

## Association between self-care and quality of life in chronic kidney disease patients

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### ABSTRACT

Our study assessed the capacity for self-care and the association with quality of life of people living with Chronic Kidney Disease. We performed a cross-sectional and correlational study. One hundred individuals in hemodialytic treatment in a substitutive kidney therapy unit in the inner state of São Paulo composed the sample. We collected data through personal interview, using a questionnaire for sociodemographic characteristics, the Appraisal of Self-Care Agency Scale – Revised (ASAS-R) and, the Kidney Disease and Quality of Life Short – Form (KDQOL-SF). The mean ASAS-R score was 60.64 ( $\pm 8.24$ ) indicating good self-care capacity. We found a positive moderate and statistically significant relationship between the capacity for self-care and the KDQOL-SF domains: symptoms/problems, cognitive function, physical function, emotional wellbeing and energy/fatigue. We concluded that self-care is related to the quality of life in hemodialytic patients with chronic kidney disease.

**Descriptors:** Self Care; Quality of Life; Renal Dialysis; Renal Insufficiency, Chronic.

### INTRODUCTION

Chronic non-communicable diseases (CNCDs) are a growing public health problem, with high levels of mortality and disability around the world<sup>(1)</sup>. Within the CNCDs, there is the Chronic Kidney Disease (CKD), characterized by abnormality of the structure and/or function of kidneys for more than three months with health implications<sup>(2)</sup>. According to the census of the Brazilian Nephrology Society, in 2011 about 91,300 patients were on dialysis in Brazil, and the estimated number of patients who started treatment in 2010 was 18,972. Most patients with CKD in renal replacement therapy perform hemodialysis (91.6%) and only 8.4% the peritoneal dialysis<sup>(3)</sup>.

Hemodialysis is a treatment that interferes with the individual's routine, imposing limitations that

affect biological, psychological and social aspects. With that, there is a rupture in the previous lifestyle, creating the need to adapt to the new condition in which the patient is<sup>(4-5)</sup>. It is necessary for the family and the health team to stimulate the individual's capacities, abilities, and potentials, so there is an adequacy of treatment and a new lifestyle<sup>(5)</sup>.

Chronic conditions, overall CKD requires continuous and permanent self-care management, besides lifestyle and behavior changes, to prevent aggravations and quality of life improvement<sup>(1)</sup>. The fact that CKD is a disease demands more discipline, self-care actions, to obtain a better quality of life<sup>(6)</sup>.

Self-care has been an alternative to stimulate individuals with chronic disease diagnoses to actively participate in the treatment, contributing to the increase in their responsibilities in assistance results<sup>(7)</sup>.

Our study considers self-care as "the individual's capacity to perform or practice activities for his benefits, to keep life, health and wellbeing"<sup>(8)</sup>. The person is competent to perform self-care, even when there is the capacity to differ factors that should be controlled, to decide what can and should be done, to plan the treatment and to develop self-care actions<sup>(8)</sup>.

The CKD patient who starts the hemodialytic treatment experiences routine changes. All limitations result in problems, as anxiety before and during treatment, significant autonomy loss, difficulty in dealing with the disease, lack of family support that can harm psychological and physical health<sup>(9)</sup>. Thus, to stimulate self-care actions in CKD patients favors the autonomy and quality of life maintenance during all hemodialytic treatment<sup>(10)</sup>.

The World Health Organization (WHO) considers the health-related quality of life (HRQoL) an important factor that addresses aspects related to health perception, physical, social and psychological functions, being an important health and wellbeing indicator for CKD patients<sup>(11)</sup>.

Considering the negative quality of life impact on self-care actions, we believe that our study will contribute to the creation of improvement strategies and maintenance of the assistance provided to CKD patients, aiming to stimulate self-care actions, and to obtain higher adherence and participation of patients and their families in the therapeutic process<sup>(12)</sup>.

The nursing role is important, integrating the health promotion team to re-establish the patient's health, as well as, to implement assistance and educational practices, bringing not only to the patient but the family, guidance that value the act to perform and to keep actions and activities for self-care<sup>(13)</sup>.

Therefore, our objective was to assess the capacity for self-care of people with chronic kidney disease in hemodialysis and to verify its relationship with quality of life.

## METHOD

We conducted a cross-sectional, correlational study and quantitative study, developed in a substitutive kidney therapy unit in the inner São Paulo state.

We selected the sample from 165 individuals attended by the substitutive kidney therapy unit during the data collection. From those, 145 were receiving hemodialysis treatment and 20, by peritoneal dialysis.

We invited all individuals in hemodialytic treatment to participate in the study, but there were refusals, deaths and in some cases, patients did not present good clinical condition. Thus, 100 participants composed the sample, who met the following eligibility criteria: to accept participating in the study, to be 18 years or older, to have a terminal CKD diagnostic, that is, in hemodialytic treatment. If according to take part in the study, all participants signed the Free and Informed Consent Term.

For the data collection, we used a questionnaire with socio-demographic characteristics, the Appraisal of Self-Care Agency Scale – Revised (ASAS-R) and the Kidney Disease and Quality of Life Short-Form (KDQOL-SF).

A group of American and Dutch academics of the Conference Group in Nursing Development (NDCG) developed the Appraisal of Self-Care Agency Scale. It has 24 items and five Likert-type response options, intended to verify health promoting behaviors<sup>(14)</sup>. The identification of adjustments in this instrument was pointed and analyzed, resulting in the ASAS-R, with the exclusion of nine items and the description of three factors (1- To have the capacity for self-care, 2- Development of capacity for self-care and 3-Lack of capacity for self-care)<sup>(15)</sup>. The scale was translated, adapted and validated to the Brazilian context, in people with diabetes mellitus in 2014<sup>(7)</sup>. Its objective is to verify the level of self-care management, regarding its operability. Fifteen questions compose the scale and the grading through a Likert-type scale range from 1 (Totally disagree) to 5 (Totally agree). Four questions refer to negative aspects, and the score should be inversed in the data analysis. The score ranges from 15 to 75 points, thus the higher scoring, the greater operated self-care capacity<sup>(7)</sup>.

The Working Group developed the KDQOL-SF in 1997, and it was validated in the Brazilian context in 2005<sup>(16)</sup>. It is a particular instrument that assesses HRQoL in the CKD context. It has 80 items, divided into 19 dimensions separately analyzed. There is no unique global assessment value of the HRQoL, but there are scores for each dimension. This analysis allows identifying real health-related issues of patients and verifying the impact in the quality of life. The final scoring of each dimension varies from zero to 100, and the higher scoring reflects improved quality of life<sup>(16)</sup>.

We applied the referred instruments before the hemodialysis session, or when not possible, in the first two hours of treatment. Considering the eventuality of few participants who had visual problems and/or low instructional level, we applied the instruments through an individual interview during 30 to 40 min. We collected data during June to August of 2014. Two students with previous specific training applied the assessment protocol.

The data were entered into a Microsoft Excel spreadsheet and analyzed using the Statistical Package for Social Sciences (SPSS for Windows), version 22.0. For the descriptive data analysis, we calculated means, minimum and maximum, standard deviation values, besides variation and frequency. We used the Cronbach's alpha ( $\alpha$ ) to verify the internal consistency of ASAS-R. We used the Kolmogorov-Smirnov test to verify data adherence to normality and the Person's correlation coefficient to analyze the relationship between ASAS-R score and the KDQOL-SF domains. In this study, the magnitude of correlations was classified

as<sup>(17)</sup>: weak (<0.3); moderate (0.3 to 0.59), strong (0.6 to 0.9) and perfect (1.0)<sup>(18)</sup>.

The study development integrally attended the Resolution 466/2012. The study was approved by the Ethics in Research with Human Beings Committee from Universidade Federal de São Carlos (Protocol nº 509.241/2014).

## RESULTS

From the 100 participants, there was a male predominance (66.0%), the mean age was 53.2 ( $\pm 14.72$ ) years, being 60.0% between 22 and 59 years and, 40% being 60 to 79 years. The majority had a stable partner (74.0%). The average education time was 7.41 ( $\pm 4.33$ ) years, and incomplete elementary school was prevalent (46.0%). The average monthly income was R\$869.73 ( $\pm 1085.83$ ) (Table 1).

**Table 1:** Distribution of sociodemographic variables of CKD patients on hemodialysis. São Carlos, SP, Brazil, 2016.

Variable	Mean ( $\pm$ SD)	Median	Observed Variation	Category distribution	N	%
Gender	--	--	--	Male	66	66.0
				Female	34	34.0
Age (in years)	53.25 ( $\pm 14.72$ )	55.0	22-79	22 to 59	60	60.0
				60 to 79	40	40.0
Marital status	--	--	--	With partner	74	74.0
				Without partner	26	26.0
Education	7.41 ( $\pm 4.33$ )	8.0	0-21	Illiterate	3	3.0
				1 to 4 years	46	46.0
				5 to 9 years	21	21.0
Per capita monthly income R\$	869.73 ( $\pm 1085.83$ )	724.0	90-10.000.00	10 years or more	30	30.0
				Up to 1 MW	58	58.0
				1.1 to 3 MW	38	38.0
				3.1 MW or more	4	4.0

We present the results of the self-care capacity assessment in Table 2. The mean score of the whole scale was 60.64 ( $\pm 8.24$ ). Within the factors assessed by the ASAS-R, factor 1 – To have capacity for self-care, presented a mean of 25.25 ( $\pm 3.45$ ), factor 2 – Development of capacity for self-care, showed a mean of 20.62 ( $\pm 3.03$ ) and, factor 3 – Lack of capacity for self-care, presented a mean of 11.45 ( $\pm 2.35$ ) (Table 2).

**Table 2:** Descriptive statistics of ASAS-R scores applied to 100 CKD patients on hemodialysis. São Carlos, SP, Brazil, 2016.

Variable	Mean (SD $\pm$ )	Median	Variation	Cronbach's alpha
Total ASAS-R	60.64 ( $\pm 8.24$ )	59.0	35-75	0.86
Having power	25.25 ( $\pm 3.45$ )	24.0	14-30	0.85
Developing power	20.62 ( $\pm 3.03$ )	20.0	10-25	0.68
Lacking power	11.45 ( $\pm 2.35$ )	11.0	06-15	0.76

The correlation between capacity for self-care and the HRQoL of people with CKD in hemodialysis treatment was positive, of moderate magnitude, with statistical significance between ASAS-R and KDQOL-SF, in the domains: symptoms/problems ( $r=0.328$ ;  $p=0.001$ ), cognitive function ( $r=0.401$ ;  $p<0.001$ ), physical function ( $r=0.375$ ;  $p<0.001$ ), emotional wellbeing ( $r=0.313$ ;  $p=0.002$ ) and energy/fatigue ( $r=0.333$ ;  $p=0.001$ ) (Table 3).

In Table 3, we observed weak correlations, statistically significant between ASAS-R and the following KDQOL-SF domains: Kidney Disease effects ( $r=0.274$ ;  $p= 0.006$ ), Social interaction quality ( $r=0.268$ ;  $p= 0.007$ ), Sleep ( $r=0.087$ ;  $p=0.562$ ), Pain ( $r=0.212$ ;  $p= 0.034$ ), General health ( $r=0.260$ ;  $p= 0.009$ ) and Social Function ( $r=0.236$ ;  $p= 0.018$ ).

**Table 3:** Person's correlation Coefficient between scores of the ASAS-R and KDQOL-SP domains applied to CKD patients in hemodialysis. São Carlos, SP, Brasil, 2016.

Dimensions	ASAS-R	
	r	p-valor
Symptoms/problems	<b>0.328</b>	<b>0.001</b>
Kidney Disease effects	<b>0.274</b>	<b>0.006</b>
Kidney Disease load	0.176	0.080
Work situation	0.018	0.861
Cognitive function	<b>0.401</b>	<b>&lt; 0.001</b>
Social interaction quality	<b>0.268</b>	<b>0.007</b>
Sexual function	0.087	0.562
Sleep	<b>0.197</b>	<b>0.049</b>
Social support	0.144	0.154
Incentive from the dialysis team	0.028	0.780
Patient satisfaction	0.025	0.802
Physical functioning	<b>0.375</b>	<b>&lt; 0.001</b>
Physical function	0.115	0.255
Pain	<b>0.212</b>	<b>0.034</b>
General health	<b>0.260</b>	<b>0.009</b>
Emotional wellbeing	<b>0.313</b>	<b>0.002</b>
Emotional function	0.124	0.219
Social function	<b>0.236</b>	<b>0.018</b>
Energy/Fatigue	<b>0.333</b>	<b>0.001</b>

## DISCUSSION

We can describe the study sample as predominantly male, of young adults and with a stable partner and, incomplete middle school. The aspects described corroborate with findings in studies with CKD patients in dialysis<sup>(19-20)</sup>.

About capacity for self-care assessed with ASAS-R, the mean score was 60.64 ( $\pm 8.24$ ). It is important to note that it can range from 15 to 75 points, the higher scoring, the greater capacity for self-care.

In the literature search for studies using ASAS-R to measure self-care level, we found a study<sup>(6)</sup> that adapted, translated and validated the ASAS-R scale for the Brazilian context, in patients with diabetes mellitus type 2, conducted in Ribeirão Preto/ SP. Within the cited results, they found a mean score of 56.8 ( $\pm 0.48$ ) in the scale application, indicating a good capacity for self-care, corroborating with data from our study, despite the different population.

In another study<sup>(21)</sup> with 627 individuals from 17 Brazilian states, the level of capacity for self-care assessed with ASAS-R presented a significant correlation with age, educational level and, income. In a subsample ( $n=134$ ) composed of chronic disease patients, they found that the higher the capacity for self-care, the lower the negative disease impact in their daily lives. They did not provide mean values of the total ASAS-R score, once the study aimed to present the psychometric properties of the Brazilian version of ASAS-R, not allowing comparison with our data.

It is important to highlight that we did not find studies using the ASAS-R scale in CKD patients on

dialysis. However, few studies address the self-care theme<sup>(22-24)</sup>.

In a study<sup>(22)</sup> conducted in Bogotá, to assess the level of operability of self-care capacity through ASAS-A (the original version of ASAS-R) in individuals doing peritoneal dialysis, there was a mean of 78.7 points in the total ASAS-A. Of the participants, 72.4% classified themselves as in the high range of self-care capacity, demonstrating similarity with data from our study, which presented good self-care capacity.

In a study<sup>(23)</sup> conducted in Rio Grande do Sul, aimed to know self-care practices used by CKD patients submitted to peritoneal dialysis, through a script with guiding questions, as: “What do you do to take care of yourself?” “What are the care that you take with food and liquid ingestion?” “How are your sleep and your resting” “How do you do your dialysis?”. They identified that nine participants performed self-care related to the disease (eating, fluid ingestion, sleep, resting, leisure and self-esteem), regarding the dialysis (catheter and procedure). Besides, they concluded that patients received guidance and they were stimulated to perform self-care in each nursing consultation. Although the study<sup>(23)</sup> did not use the same scale as us to allow data comparison, it is important to consider that patients also performed self-care, once the results indicated the majority as having adequate capacity for self-care.

A study<sup>(24)</sup> with 214 patients of many Dialysis Centers in São José do Rio Preto – SP verified the association of the functional independence, through an instrument Functional Independence Measure (FIM), self-care capacity using ASAS-A and, sociodemographic and clinical variables in CKD patients receiving hemodialytic treatment. Authors identified satisfactory results for functional independence (mean = 118.38) and capacity for self-care (mean = 94.53), corroborating with our study. Besides, the referred study allowed identifying variables as gender, age, comorbidities and complications related to the dialytic treatment as being harmful factors for functional independence and capacity for self-care. Also, at the measure that age increased, the functional independence and the capacity for self-care capacity decreased. Also, more comorbidities are related to lower independence and a lower capacity for self-care.

In the search for studies addressing the self-care relationship with HRQoL, we found only one study<sup>(25)</sup> that assessed 43 individuals through a form to evaluate self-care needs and KDQOL-SF. The results indicated the need of nursing guidance for self-care related to physical health issues related to nutritional therapy, fluid ingestion, hemodialysis complications, anticoagulation and, physical activity practice. About emotional function, there was an association of groups and leisure activities and for physical function and, disease overload with physical activity practice. The authors also affirmed that at the measure that the patient reaches autonomy and independence in actions for self-care, the dimensions affected by KDQOL-SF improved as emotional issues, social support, effects of renal disease.

The majority of studies<sup>(21-25)</sup> had patients signaling and suggesting the relevance of conducting actions for self-care. As the pathology itself, demands more attention, restrictions, and knowledge, making the CKD patients perform more daily actions for their care and benefit, aiming to keep health, wellbeing, and control of their treatment, searching for quality of life.

## CONCLUSION

We concluded that individuals with chronic kidney disease in hemodialytic treatment present a good level of capacity for self-care. Also, there is a positive and directly proportional correlation between self-care and HRQoL.

We expect this study to positively contribute to the construction of strategies for maintenance, implementation, and assistance provided to chronic renal patients. Once changes in some HRQoL domains identified in our study such as symptoms/problems, cognitive functions, quality of social interaction, sleep, social function, within others, can be worked by the patient, family, and team.

Some strategies can contribute to improving the quality of life affected domains, as ludic activities during hemodialysis sessions to improve cognitive functions, the strengthening of the social interaction quality in the treatment environment involving the whole team, guidance about sleep quality, basic information to patients, within other strategies. They minimize the disease impact, improve actions for self-care, as well as, contribute to the quality of life improvement.

This study limitation relates to the cross-sectional design that impedes the identification of temporal precedence of studied factors, compromising the evidence of cause-effect relationships.

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