Original Article

Coping and quality of life in patients on kidney transplant waiting lists

Coping e qualidade de vida em pacientes em lista de espera para transplante renal

Diego Silveira Siqueira[1]
Bartira Ercília Pinheiro da Costa[1]
Ana Elizabeth Prado Lima Figueiredo[1]

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Corresponding author
Diego Silveira Siqueira
Av. Ipiranga, 6690,
90619-900, Porto Alegre, RS, Brazil.
diego.siqueira@factum.edu.br

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Abstract

Objective: To characterize the coping and quality of life profile of patients on kidney transplant waiting lists.

Methods: Cross-sectional study with a quantitative approach, which entailed interviews with patients over 18 years of age, able to read and write, and on a kidney transplant waiting list. Patients waiting for more than one organ were excluded. The results were presented using descriptive statistics - absolute and relative distribution (n - %), as well as central tendency and variability measurements. The data distribution of the continuous variables was analyzed by the Kolmogorov-Smirnov test. In the comparison of the relative scores of the styles and dimensions for quality of life between two independent groups, the Mann-Whitney U test was used. When the continuous variables were compared with the types of treatment (with number of cases over five), the Kruskal-Wallis post-hoc Dunn test was used. The linearity relationship between the scores of the Jalowiec *Coping* Scale (JCS) styles and the SF-36 dimensions was determined through the Spearman correlation coefficient. The data was analyzed using the Statistical Package for the Social Sciences, version 20.0 (SPSS Inc., Chicago, IL, USA, 2008) for Windows. For the statistical decision criteria, a level of significance of 5% was adopted.

Results: Of the total 58 patients, 30 (51.7%) were men, with a mean age of 44.6 (±15.2) years. The coping profile was self-reliant (42) and optimistic (6). The dimensions with the best quality of life were: pain (67.2%), social aspects (66.6) and mental health (65.4). There was a significant correlation ($r<0.333$) between the palliative style and vitality ($r=-0.288$; $p=0.028$) and the palliative style and social aspects ($r=-0.283$; $p=0.031$). There was also a significant correlation between general health status and the emotive ($r=-0.424$; $p=0.025$) and palliative styles ($r=-0.524$; $p=0.004$), as well as between vitality and the palliative style ($r=-0.530$; $p=0.004$). Among men, there was a significant correlation ($0.300<r\leq0.600$) in the comparison between the pain dimension and the confrontational ($r=-0.413$; $p=0.023$) and emotive ($r=-0.370$; $p=0.044$) styles.

Conclusion: The study identified the coping profile of patients on hemodialysis and a kidney transplant waiting list. A self-reliant and optimistic profile was noted among most patients, and there were positive results on the quality of life of this population in relation to improvement in pain, social aspects and mental health. However, quality of life was negatively affected in reference to physical and emotional aspects.

Resumo

Objetivo: Caracterizar o perfil de enfrentamento e qualidade de vida dos pacientes em lista de espera de transplante renal.

Métodos: Estudo transversal, com abordagem quantitativa, foram entrevistados pacientes maiores de 18 anos, alfabetizados e em lista de espera de transplante renal. Foram excluídos os pacientes em espera de mais de um órgão. A apresentação dos resultados ocorreu pela estatística descritiva - distribuição absoluta e relativa (n - %), bem como, pelas medidas de tendência central e de variabilidade, sendo que, o estudo da distribuição de dados das variáveis contínuas ocorreu pelo teste de *Kolmogorov-Smirnov*. Na comparação das pontuações relativas dos estilos e das dimensões para qualidade de vida entre dois grupos independentes foi utilizado o teste de *Mann Whitney* U. Quando as variáveis contínuas foram comparadas aos tipos de tratamentos (com numero de casos superior a 5) foi utilizado o teste de *KruskalWallys-PostHocDunn*. A relação de linearidade entre os escores dos estilos ECJ e as dimensões da SF36 ocorreu pelo coeficiente de correlação de e *Spearman*. Os dados foram analisados no programa *Statistical Package for Social Sciences* versão 20.0 (SPSS Inc., Chicago, IL, USA, 2008) para *Windows*, sendo que, para critérios de decisão estatística adotou-se o nível de significância de 5%.

Resultados: Do total de 58 pacientes, 30 (51,7%) eram do sexo masculino com média de idade de 44,6 (±15,2) anos. O perfil de enfrentamento foi o Autoconfiante (42) e Otimista (6) pacientes. As dimensões com a melhor qualidade de vida foram: a dor (67,2), aspectos sociais (66,6) e saúde mental (65,4). Houve correlação significativa, ($r<0,333$), entre o estilo paliativo e vitalidade ($r=-0,288$; $p=0,028$) e paliativo e aspectos sociais ($r=-0,283$; $p=0,031$). O Estado Geral de Saúde e os estilos Emotivo ($r=-0,424$; $p=0,025$) e Paliativo ($r=-0,524$; $p=0,004$), bem como, entre a Vitalidade e o estilo Paliativo ($r=-0,530$; $p=0,004$) apresentaram correlação significativa. Nos homens houve correlação significativa ($0,300<r\leq0,600$) na comparação da dimensão Dor com os estilos Confrontivo ($r=-0,413$; $p=0,023$) e Emotivo ($r=-0,370$; $p=0,044$).

Conclusão: O estudo identificou o perfil de enfrentamento dos pacientes em hemodiálise e em lista de espera de transplante renal. Destaca-se o perfil *Coping* autoconfiante e otimista na maioria dos pacientes, bem como, o impacto na qualidade de vida dessa população destacando-se resultados positivos em relação à melhoria da Dor, Aspectos sociais e Saúde mental, porém ficou evidente o comprometimento da qualidade de vida no que se refere aos aspectos físicos e emocionais.

[1]Pontifícia Universidade Católica do Rio Grande do Sul, Porto Alegre, RS, Brazil.
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Introduction

Chronic Kidney Disease is characterized by structural or functional changes in the kidneys for more than three months, with health implications, where systemic hypertension and diabetes mellitus are the main risk factors.[1]

Renal replacement therapy is recommended for patients with stage 5 chronic kidney disease. Treatment options are: hemodialysis, peritoneal dialysis, and transplantation.[2] According to the 2014 census of the Brazilian Society of Nephrology, there were an estimated 112,004 patients on dialysis treatment. Of the prevalent patients, 91% were on hemodialysis and 9% on peritoneal dialysis.[3]

Hemodialysis is a treatment that uses high-tech equipment and materials to remove toxic substances and excess fluid from the organism. Average treatment time is four hours per session, three times a week, depending on the patient's clinical status. This treatment has various limitations and restrictions, and causes significant changes in the daily lives of patients, such as physical, sexual, psychological, family and social limitations, which can negatively impact their quality of life.[4]

Kidney transplants are the ideal treatment option and lead to the best quality of life since they totally or partially restore kidney function, freeing the patient from dependency on dialysis.[5]

According to the Brazilian Association of Organ Transplantation, the number of transplants from deceased donors is five times higher than from live donors.[6] Organ transplantation in Brazil is covered by the Brazilian unified health system (SUS) and depends on spontaneous donations from the population..[7] In 2016, there were 5,877 transplants in Brazil, 2,651 of which were kidney transplants. In that same year, Rio Grande do Sul (RS) was the state with the second highest number of kidney transplants, totaling 291.[6]

Placement on a waiting list is the only option for kidney patients without contraindications and who cannot find a donor among family members up to the fourth degree of kinship, such as a nephew/niece. It can also be the spouse or any other person, in which case judicial authorization is required according to Law No. 10211 of March 23, 2001, which regulates the donation of organs and tissues in Brazil from human bodies.[7]

While waiting for a kidney transplant, patients need dialysis, which imposes a heavy burden, limitations and restrictions on the individual and family. Being on a transplant waiting list represents the hope of better quality of life and improved life expectancy. Each person copes with stressful situations differently depending on psychological preparedness, clinical status and family support.[8]

The stress process triggers coping strategies. The definition currently used the most in coping strategy studies involves an individual variable represented by how people normally react to stress, determined by personal factors, situational demands and available resources.[9]

The concept of coping, referred to as "confrontational strategies" in Brazil, has already undergone various modifications and evolved over time, as an increased number of studies on the theme have been done. In the view of some authors, the English term "coping", which does not have an exact translation in Portuguese, should be translated as "dealing with" (*lidar com,* in Portuguese), which is closer to the English term "coping", instead of "confronting" (*enfrentar*, in Portuguese). According to these authors, confronting has an active connotation, of fighting. Using this term in Portuguese would exclude a set of strategies related to avoidance and escape from stressful situations and stimuli, i.e., strategies that do not involve taking direct and active measures against the stressor.[10]

The first coping model to be elaborated was a cognitive model, based on factorial analysis, where coping was divided into two groups: coping focused on emotions and coping focused on the problem. The first involves fantasy and other activities aimed at emotional regulation of the person in relation to the stressful situation. The second deals with a set of efforts to manage, change, resolve, reformulate, or minimize the harmful effects of the situation. However, other studies have identified the existence of other coping strategies, such as: seeking social support, religion and distraction.[11,12]

The Jalowiec Coping Scale (JCS) was initially designed to assess stress and coping in hypertensive patients in emergency units. Since its creation, the instrument has been translated into over 20 languages and applied in various scenarios.[13]

The JCS is an affirmative list, composed of 60 items, whose purpose is to identify coping strategies when there are stressful elements. Respondents mark the questions that identify with their problem at that moment. Based on the analysis of the participants' answers, they are classified into two types of coping, one focused on the problem and the other focused on emotions. There are eight subtypes of coping: confrontational (resolves the problem by fighting it), evasive (detaches emotionally from the problem), optimistic (thinks positively in relation to the problem), fatalistic (thinks negatively in relation to the problem), emotive (expresses emotions related to the problem), palliative (puts the problem into perspective), supportive (uses personal, professional and/or spiritual support to cope with the problem) and self-reliant (seeks to cope with the problem alone). This scale was translated and validated in a study with healthy older people in 2000.[14,15]

Health-related quality of life generally involves the perception of health and the impact of social, psychological and physical aspects on it, which include health-related aspects.[16]

Health-related quality of life assessments have been used to determine the aspects associated with diseases or linked to therapeutic interventions. This type of assessment tends to be multidimensional in nature, even though the emphasis is on symptoms, incapacities or limitations caused by diseases. Various instruments can be used to assess the quality of life of people suffering from chronic kidney disease, such as the Medical Outcomes Study 36-item Short-Form Health Survey (SF-36), the Kidney Disease Quality of Life - Short Form (KDQOL-SF™), the World Health Organization Quality of Life (WHOQOL), or the Quality of Well-Being Scale (QWB).[17-19]

The scale in English was translated and validated into Brazilian Portuguese. The SF-36 is an instrument used to assess quality of life of patients on kidney transplant waiting lists. It has 36 structured questions that yield scores in eight quality of life dimensions: Functional capacity (10 items); Limitations due to physical aspects (4 items); Pain (2 items); General health status (5 items); Vitality (4 items); Social aspects (2 items); Emotional aspects (3 items); Mental health (5 items); and another assessment question that compares current health perception versus one year before. It also evaluates biopsychosocial aspects and is more suitable for monitoring the quality of life of patients on hemodialysis.[20,21]

Studies assessing quality of life in patients suffering from chronic kidney disease unanimously conclude that kidney transplants provide the best quality of life, but there is still controversy over what the second-best treatment option would be. The tendency leans toward home-based therapies, such as peritoneal dialysis.[22,23]

Therefore, the objective of this study was to characterize the coping profile of patients on hemodialysis and a kidney transplant waiting list based on the JCS associated with the SF-36 quality of life.

Methods

This was a cross-sectional study with a quantitative approach, which entailed interviews with patients over 18 years of age, able to read and write, and on the kidney transplant waiting list from Hospital São Lucas of the Pontifical Catholic University of Rio Grande do Sul (HSL/PUCRS). Patients waiting for more than one organ were excluded from the study. The data was collected in the hospital, after a free and informed consent was signed by each patient. The researcher administered the questionnaire with sociodemographic information, whereas the JCS and Quality of Life (SF-36) instruments were self-administered.

To identify the coping style used by the patients for dealing with stressors using the JCS[20], a relative score was used which provides a parameter for considering an individual's efforts within

a copying style.[20] The items that comprise the JCS coping styles[21] are: Confrontational: items from numbers 4, 13, 16, 25, 27, 29, 33, 38, 43 and 45; Evasive items from numbers 7, 10, 14, 18, 20, 21, 28, 35, 40, 48, 55, 56 and 58; Optimistic: items from numbers 2, 5, 30, 32, 39, 47, 49, 50 and 54; Fatalist: items from numbers 9, 12, 23 and 60; Emotive: items from numbers 1, 8, 24, 46 and 51; Palliative: items from numbers 3, 6, 26, 34, 36, 44 and 53; Supportive: items from numbers 11, 15, 17, 42 and 59; Self-reliant: items from numbers 19, 22, 31, 37, 41, 52 and 57.

The relative score was obtained by adding up the number of items marked with an "x", divided by the number of items contained in the subscale, called the middle score, and then dividing the middle score of each subscale by the sum of the total middle scores.[20,24] The highest score among the relative scores is considered the most used coping style for dealing with stressors.

The confrontational and supportive coping styles are classified as a type of coping that focuses on the problem, whereas the other styles (evasive, fatalistic, optimistic, emotive, palliative and self-reliant) focus on emotion.

The SF-36 quality of life assessment form is composed of 11 questions and 36 items that encompass eight components (domains or dimensions), represented by functional capacity (10 items), physical aspects (4 items), pain (2 items), general health status (5 items), vitality (4 items), social aspects (2 items), emotional aspects (3 items), mental health (5 items) and a comparative question on current health perception versus one year before. The individual receives a score in each domain, ranging from 0 to 100, with zero being the worst score and 100 the best.[19]

The results were presented using descriptive statistics-absolute and relative distribution (n-%), as well as central tendency and variability measurements. The data distribution of the continuous variables was analyzed using the Kolmogorov-Smirnov test.

In the comparison of the relative scores of the styles and quality of life dimensions between two independent groups, the Mann-Whitney U test was used. When the continuous variables were compared with the types of treatment (with number of cases over five), the Kruskal-Wallis post-hoc Dunn test was used. The linearity relationship between the scores of the JCS styles and the SF-36 dimensions was determined through the Spearman correlation coefficient. The data was analyzed using the Statistical Package for the Social Sciences, version 20.0 (SPSS Inc., Chicago, IL, USA, 2008) for Windows. For the statistical decision criteria, a level of significance of 5% was adopted.

The study adhered to ethical precepts and was approved by the Research Ethics Committee of PUCRS under Opinion No. CAAE 47843515.3.0000.5336.

Results

The results correspond to a sample of 58 patients with a mean age of 44.6 (±15.2) years, of whom 12.3% (n=7) were over 65 years old. Men accounted for 51.7% (n=30) of the patients. The median of the length of time on dialysis until the time of the interview was 788 days (equivalent to 2.1 years), with a range of 40 to 7,800 days. The most prevalent level of education was incomplete elementary school (29.8%; n=17); 54.4% (n=31) of the patients were married, 37.5% (n=21) had one child, and the most prevalent religion was Catholic (62.5%; n=35). In the information for the JCS relative scores presented in table 1, the self-reliant dimension had the highest mean score (0.455±0.386). The second highest mean was for the optimistic style (0.404±0.351). Both of these styles focus on emotions. The least prevalent style was the emotive, which had the lowest mean (0.263±0.356).

Forty-two patients had profiles that were characterized as self-reliant and optimistic, six as palliative and fatalistic, three as evasive and supportive, and one as confrontational and emotive. Table 2 presents a comparison between the JCS style scores and SF-36 quality of life scores, through the Spear-

Table 1. Central tendency and variability measurement for relative scores from the JCS domains

JCS Styles£	Mean	Standard deviation	Median	Minimum	Maximum
Confrontational	0.320	0.289	0.128	0.000	1.066
Evasive	0.378	0.318	0.146	0.000	1.053
Optimistic	0.404	0.351	0.168	0.000	1.152
Emotive	0.263	0.356	0.114	0.000	2.087
Palliative	0.381	0.344	0.159	0.000	1.135
Supportive	0.333	0.291	0.150	0.000	1.018
Fatalistic	0.296	0.376	0.105	0.000	1.455
Self-reliant	0.455	0.386	0.199	0.000	1.543

£ - Variables with asymmetric distribution (Kolmogorov-Smirnov; p<0.05)

man correlation coefficient. Significant correlations were detected between the palliative style and vitality (r=-0.288; p=0.028), as well as between the palliative style and social aspects (r=-0.283; p=0.031). In two results, the correlation was characterized as weak (r<0.333) and negative, indicating that the higher the palliative style scores the lower the quality of life scores in vitality and social aspects.

Table 2. Spearman correlation coefficient between the JSC styles and the SF-36 quality of life dimensions

JCS Styles	Quality of life SF-36*							
	FC	PA	P	GHS	V	SA	EA	MH
Confrontational	-0.085	-0.205	-0.202	-0.123	-0.171	-0.189	-0.093	0.055
Evasive	-0.061	-0.145	-0.206	-0.060	-0.140	-0.248	-0.051	0.003
Optimistic	-0.007	-0.130	-0.121	-0.156	-0.181	-0.245	-0.092	-0.008
Emotive	-0.097	-0.176	-0.241	-0.124	-0.074	-0.235	-0.088	-0.061
Palliative	-0.117	-0.208	-0.227	-0.158	-0.288	-0.283	-0.177	-0.207
Supportive	-0.046	-0.209	-0.163	-0.082	-0.060	-0.036	0.002	-0.047
Fatalistic	-0.020	-0.204	-0.202	-0.052	-0.215	-0.175	-0.091	-0.194
Self-reliant	-0.096	-0.243	-0.249	-0.058	-0.008	-0.103	-0.038	-0.012

*Significant correlation with a significance level of 5%; FC - Functional Capacity; PA - Physical Aspects; P - Pain; GHS - General Health Status; V - Vitality; SA - Social Aspects; EA - Emotional Aspects; MH - Mental Health

Table 3 presents the means, standard deviations and medians for the relative scores from the JCS domains and the SF-36 scores according to sex. When the sex variable was examined, there was no difference in reference to quality of life on the JCS dimensions.

It was also noted in women that there was a significant negative correlation classified as moderate between general health status and the emotive (r=-0.424; p=0.025) and palliative (r=-0.524; p=0.004) styles, as well as between vitality and the palliative style (r=-0.530; p=0.004).

With respect to correlation in men, there was a negative significance classified as moderate (0.300<r≤0.600) in the comparison between the pain dimension and the confrontational (r=-0.413; p=0.023) and emotive (r=-0.370; p=0.044) styles, indicating that high scores in the pain dimension were correlated to low scores in the confrontational and emotive styles. Another result that was representative was in the comparison between the social aspects dimension and the evasive style (r=-0.440; p=0.015), where high scores in social aspects were correlated with low scores in the evasive style.

Discussion

The sociodemographic characteristics of the patients on dialysis and the kidney transplant waiting list in this study were similar to other studies with patients with kidney diseases. One study with 107 patients on hemodialysis in southern Brazil produced the following results: mean age of 51.1 years and standard deviation of 14.3 years, and in relation to sex, men were predominant (62.2%).[25] Differing from the 2016 census[3], the percentage of patients over 65 years of age was lower than the national mean of 30-35%.[26]

The findings in the present study regarding education, marital status and number of children were similar to another study where most of the participants had completed high school (48.6%) were married or lived in a conjugal relationship (67.7%) and most had children (81.2%).[26]

With respect to religion, Catholicism predominated with 62.5% (n=35). The fact that most of the patients were believers was a positive factor, in terms of helping them cope better with the situations they experience. Religion did not eliminate symptoms of anxiety, but helped reduce them. Religion is an instrument that promotes social integration that not only integrates members of the family. Due to their beliefs and principles, people who practice a religion draw in other people who need to and can share their needs or experiences and recognize that helping others is a way of alleviating their own fears and anxieties.[27]

Table 3. Means, standard deviations and medians for the relative scores of the JCS styles and SF-36 scores according to sex

Instruments	Sex Women (n=28)			Sex Men (n=30)			p§
	Mean	Standard deviation	Median	Mean	Standard deviation	Median	
JCS Styles							
Confrontational	0.345	0.290	0.130	0.297	0.291	0.126	0.269
Evasive	0.391	0.313	0.145	0.366	0.327	0.149	0.932
Optimistic	0.430	0.366	0.174	0.379	0.341	0.167	0.503
Emotive	0.259	0.300	0.118	0.266	0.407	0.106	0.560
Palliative	0.455	0.382	0.170	0.313	0.293	0.149	0.133
Supportive	0.380	0.337	0.142	0.289	0.237	0.150	0.828
Fatalistic	0.278	0.337	0.106	0.313	0.414	0.104	0.969
Self-reliant	0.495	0.388	0.210	0.417	0.388	0.192	0.494
SF-36							
Functional Capacity	60.4	26.9	65.0	64.2	25.1	65.0	0.668
Physical Aspects	20.1	30.1	0.0	21.9	32.7	0.0	0.965
Pain	66.0	29.6	63.0	68.4	25.1	71.5	0.716
General Health Status	54.8	17.6	52.0	53.4	15.9	52.0	0.551
Vitality	59.1	25.1	60.0	55.8	20.0	55.0	0.407
Social Aspects	66.6	26.2	62.0	66.7	24.5	62.0	0.807
Emotional Aspects	37.2	38.9	33.0	35.5	40.1	33.0	0.682
Mental Health	63.3	25.3	60.0	67.5	18.3	66.0	0.543

§ - Mann-Whitney U Test

A study by Souza found that the better the cognitive performance of elderly people, the greater the tendency to use coping strategies focused on the problem.[28] The second highest mean was in the optimism style, which is based on positive thoughts, mental formulations and positive comparisons in relation to the problem. The style that was manifested the least was the emotive. The present study did not examine the coping style separately in patients over 65 years of age, but age was inversely associated with the emotive and fatalistic styles, i.e., the older the patient, the more fatalistic and emotive the person becomes.

This data is compatible with the results from a systematic literature review on the coping methods of people on hemodialysis treatment, where patients preferred to use strategies that focused on the problem.[29] However, the authors of this study suggested that this was due to a difficulty of these patients in coping with changes in the feelings they were experiencing. Therefore, they chose to use less the strategy focusing on emotions.

Another study also found that the optimistic style was the most prevalent, followed by the fatalistic and self-reliant styles, unlike the present study, where the self-reliant was detected the most. It also found a difference between styles and therapies, where the palliative style was more frequent for patients on hemodialysis. However, for those on peritoneal dialysis, the optimistic style was more common.[30]

A study with patients on peritoneal dialysis found a higher prevalence of the optimistic style, followed by self-reliant,[30] similar to the results of the present study where self-reliant was followed by optimistic, in both focuses and emotion.

Determining the coping profile of patients is essential and may serve to guide strategies to empower these patients by the professional patient support network that emerges within this context of struggle, but also of fear and emotional destabilization. The coping profile helps diagnose the physical and psychological situation of patients and provides direction for quality patient care planning, in order to achieve better results.

In the questions related to SF-36 quality of life, the dimensions where the participants had better quality of life were pain, social aspects and mental health. The dimensions that most affected quality of life were physical and emotional aspects.

Another study compared pre- and post-kidney transplant quality of life and identified coping strategies used after the transplant. Seventeen patients participated, who responded to the SF-36 Quality of

Life Inventory and to the Coping Inventory. There was no significant difference between the quality of life assessments in the pre- and post-transplant periods for the variables investigated by the SF-36. The main concerns pointed out were side-effects of the drugs, medical consultations, body image changes and length of hospital stay.

A challenge of this study was that the nurses' work was focused on the more fragile aspects of the patients when they prepared the personalized and holistic care plans for patients under their care. In relation to the work of nurses, studies of this sort can help enhance the nursing care given to patients and greatly assist the practices of these professionals when they work with chronic kidney patients.

Conclusion

The present study identified the coping profiles of patients on hemodialysis and kidney transplant waiting lists. A self-reliant and optimistic profile was noted among most patients. The results in relation to the impact on the quality of life of this population were positive with respect to improvement in pain, social aspects and mental health. However, quality of life was negatively affected in reference to physical and emotional aspects.

Collaborations

Siqueira DS, Costa BEP and Figueiredo AEPL contributed to the project design, relevant critical review of the intellectual content, interpretation of the data, and approval of the final version for publication.

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