patients with CKD on dialysis, is necessary, and clinics that provide dialysis treatment to these patients should offer a multiprofessional team with psychologists, social workers and professionals already involved in direct care, such as physicians, nurses and nutritionists, to improve the quality of life of patients and caregivers, and reduce the burden on caregivers of these patients.

REFERENCES

1. Júnior JER. Doença Renal Crônica: Definição, Epidemiologia e Classificação. J Bras Nefrol 2004;26(suppl 3):1-3. <https://www.bj nephrology.org/en/article/doenca-renal-cronica-definicao-epidemiologia-e-classificacao/>
2. Bastos MG, Bregman R, Kirstzan GM. Doença Renal Crônica: frequente e grave, mas também tratável e prevenível. Rev Assoc Méd Bras 2010;56:248-53. <https://doi.org/10.1590/S0104-42302010000200028>
3. Lugon JR. Doença Renal Crônica no Brasil: um problema de saúde pública. J Bras Nefrol 2009;31(suppl 1):2-5. <https://www.bj nephrology.org/article/doenca-renal-cronica-no-brasil-um-problema-de-saude-publica/>
4. Filho NS, Brito DJA. Doença Renal Crônica: A Grande Epidemia Deste Milênio. J Bras Nefrol 2006;28(2 suppl1):1-5. <https://www.bj nephrology.org/article/doenca-renal-cronica-a-grande-epidemia-deste-milenio/>
5. Marinho AWGB, Penha AP, Silva MT, Galvão TF. Prevalência de doença renal crônica em adultos no Brasil: uma revisão sistemática da literatura. Cad Saúde Col 2017;3:379-88. <https://doi.org/10.1590/1414-462X201700030134>
6. Jha V, Garcia-Garcia G, Iseki K, Li Z, Naicker S, Plattner B, *et al.* Chronic Kidney disease: global dimensions and perspectives. Lancet 2013;382:260-72. [https://doi.org/10.1016/S0140-6736\(13\)60687-X](https://doi.org/10.1016/S0140-6736(13)60687-X)
7. Alcade PR, Kirsztajn GM. Gastos do Sistema Único de Saúde brasileiro com doença renal crônica. J Bras Nefrol 2018;2:122-9. <https://doi.org/10.1590/2175-8239-JBN-3918>
8. Romagnani P, Remuzzi G, Glassock R, Levin A, Jager KJ, Tonelli M, *et al.* Chronic kidney disease. Nat Rev Dis Primers 2017;3:17088. <https://doi.org/10.1038/nrdp.2017.88>

9. Fráguas G, Soares SM, Silva PAB. A família no contexto do cuidado ao portador de nefropatia diabética: demandas e recursos. *Esc Anna Rev Enferm* 2008;2:271-7. <https://doi.org/10.1590/S1414-81452008000200011>
10. Moreno V. Familiares de pacientes em hemodiálise: convivendo com condição crônica de saúde. *Rev Rene* Fortaleza 2008;4:49-56. <https://doi.org/10.15253/2175-6783.2008000400006>
11. Brito DCS, Machado EL, Reis IA, Moreira DP, Nébias THM, Cherchiglia ML. Modality transition on renal replacement therapy and quality of life of patients: a 10-year follow-up cohort study. *Qual Life Res* 2019;6:1485-95. <https://doi.org/10.1007/s11136-019-02113-z>
12. Alves KB, Guillarducci NV, Santos TR, Baldoni AO, Otoni A, Pinto SWL, *et al.* Is quality of life associated with compliance to pharmacotherapy in patients with chronic kidney disease undergoing maintenance hemodialysis? *Einstein* 2018;16:1-7. <https://doi.org/10.1590/S1679-45082018AO4036>
13. Teles F, Albuquerque AL, Lins IKFG, Medrado PC, Costa AFP. Quality of life and depression in haemodialysis patients. *Psychol Health Med* 2018;9:1069-78. <https://doi.org/10.1080/13548506.2018.1469779>
14. Bai YL, Chang Y, Chiou C, Lee B. Mediating effects of fatigue on the relationship among sociodemographic characteristics, depression, and quality of life in patients receiving hemodialysis. *Nurs Health Sci* 2019;2:231-8. <https://doi.org/10.1111/nhs.12587>
15. Ahlawat R, Tiwari P, Cruz S. Prevalence of Depression and its Associated Factors among Patients of Chronic Kidney Disease in a Public Tertiary Care Hospital in India: A Cross-sectional Study. *Saudi J Kidney Dis Transpl* 2018;5:1165-73. <https://doi.org/10.4103/1319-2442.243972>
16. Khan A, Khan AH, Adnan AS, Sulaiman SAS, Mustaq S. Prevalence and predictors of depression among hemodialysis patients: a prospective follow-up study. *BMC Public Health* 2019;19:531. <https://doi.org/10.1186/s12889-019-6796-z>
17. Cirillo L, Cutruzzulà R, Somma C, Gregori M, Cestone G, Pizzarelli C, *et al.* Depressive Symptoms in Dialysis: Prevalence and Relationship with Uremia-Related Biochemical Parameters. *Blood Purif* 2018;46:286-91. <https://doi.org/10.1159/000491014>
18. AlShahrani MA, Alayed ASM, AlShehri AH, Solaiman O, Awadalla NJ, Alhomrany M. Depression and Impaired Work Productivity among Hemodialysis Patients in South Region of Saudi Arabia. *Saudi J Kidney Dis Transpl* 2018;5:1133-8. <https://doi.org/10.4103/1319-2442.243970>
19. Kazama S, Kazama JJ, Wakasugi M, Ito Y, Narita I, Tanaka M, *et al.* Emotional disturbance assessed by the Self-Rating Depression Scale test is associated with mortality among Japanese Hemodialysis patients. *Fukushima J Med Sci* 2018;1:23-9. <https://doi.org/10.5387/fms.2016-21>
20. Cheng H, Ho C, Hung K. Affective and cognitive rather than somatic symptoms of depression predict 3-year mortality in patients on chronic hemodialysis. *Scient Rep* 2018;1:1-12. <https://doi.org/10.1038/s41598-018-24267-5>
21. Dias DR, Shiozawa P, Miorin LA, Cordeiro Q. Prevalência de sintomas depressivos e ansiosos em pacientes com doença renal crônica em programa de hemodiálise: um estudo transversal. *Arq Med Hosp Fac Cienc Med Santa Casa São Paulo* 2015;60:65-71. <https://arquivosmedicos.fcmsantacasasp.edu.br/index.php/AMSCSP/article/view/152>
22. Barros BP, Nishiura JL, Heilberg IP, Kirsztajn GM. Anxiety, depression, and quality of life in patients with familial glomerulonephritis or autosomal dominant polycystic kidney disease. *J Bras Nefrol* 2011;2:120-8. <https://doi.org/10.1590/S0101-28002011000200002>
23. Rudnicki T. Preditores de qualidade de vida em pacientes renais crônicos. *Est Psicol* 2007;3:343-51. <https://doi.org/10.1590/S0103-166X2007000300006>
24. Balconi M, Angioletti L, Filippis D, Bossola M. Association between fatigue, motivational measures (BIAS/BAS) and semi-structured psychosocial interview in hemodialytic treatment. *BMC Psychol* 2019;23:49. <https://doi.org/10.1186/s40359-019-0321-0>

25. Zuo M, Tang J, Xiang M, Long Q, Dai J, Hu X. Relationship between fatigue symptoms and subjective and objective indicators in hemodialysis patients. *Inter Urol Nephrol* 2018;7:1329-39. <https://doi.org/10.1007/s11255-018-1871-4>
26. Bossola M, Stasio ED, Marzetti E, Lorenzis KD, Pepe G, Vulpio C. Fatigue is associated with high prevalence and severity of physical and emotional symptoms in patients on chronic hemodialysis. *Inter Urol Nephrol* 2018;7:1341-6. <https://doi.org/10.1007/s11255-018-1875-0>
27. Terra FS, Costa AMDD, Figueiredo ET, Moraes AM, Costa MD, Costa RD. As principais complicações apresentadas pelos pacientes renais crônicos durante as sessões de hemodiálise. *Rev Bras Clín Med* 2010;3:187-92. <http://files.bvs.br/upload/S/1679-1010/2010/v8n3/a001.pdf>
28. Schwartz E, Muniz RM, Burille AZ, Zilmer JGV, Silva DA, Feijó AM, *et al.* As redes de apoio no enfrentamento da doença renal crônica. *Rev Min Enferm* 2009;2:193-201. <https://doi.org/10.33361/RPQ.2019.v.7.n.15.292>
29. Bardak S, Demir S, Aslan E, Turgutalp K, Celickan HD, Dolarslan ME, *et al.* The other side of the coin in renal replacement therapies: the burden on caregivers. *Int Urol Nephrol* 2019;51:343-9. <https://doi.org/10.1007/s11255-018-2029-0>
30. Priego EA, Ruiz AIA, Blanco RG, Montero RC. Análisis de la sobrecarga del cuidador del paciente en diálisis. *Enferm Nefrol* 2018;3:213-24. <https://doi.org/10.4321/s2254-28842018000300002>
31. Mok M, Liu CKM, Lam MF, Kwan LPY, Chan GCW, Ma MKM, *et al.* A longitudinal study on the prevalence and risk factors for depression and anxiety, quality of life, and clinical outcomes in incident peritoneal dialysis patients. *Periton Dial Inter* 2018;39:2-9. <https://doi.org/10.3747/pdi.2017.00168>
32. Pereira BS, Fernandes NS, Melo NP, Abrita R, Grincenkov FRS, Fernandes NMS. Beyond quality of life: a cross sectional study on the mental health of patients with chronic kidney disease undergoing dialysis and their caregivers. *Health Qual Life Outcomes* 2017;74:1-10. <https://doi.org/10.1186/s12955-017-0646-4>
33. Costa FG, Coutinho MPL. Síndrome depressiva: um estudo com pacientes e familiares no contexto da doença renal crônica. *Est Interdiscip Psicol* 2016;;38-55. http://pepsic.bvsalud.org/scielo.php?script=sci_arttext&pid=S2236-64072016000100004
34. Rioux J, Narayanan R, Chan C. Caregiver burden among nocturnal home hemodialysis patients. *Hemodial Int* 2012;16:214-9. <https://doi.org/10.1111/j.1542-4758.2011.00657.x>
35. Arechabala MC, Catoni MI, Palma E, Barrios S. Depression and self-perceived burden of care by hemodialysis patients and their caregivers. *Rev Panam Salud Publica* 2011;30:74-9. <https://doi.org/10.1590/s1020-49892011000700011>
36. Suri RS, Larive B, Grag AX, Hall YN, Pierratos A, Chertow GM, *et al.* Burden on caregivers as perceived by hemodialysis patients in the Frequent Hemodialysis Network (FHN) trials. *Nephrol Health Psychol* 2011;16:520-9. <https://doi.org/10.1093/ndt/gfr007>
37. Ferreira HP, Martins RC, Braga ALF, Garcia ALB. O impacto da doença crônica no cuidador. *Rev Bras Clín Med* 2012;10:278-84. <http://files.bvs.br/upload/S/1679-1010/2012/v10n4/a3045.pdf>
38. Fan SL, Sathick I, McKitty K, Punzalan S. Quality of life of caregivers and patients on peritoneal dialysis. *Nephrol Dial Transplant* 2008;23:1713-9. <https://doi.org/10.1093/ndt/gfm830>
39. Hall R, Luciano A, Pieper C, Colón-Emeric CS. Association of Kidney Disease Quality of Life (KDQOL-36) with mortality and hospitalization in older adults receiving hemodialysis. *BMC Nephrol* 2018;19:2-9. <https://doi.org/10.1186/s12882-017-0801-5>
40. Santos BTU, Araújo STC, Torres DG, Bastos SSF, Azevedo AL, Neves KC. Integralidade do cuidado-permanência na nefrologia: concepções de enfermeiros. *Rev Esc Enferm USP* 2019;53:1-8. <http://doi.org/10.1590/S1980-220X2018043703523>
41. Duteau J. Understanding the lived experience of loss and grieving in persons with end stage renal disease: a human becoming approach. *CANNT J* 2010;20:18-22. <https://pubmed.ncbi.nlm.nih.gov/20642161/>

- 42.Pereira BS, Fernandes NMS. Psicologia e Nefrologia: teoria e prática. Novo Hamburgo: Sinopsys, 2022.
- 43.Kim HJ, Kim DW, Rhee H, Song SH, Park SK, Kim SW, *et al.* Rapid decline in kidney function is associated with rapid deterioration of health-related quality of life in chronic kidney disease. *Nature Sci Rep* 2023;13:1786. <https://doi.org/10.1038/s41598-023-28150-w>
- 44.Shen YC, Chen Y, Huang S, Yao X, Kanwar YS, Zhan M. The Association between Symptoms of Depression and Anxiety, Quality of Life, and Diabetic Kidney Disease among Chinese Adults: A Cross-Sectional Study. *Int J Environ Res Public Health* 2023;20:475. <https://doi.org/10.3390/ijerph20010475>
- 45.Flória I, Kontele I, Grammatikopoulou MG, Sergentanis TN, Vassilakou T. Quality of Life of Hemodialysis Patients in Greece: Associations with Socio-Economic, Anthropometric and Nutritional Factors. *Int J Environ Res Public Health* 2022;19:15389. <https://doi.org/10.3390/ijerph192215389>
- 46.Milić J, Milić Vranješ I, Šantić K, Šantić A, Vuksan-Ćusa Z, Zibar L. Levels of depression and anxiety and the body image of female patients on renal replacement therapy. *Psychiatr Danub* 2022;34:79-85. <https://pubmed.ncbi.nlm.nih.gov/36752246/>
- 47.Sharma R, Sharma SC, Chalise P, Regmee J, Sharma S. Anxiety and Depression among Patients with Chronic Kidney Disease Undergoing Haemodialysis in a Tertiary Care Centre: A Descriptive Cross-sectional Study. *J Nepal Med Assoc* 2022;60:634-7. <https://doi.org/10.31729/jnma.7608>
48. Alshelleh S, Alhourri A, Taifour A, Abu-Hussein B, Alwreikat F, Abdelghani M, *et al.* Prevalence of depression and anxiety with their effect on quality of life in chronic kidney disease patients. *Sci Rep* 2022;12:17627. <https://doi.org/10.1038/s41598-022-21873-2>
- 49.Al Naamani Z, Gormley K, Noble H, Santin O, Al Maqbali M. Fatigue, anxiety, depression and sleep quality in patients undergoing haemodialysis. *Al Naamani et al. BMC Nephrol* 2021;22:157. <https://doi.org/10.1186/s12882-021-02349-3>
- 50.Marcolino JAM, Suzuki FM, Alli LAC, Gozzani JL, Mathias LAST. Medida da Ansiedade e da Depressão em Pacientes no Pré-Operatório. Estudo Comparativo. *Rev Bras Anestesiol* 2007;57:157-66. <https://doi.org/10.1590/S0034-70942007000200004>
- 51.Siqueira MMM. Construção e validação da escala de percepção de suporte social. *Psicol Est* 2008;13:381-8. <https://doi.org/10.1590/S1413-73722008000200021>
- 52.Mota DCF, Pimenta CAM, Fich MI. Pictograma de Fadiga: uma alternativa para avaliação da intensidade e impacto da fadiga. *Rev Esc Enferm USP* 2009;43:1080-7. <https://doi.org/10.1590/S0080-62342009000500012>
- 53.Lipp ME. Manual do Inventário de Sintomas de Estresse para Adultos de Lipp (ISSL). São Paulo: Casa do Psicólogo, 2014.
- 54.Ciconelli RM, Ferraz MB, Santos W, Meinão I, Quaresma MR. Tradução para a língua portuguesa e validação do questionário genérico de avaliação de qualidade de vida SF-36 (Brasil-SF-36). *Rev Bras Reumatol* 1999;39:143-50. <https://pesquisa.bvsalud.org/portal/resource/pt/lil-296502>
- 55.Barreti P. O novo censo Brasileiro deu diálise. *Braz J Nephrol* 2022;44:308-9. <https://doi.org/10.1590/2175-8239JBN-2022-E006pt>
- 56.Samaan F, Gutierrez M, Kirsztajn GM, Sesso RC. Razão oferta/necessidade de consultas médicas, exames de diagnóstico e acompanhamento da doença renal crônica no Sistema Único de Saúde: estudo descritivo, estado de São Paulo, 2019. *Epidemiol Serv Saúde* 2022;31:1-16. <https://doi.org/10.1590/S2237-96222022000200014>
- 57.Ribeiro RC, Oliveira GASA, Ribeiro DF, Bertolin DC, Cesarino CB, Lima LCEQ, *et al.* Caracterização e etiologia da insuficiência renal crônica em unidade de nefrologia do interior do Estado de São Paulo. *Acta Paul Enferm* 2008;21:207-11. <https://doi.org/10.1590/S0103-21002008000500013>
- 58.Aguiar LK, Prado RR, Gazzinelli A, Malta DC. Fatores associados à doença renal crônica: inquérito epidemiológico da Pesquisa Nacional de Saúde. *Rev Bras Epidemiol* 2020;23:E200044. <https://doi.org/10.1590/1980-54972020004>

- 59.Lima AGT. Perfil e experiências de cuidadores de crianças e adolescentes em terapia renal substitutiva. *Braz J Hea* 2020;5:12477-92. <https://doi.org/10.34119/bjhrv3n5-091>
- 60.Costa FG, Coutinho MPL. Síndrome depressiva: um estudo com pacientes e familiares no contexto da doença renal crônica. *Est Interdisc Psicol* 2016;7:38-55. <https://doi.org/10.5433/2236-6407.2016v7n1p38>
- 61.Laguado-Jaimes E. Perfil del cuidador del paciente con Enfermedad Renal Crónica: una revisión de la literatura. *Enferm Nefrol* 2019;22:352-9. <https://doi.org/10.4321/S2254-28842019000400002>
- 62.Thomé EGR, Meyer DEE. Mulheres cuidadoras de homens com doença renal crônica: uma abordagem cultural. *Texto Contexto Enferm* 201;20:503-11. <https://doi.org/10.1590/S0104-07072011000300011>
- 63.Muscat P, Weinman J, Farrugia E, Callus R, Chilcot J. Illness perceptions predict distress in patients with chronic kidney disease. *BMC Psychol* 2021;7:75. <https://doi.org/10.1186/s40359-021-00572-z>
- 64.Ling TW, Khuan L, Baharom A, Arshad MM. Coping Strategies of Patients with End Stage Kidney Disease on Hemodialysis: A Systematic Review. *Nephrol Nurs J* 2021;48:31-48. <https://pubmed.ncbi.nlm.nih.gov/33683842/>
- 65.Eloia SMC, Ximenes AM, Eloia SC, Neto NMG, Barros LM, Caetano JA. Religious coping and hope in chronic kidney disease: a randomized controlled trial. *Rev Esc Enferm USP* 2021;55:e20200368. <https://doi.org/10.1590/1980-220X-REEUSP-2020-0368>
- 66.Fradelos EC. Spiritual Well-Being and Associated Factors in End-Stage Renal Disease. *Sci World J* 2021;30:6636854. <https://doi.org/10.1155/2021/6636854>
- 67.González-Flores CJ, García-García G, Lerma A, Pérez-Grovas H, Meda-Lara R, Guzmán-Saldaña RME, et al. Resilience: A Protective Factor from Depression and Anxiety in Mexican Dialysis Patients. *Int J Environ Res Public Health* 2021;14:11957. <https://doi.org/10.3390/ijerph182211957>
- 68.García-Martínez P, Ballester-Arnal R, Gandhi-Morar K, Castro-Calvo J, Gea-Caballero V, Juárez-Vela R, et al. Perceived Stress in Relation to Quality of Life and Resilience in Patients with Advanced Chronic Kidney Disease Undergoing Hemodialysis. *Int J Environ Res Public Health* 2021;18:536. <https://doi.org/10.3390/ijerph18020536>
- 69.García-Martínez P, Ballester-Arnal R, Gandhi-Morar K, Temprado-Albalat MD, Collado-Boira E, Saus-Ortega C, et al. Factors Associated With Resilience During Long-Term Hemodialysis. *Nurs Res* 2023;72:58-65. <https://doi.org/10.1097/NNR.0000000000000627>
- 70.Kalantar-Zadeh K, Li PK, Tantisattamo E, Kumaraswami L, Liakopoulos V, Lui SF, et al. Living well with kidney disease by patient and care-partner empowerment: kidney health for everyone everywhere. *Clin Exp Nephrol* 2021;25:567-73. <https://doi.org/10.1007/s10157-021-02044-5>
- 71.Sein K, Damery S, Baharani J, Nicholas J, Combes G. Emotional distress and adjustment in patients with end-stage kidney disease: A qualitative exploration of patient experience in four hospital trusts in the West Midlands, UK. *PLoS One* 2020;15:e0241629. <https://doi.org/10.1371/journal.pone.0241629>
- 72.Georgianni G, Polikandrioti M, Alikari V, Vasilopoulos G, Zartaloudi A, Koutelekos I, et al. Factors Affecting Anxiety and Depression in Caregivers of Hemodialysis Patients. *Adv Exp Med Biol* 2021;1337:47-58. https://doi.org/10.1007/978-3-030-78771-4_6
- 73.Moreno V. Familiares de pacientes em hemodiálise: convivendo com condição crônica de saúde. *Rev Rene Fortaleza* 2008;9:49-56. <https://pesquisa.bvsalud.org/porta1/resource/pt/lil-519413>
- 74.Paula ES, Nascimento SC, Rocha SMM. A influência do apoio social para o fortalecimento de famílias com crianças com insuficiência renal crônica. *Rev Lat-Am Enferm* 2008;16:1-8. <https://doi.org/10.1590/S0104-11692008000400007>
- 75.Gonçalves TR, Pawlowski J, Bandeira DR, Piccinini CA. Avaliação de apoio social em estudos brasileiros: aspectos conceituais e instrumentos. *Cienc Saúde Col* 2011;16:1755-69. <https://doi.org/10.1590/S1413-81232011000300012>

- 76.Yıldız I, Kavurmacı M. Comparison of care burden of hemodialysis and kidney transplant patients. *J Parathyroid Dis* 2022;10:e10151. <https://doi.org/10.34172/jpd.2022.10151>
- 77.Cardoso L, Vieira MV, Ricci MAM, Mazza RS. Perspectivas atuais sobre a sobrecarga do cuidador em saúde mental. *Rev Esc Enferm USP* 2012;46:513-7. <https://doi.org/10.1590/S0080-62342012000200033>
- 78.Borges DCS, Furino FO, Barbieri MC, Souza ROD, Alvarenga WA, Dupas G. A rede e apoio social do transplantado renal. *Rev Gaúcha Enferm* 2016;37:e59519. <https://doi.org/10.1590/1983-1447.2016.04.59519>
- 79.Oliveira ABP, Schmidt DB, Amatneeks TM, Santos JC, Cavallet LHR, Michel RB. Qualidade de vida de pacientes em hemodiálise e sua relação com mortalidade, hospitalizações e má adesão ao tratamento. *J Bras Nefrol* 2016;38:411-20. <https://doi.org/10.5935/0101-2800.20160066>
- 80.Rossi F, Fernandes N, Chaoubah A, Bastos K, Qureshi AR, Pécoits-Filho R, *et al.* Fatores associados à qualidade de vida de pacientes incidentes em diálise peritoneal no Brasil (BRAZPD). *J Bras Nefrol* 2011;33:38-44. <https://doi.org/10.1590/S0101-28002011000100005>
- 81.Bartlow B. What, me grieve? Grieving and bereavement in daily dialysis practice. *Hemodial Int* 2006;10(Supl 2):S46-50. <https://doi.org/10.1111/j.1542-4758.2006.00118.x>
- 82.Amaral TB, Tavares CMM. Saúde mental de pessoas convivendo com doença renal crônica em terapia renal substitutiva. *Res Soc Develop* 2022;11:e3711225417. <http://doi.org/10.33448/rsd-v11i2.25417>
- 83.Barberis N, Cernaro V, Costa S, Montalto G, Lucisano S, Larcán R, *et al.* The relationship between coping, emotion regulation, and quality of life of patients on dialysis. *Inter J Psychiatr Med* 2017;52:111-23. <https://doi.org/10.1177/0091217417720893>
- 84.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;19:321. <https://doi.org/10.1186/s12882-018-1120-1>
- 85.Bargiel-matusiewicz A, Stelmachowska P. The positive influence of psychological intervention on the level of anxiety and depression in dialysis patients: A pilot study. *Int J Artif Organs* 2019;42:167-74. <https://doi.org/10.1177/0391398818823765>
- 86.Kim Y. Experience of the waiting area as perceived by haemodialysis patients and family carers. *J Adv Nurse* 2017;74:364-72. <https://doi.org/10.1111/jan.13448>