Esc Anna Nery 2021;25(4):e20200486

Level of activation and quality of life related to the health of people in hemodialysis

Nível de ativação e qualidade de vida relacionada à saúde de pessoas em hemodiálise

Nivel de activación y la calidad de vida relacionada com la salud de personas en hemodiálisis

Denise Rocha Raimundo Leone[1]
Gabriela Amorim Pereira[1]
Arison Cristian de Paula Silva[2]
Aline Silva de Aguiar[3]

1. Universidade Federal de Juiz de Fora, Faculdade de Medicina Curso de Doutorado em Saúde Coletiva, Programa de Pós-Graduação Stricto Sensu em Saúde Coletiva. Juiz de Fora, MG, Brasil.

2. Universidade do Estado do Rio de Janeiro, Faculdade de Enfermagem, Residência de Enfermagem em Nefrologia. Rio de Janeiro, RJ, Brasil.

3. Universidade Federal de Juiz de Fora, Departamento de Nutrição do Instituto de Ciências Biológicas. Juiz de Fora, MG, Brasil.

Abstract

Objective: to associate the level of activation with the health-related quality of life of people undergoing hemodialysis. **Method:** a quantitative, cross-sectional and correlational study with 162 people on hemodialysis treatment. Data was collected by applying questionnaires for sociodemographic, socioeconomic and clinical characterization of the Kidney Disease Quality of Life Short Form and the Patient Activation Measure scale. Secondary data were collected from medical records. For data analysis, descriptive statistics and logistic regression were used. **Results:** hemodialysis patient activation was positively associated with the domains symptoms, physical functioning, general health, emotional well-being, energy/fatigue and the mental component of health-related quality of life. **Conclusion and implication for the practice:** since activation is related to health-related quality of life, in care practice, this metric should be considered when implementing measures to increase the health-related quality of life of people on hemodialysis.

Keywords: Self-management; Self-care; Patient Participation; Hemodialysis; Quality of Life

Resumo

Objetivo: associar o nível de ativação com a qualidade de vida relacionada à saúde de pessoas que realizam o tratamento hemodialítico. **Método:** estudo quantitativo, transversal e correlacional com 162 pessoas em tratamento hemodialítico. Os dados foram coletados por meio da aplicação de questionários para a caracterização sociodemográfica, socioeconômica e clínica do *Kidney Disease Quality of Life Short Form* e da escala *Patient Activation Measure.* Os dados secundários foram coletados por meio do prontuário médico. Para a análise dos dados, utilizaram-se a estatística descritiva e a regressão logística. **Resultados:** a ativação do paciente em hemodiálise associou-se positivamente com os domínios sintomas, funcionamento físico, saúde geral, bem-estar emocional, energia/fadiga e o componente mental da qualidade de vida relacionada à saúde. **Conclusão e implicação para a prática:** como a ativação apresenta relação com a qualidade de vida relacionada à saúde, na prática assistencial, essa métrica deve ser considerada ao implementar medidas que visem a aumentar a qualidade de vida relacionada à saúde das pessoas em hemodiálise.

Palavras-chave: Autogestão; Autocuidado; Participação do Paciente; Hemodiálise; Qualidade de Vida.

Resumen

Objetivo: asociar el nivel de activación con la calidad de vida relacionada con la salud de las personas en hemodiálisis. **Método:** estudio cuantitativo, transversal y correlacional con 162 personas en hemodiálisis. Los datos se recolectaron mediante la aplicación de cuestionarios para la caracterización sociodemográfica, socioeconómica y clínica del *Kidney Disease Quality of Life Short Form* y la escala *Patient Activation Measure*. Los datos secundarios se recopilaron a través de historias clínicas. Para el análisis de los datos se utilizó la estadística descriptiva y la regresión logística. **Resultados:** la activación del paciente en hemodiálisis se asoció positivamente con los dominios síntomas, funcionamiento físico, salud general, bienestar emocional, energía / fatiga y el componente mental de la calidad de vida relacionada con la salud. **Conclusión e implicación para la práctica:** dado que la activación presenta una relación con la calidad de vida relacionada con la salud, en la práctica asistencial esta métrica debe ser considerada a la hora de implementar medidas dirigidas a incrementar la calidad de vida relacionada con la salud de las personas en hemodiálisis.

Palabras clave: Autogestión; Autocuidado; Participación del paciente; Hemodiálisis; Calidad de vida.

Corresponding author:
Denise Rocha Raimundo Leone.
E-mail: de_rocha@ymail.com.

Submitted on 12/10/2020.
Accepted on 02/09/2021.

DOI:https://doi.org/10.1590/2177-9465-EAN-2020-0486

INTRODUCTION

Hemodialysis (HD) is the most widely used type of renal clearance globally. In Brazil, it was estimated that in 2018, there were 123,187 people on hemodialysis treatment, which corresponds to 92.3% of patients on chronic dialysis.[1] When considering the entire Latin American region, HD is the method of Renal Replacement Therapy (RRT) performed by 75% of patients with end-stage Chronic Kidney Disease (CKD).[2] In the United States, HD was the treatment of 62.7% of people with CKD in the year 2017[3] and in the UK, more than 25,000 people undergo this treatment.[4]

Although HD provides survival of the person with terminal CKD, patients undergoing this treatment report numerous difficulties, among them, the management of CKD symptoms, lifestyle changes arising from the need to travel to the dialysis center, food and water restrictions, the impairment of work activities, physical activities and leisure. These factors interfere in the daily life of HD patients and, consequently, in their Health-Related Quality of Life (HRQOL).[5-7]

In this context, knowing the factors that are associated with the HRQOL of patients on hemodialysis is important, because measuring HRQOL defines the burden of disease, injuries and/or disability for individuals,[8] besides reflecting how the patient copes and what are the implications of the disease and its treatment.[9] In addition, it helps in directing the health professional's actions regarding the variables that need to be stimulated or changed in order to obtain a better HRQOL.

There is evidence that people on HD have worse HRQOL when compared to chronic kidney disease patients who are on another method of RRT for CKD.[10,11] And that greater activation of the chronically ill patient is related to better HRQOL.[12]

Patient activation refers to the patient's ability and willingness to effectively self-manage their health and is subdivided into four levels that consider people's knowledge, skills, and motivation with their health care.[13] Thus, activating adults with chronic non-communicable diseases for patient participation in self-management activities is essential for improving overall health and HRQOL.[14]

In a systematic review that identified, through 36 articles, the variables that most influenced the HRQOL of people on renal dialysis, the variable activation was not used.[15] In addition, studies associating patient activation with HRQOL in people with CKD are limited[16,17] and, when considering people on hemodialysis treatment, are even more restricted.[17] In this sense, little is known about the relationship between activation of HD patients and their HRQOL.

And when considering that activation is positively related to better self-reported health of patients in HD[17] and to a lower symptom burden of patients in all stages of CKD, including those on dialysis,[4] it may be a factor that interferes with HRQOL.[4,17] In this sense, the question that guided this study was: "What is the association between the level of activation and HRQOL of people on hemodialysis? It is hypothesized that a higher level of activation is favorable to a better HRQOL. Thus, the objective was to associate the level of activation with HRQOL of people undergoing hemodialysis treatment.

METHOD

Quantitative, cross-sectional and correlational study conducted in a hemodialysis service located in a municipality of Zona da Mata Mineira, in the state of Minas Gerais, Brazil. The service has the capacity to care for 240 patients and works in three shifts, the first from six to ten o'clock, the second from 11 am to 3 pm and the third from 4 pm to 8 pm.

All 221 patients who underwent HD were invited to participate in the study, however, after applying the eligibility criteria, which were being over 18 years, lucid and oriented, expressing themselves through verbal language and being in HD for a period exceeding three months, as reported by nurses of the HD service, and the exclusion criteria, which were being hospitalized, being in transit, that is, temporarily performing hemodialysis treatment in another dialysis service due to travel, or being transplanted during the data collection period, the study sample consisted of 162 patients (response rate: 73,3%).

Of the 59 people who were excluded, 26 did not have the cognitive capacity to answer the interviews, 19 refused to participate, four were hospitalized, two were in transit, two transplanted, and six died.

Data collection occurred between the months of January and April 2019. The participants were recruited during the period when they were undergoing HD. After accepting to participate in the research and signing the Free and Informed Consent Term (FICT), we collected primary data through a structured interview and secondary data through analysis of medical records.

As an instrument for data collection, a structured questionnaire was used for sociodemographic and clinical evaluation, which contained questions related to age, skin color, education, income, marital status, occupation, need for caregiver to perform the Activities of Daily Living (ADL), smoking habit, alcoholism, time of HD, underlying disease, type of vascular access, performance of another type of RRT, number of comorbidities, presence of residual renal diuresis, continuous use of medication, among others.

For the socioeconomic evaluation of the participants, we applied the questionnaire of socioeconomic and family classification of the Brazilian Association of Companies and Research (APEP), which classifies the households into six strata, A, B1, B2, C1, C2, D-E, by measuring the comfort items that people have in their homes, the education of the head of the household, the type of sidewalk of the street where the participant's residence is located and the source of water that supplies the household.[18]

HRQOL was measured by the Kidney Disease Quality of Life Short Form (KDQOL-SF). This is a quality of life assessment instrument specific for people on dialysis treatment. It consists of 24 questions that encompass 80 items related to kidney disease, the effects of kidney disease on quality of life, the burden of kidney disease, work status, cognitive function, quality of social interaction, physical and mental health, and overall health of the

individual. To obtain the result, the data for each dimension is converted into scores ranging from zero to 100, where the closer to 100, the better the quality of life.[19-20]

Patient activation was assessed by means of the 13-item Patient Activation Measure® (PAM-13®), adapted and validated for use in Brazil,[21] which measures the individual's knowledge, skill, and confidence in self-management. It is a Likert scale with 13 questions and five response options. The points obtained with the application of the scale are converted into the activation score, which is between zero and 100 points, and the closer to 100, the more activated the patient is.[13,22-23]

According to the activation score, the patient is classified into four levels. In level 1 (score between 0 - 47.0), patients do not understand the importance of their role in self-management of health; in level 2 (activation score between 47.1 - 55.1), the individual lacks the self-confidence and knowledge to act; at level 3 (PAM -13 between 55.2 - 72.4), patients engage in the health behaviors that are recommended, and at level 4 (activation between 72.5 - 100), people are proactive about their health, and have many health behaviors.[22]

Secondary data, concerning hemoglobin and KTV values, were collected from the participants' medical records and used as adjustment factors in the data analysis.

Statistical analysis of the data was done using the Statistical Package for the Social Science SPSS®, version 23.0, and STATA, version 13.0 software. A statistical significance of 5% was adopted. For the analysis of socio-demographic and clinical characteristics, descriptive statistics were used; the quantitative variables were presented by median and interquartile range, since they had asymmetric distribution, and the categorical variables, in relative and absolute values.

To evaluate the relationship between activation and HRQL, logistic regression was applied. Participants with scores above the 50th percentile in each of the KDQOL-SF domains were considered to have a higher HRQOL. To this end, we estimated the Odds Ratio (OR) of greater QOL according to the independent variable, which was the level of activation.

At first, simple logistic regression was performed for all HRQOL domains and, subsequently, for the domains in which the prevalence ratio was less than 0.05 significance, adjustments were made for possible confounding factors. The first adjustment was made for sex and age and the second for sex, age, and time on hemodialysis, number of comorbidities, hemoglobin, and KTV. We chose to use these adjustment variables because there is evidence that they may be related to HRQOL.[24] For the OR effect measure, a 95% Confidence Interval (95% CI) was calculated.

All ethical aspects involving research with human beings were observed, and only after approval by the Research Ethics Committee of number 3,089,035 and CAAE: 02592418.4.0000.5147, which occurred in December 2018, data collection began.

RESULTS

Of the 162 study participants, most (62.9%) were men, aged 60 years or older (53%), self-declared black or mulatto (61.7%), and had incomplete elementary school education or were illiterate (55%). There was a predominance of people who did not have a partner (50.6%), who did not live alone (83.9%) and were beneficiaries of the National Institute of Social Security (INSS) (85.2%).

As for personal income, 30.3% of the interviewees received three or more minimum wages. Regarding the household classification, there was a preponderance of households classified as C2 (25.3%). Most interviewees did not need a companion to go to the HD service (76%) and did not need a caregiver to help and/or perform the ADLs (88.4%).

Regarding the level of activation, 23.5% of the participants were classified as level 1 of activation; 29%, level 2; 18%, level 3, and 29%, level 4. The sociodemographic characterization of the interviewees, according to the level of activation, is described in Table 1.

Regarding the clinical variables, hypertension predominated as the underlying disease for CKD, which was diagnosed in 40.3% of participants. Moreover, 50.6% had a comorbidity, 72.7% had been using HD for less than five years, 61.9% used the arteriovenous fistula as vascular access, 92% had not previously undergone another type of renal replacement therapy, 75.3% had residual renal diuresis, 91.4% used continuous medication, 90.1% reported not being smokers, and 84.6% reported not being alcoholics.

Regarding laboratory tests, with the exception of hemoglobin, whose 61.1% of HD patients had inadequate serum levels, in all other electrolytes, there was a predominance of adequate serum levels, being 50.5% for potassium and phosphorus, 75.9% for calcium and 79.6% for sodium. The ideal KTV (<1.2) was present in 72.2% of the participants. Furthermore, in most of these (85.8%), the interdialytic interval gain was equal to or less than 5% of dry weight. The categorization of the clinical data, according to the level of activation of the patients, is shown in Table 2.

Regarding HRQOL, Table 3 shows the mean, median, interquartile range and minimum and maximum values of all HRQOL domains that are analyzed by the KDQOL-SF. It is noteworthy that the KDQOL-SF domains had asymmetrical distribution; however, aiming at the possibility of comparisons, we chose to also present the mean value.

When considering the specific dimensions, the worst scores were attributed to work status and CKD burden and the best scores, to dialysis staff encouragement and social support. It is observed, taking into account the domains of the generic dimensions, that the physical health component and social function scored the worst and best, respectively.

In the univariate analysis, as shown in Table 4, patients with level 4 activation were 3.72 times more likely to have better physical functioning and better overall health when compared to participants with level 1 activation. In addition, they were 2.76 times more likely to have better emotional well-being and higher scores in the symptom domain, 4.62 times more likely to have more energy, and 3.82 times more likely to have better scores in the mental component when compared to patients classified as activation level 1. With regard to the encouragement domain of

Table 1. Sociodemographic characterization of hemodialysis patients (n=162) according to activation level, Juiz de Fora, MG, Brazil, 2019.

Sociodemographic Data	Level PAM							
	Level 1		Level 2		Level 3		Level 4	
	n	%	n	%	n	%	n	%
Gender								
Male	24	14.8%	29	17.9%	20	12.3%	29	17.9%
Female	14	8.7%	18	11.1%	10	6.2%	18	11.1%
Age								
Under 60 years old	21	13%	16	9.9%	17	10.5%	22	13.6%
60 years or more	17	10.5%	31	19.1%	13	8%	25	15.4%
Skin color								
Not White (black and brown)	29	17.9%	29	17.9%	19	11.7%	23	14.2%
White	9	5.6%	18	11.1%	11	6.8%	24	14.8%
Years of study								
Illiterate or incomplete elementary school	25	15.4%	30	18.6%	13	8%	21	13%
Complete elementary education	2	1.2%	3	1.8%	3	1.8%	5	3.1%
High School or Technical School	9	5.6%	12	7.4%	10	6.2%	10	6.2%
Higher education	2	1.2%	2	1.2%	4	2.5%	11	6.8%
Marital status								
With partner	17	10.5%	21	13%	16	9.9%	26	16%
Without companion	21	13%	26	16%	14	8.6%	21	13%
Lives alone								
Yes	4	2.5%	9	5.6%	5	3.1%	8	4.9%
No	34	21%	38	23.4%	25	15.4%	39	24.1%
INSS beneficiary								
Yes	35	21.6%	42	26%	23	14.2%	38	23.4%
No	3	1.8%	5	3.1%	7	4.3%	9	5.6%
Personal income								
1 minimum wage	7	4.3%	13	8%	4	2.5%	13	8%
2 minimum wage	14	8.7%	11	6.8%	6	3.7%	11	6.8%
3 minimum wage	5	3.1%	10	6.2%	7	4.3%	6	3.7%
Over 3 minimum wages	10	6.2%	12	7.4%	12	7.4%	15	9.3%
Doesn't know/No answer	2	1.2%	1	0.6%	1	0.6%	2	1.2%
Economic classification of the household								
A	2	1.2%	1	0.6%	5	3.1%	6	3.7%
B1	1	0.6%	4	2.5%	5	3.1%	9	5.6%
B2	12	7.4%	8	4.9%	3	1.8%	13	8%
C1	9	5.6%	9	5.6%	6	3.7%	9	5.6%
C2	8	4.9%	16	9.9%	10	6.2%	7	4.3%

Source: research data.

Table 1. Continued...

Sociodemographic Data	Level PAM							
	Level 1		Level 2		Level 3		Level 4	
	n	%	n	%	n	%	n	%
D-E	6	3.7%	9	5.6%	1	0.6%	3	1.8%
Companion for hemodialysis								
Yes	15	9.3%	18	11.1%	3	1.8%	3	1.8%
No	23	14.2%	29	17.9%	27	16.7%	44	27.2%
Needs caregiver for activities of daily living								
No	30	18.6%	39	24.1%	28	17.3%	46	28.4%
Yes	8	4.9%	8	4.9¨%	2	1.2%	1	0.6%

Source: research data.

Table 2. Clinical characterization according to the activation level of patients on hemodialysis (n=162), Juiz de Fora, MG, Brazil, 2019.

Clinical data	Level 1		Level 2		Level 3		Level 4	
	n	%	n	%	n	%	n	%
Baseline disease								
Hypertension	15	9.3%	21	13%	14	8.7%	15	9.3%
Diabetes	8	4.9%	13	8%	3	1.8%	4	2.5%
Hypertension + Diabetes Mellitus	9	5.6%	7	4.3%	6	3.7%	15	9.3%
Glomerulopathies	3	1.8%	2	1.2%	1	0.6%	3	1.8%
Others	1	0.6%	0	0%	3	1.8%	3	1.8%
Doesn't know/No answer	2	1.2%	4	2.5%	3	1.8%	7	4.3%
Number of comorbidities								
1	18	11.1%	25	15.4%	16	9.9%	23	14.2%
2	16	9.9%	12	7.4%	10	6.2%	22	13.5%
>3	4	2.5%	10	6.2%	4	2.5%	2	1.2%
Time in HD								
Less than 5 years	28	17.2%	37	22.8%	16	9.9%	37	22.8%
5 years or more	10	6.2%	10	6.2%	14	8.7%	10	6.2%
Vascular access type								
Double lumen catheter	13	8%	15	9.2%	14	8.7%	15	9.2%
Arteriovenous fistula	24	14.8%	30	18.6%	16	9.9%	30	18.6%
Both	1	0.6%	2	1.2%	0	0%	2	1.2%
Previous Renal Replacement Therapy								
No	37	22.8%	45	27.8%	26	16%	41	25.4%
Yes	1	0.6%	2	1.2%	4	2.5%	6	3.7%
Residual renal diurese								
Yes	27	16.7%	40	24.7%	17	10.5%	38	23.4%
No	11	6.8%	7	4.3%	13	8%	9	5.6%

Source: research data.

Table 2. Continued...

Clinical data	Level 1		Level 2		Level 3		Level 4	
	n	%	n	%	n	%	n	%
Continuous medication use								
Yes	32	19.8%	44	27.2%	29	17.9%	43	26.5%
No	4	2.5%	3	1.8%	1	0.6%	4	2.5%
Doesn't know/No answer	2	1.2%	0	0%	0	0%	0	0%
Smoker								
No	36	22.2%	42	26%	25	15.4%	43	26.5%
Yes	2	1.2%	5	3.1%	5	3.1%	4	2.5%
Drinker								
No	32	19.8%	42	26%	23	14.2%	40	24.6%
Yes	6	3.7%	5	3.1%	7	4.3%	7	4.3%
KTV								
>1.2	27	16.6%	42	26%	21	13%	27	16.6%
<1.2	11	6.8%	5	3.1%	9	5.6%	20	12.3%
Hemoglobin								
>11 d/dL	11	6.8%	19	11.7%	14	8.7%	19	11.7%
<11 d/dL	27	16.6%	28	17.3%	16	9.9%	28	17.3%
Potassium								
Adequate (between 3.5 and 5.0 mEq/L)	22	13.5%	24	14.8%	19	11.7%	17	10.5%
Inadequate	16	9.9%	23	14.2%	11	6.8%	30	18.6%
Fósforo								
Adequate (between 3.5 and 5.0 mEq/L)	19	11.7%	29	17.9%	12	7.4%	22	13.5%
Inadequate	19	11.7%	18	11.2%	18	11.2%	25	15.4%
Sódio								
Adequate (between 3.5 and 5.0 mEq/L)	33	20.4%	33	20.4%	24	14.8%	39	24%
Inadequate	5	3.1%	14	8.7%	6	3.7%	8	4.9%
Cálcio								
Adequate (between 3.5 and 5.0 mEq/L)	25	15.4%	38	23.5%	23	14.2%	37	22.8%
Inadequate	13	8%	9	5.6%	7	4.3%	10	6.2%
Weight gain in the interdialytic interval								
<5%	33	20.4%	40	24.7%	26	16%	40	24.7%
>5%	5	3.1%	7	4.3%	4	2.5%	7	4.3%

Source: research data.

the dialysis staff, those considered level 2 activation were 4.22 times more likely to score higher in this domain when compared to level 1 patients.

After adjustment for possible confounding variables, highly activated persons (level 4) maintained higher odds of having better HRQL in the domains symptoms (OR = 3.11; CI: 1.21-7.94), physical functioning (OR = 4.18; CI: 1.64-12.24), general health (OR = 3.49; CI: 1.39-8.75), emotional well-being (OR = 3.12, CI: 1.22-8.02), energy/fatigue (OR = 4.79; CI: 1.82-12.55), and mental component (OR:4.33; CI: 1.68-11.11) compared to those with the lowest level of activation (level 1), as shown in Table 5.

Table 3. Dimensions of health-related quality of life of hemodialysis patients, Juiz de Fora, MG, Brazil, 2019.

	Quality of life					
Dimensions	**Mean**	**Median**	**Interval Interquartile**	**Minimum**	**Maximum**	**N**
Specific dimensions						
Symptoms	77.70	81.25	20.83	31.25	100.00	162
Effects of Chronic Kidney Disease	71.74	75.00	28.13	0.00	100.00	162
Burden of Chronic Kidney Disease	54.90	56.25	56.25	0.00	100.00	162
Work Status	25.00	0.00	50.00	0.00	100.00	162
Cognitive Function	81.28	86.67	26.67	13.33	100.00	162
Social Interaction	81.98	86.67	33.33	20.00	100.00	162
Sexual Function	84.76	100.00	25.00	0.00	100.00	73
Sleep	69.95	72.50	38.13	5.00	100.00	162
Social Support	86.63	100.00	16.67	0.00	100.00	162
Dialysis staff encouragement	86.81	100.00	25.00	0.00	100.00	162
Patient satisfaction	74.07	83.33	16.67	33.33	100.00	162
Generic Dimensions – SF36						
Global health	68.95	70.00	30.00	0.00	100.00	162
Physical Function	53.46	55.00	55.00	0.00	100.00	162
Limitation of physical functions	42.44	50.00	75.00	0.00	100.00	162
Pain	65.12	70.00	65.00	0.00	100.00	162
General health	58.55	60.00	35.00	5.00	100.00	162
Emotional well-being	69.53	72.00	37.00	4.00	100.00	162
Emotional role	54.53	66.67	66.67	0.00	100.00	162
Social role	69.91	75.00	50.00	0.00	100.00	162
Fatigue/Energy	58.12	62.50	41.25	0.00	100.00	162
Physical Health Component	40.15	42.37	16.73	14.22	58.72	162
Mental health component	46.31	47.90	16.47	17.33	68.68	162

Source: research data.

DISCUSSION

In this study, people with level 4 activation were more likely to have better HRQOL in the domains symptoms, physical functioning, general health, emotional well-being, energy/fatigue, and mental component when compared to those with level 1 activation.

Corroborating the findings of this study, patient activation was closely related to HRQOL in a British cohort of 3325 patients in all stages of CKD. In this cohort, the 5-level EQ-5D Version (EQ5D-5L QoL domains) instrument was used to measure quality of life. It was found that patients with low activation (levels 1 and 2) were more likely to report moderate problems in all domains that make up the instrument, which are mobility, self-care, performance of usual activities, besides the presence of pain and anxiety, when compared to patients with high activation (levels 3 and 4).[4, 25-26]

In this study, patients with level 4 activation were more likely to have better HRQOL in the mental health composite compared to patients in level 1 activation. In previous research involving patients at all levels of CKD, worse activation was associated with worse mental health component scores in men.[16] Considering the high prevalence of anxiety and depression in this population,[27-28] activation aids may be an effective strategy to reduce mental disorders and consequently improve the mental health and HRQOL of these individuals.

In this study, patients who had a higher level of activation were more likely to have better HRQOL, considering the symptom domain. Unlike the findings of this study, in a research of 305 people in all stages of CKD, activation was not associated with this domain.[16] And a possible justification for this divergence may be the difference between the stages of CKD in which the participants who comprised the two samples of studies were, since the presence of symptoms varies according to the severity of CKD.

Table 4. Component odds ratio (OR) and Confidence Interval (CI) of health-related quality of life components, above the 50† percentile according to the activation level of HD patients, Juiz de Fora, MG, Brazil, 2019.

OR (CI95%)	Activation Level			
	1	2	3	4
Symptom	1.0	2.12 (0.88-5.09)	1.71 (0.64-.53)	2.76 (1.14-6.68)*
Effect of CKD	1.0	0.69 (0.29-1.64)	0.55 (0.21-1.46)	0.90 (0.37-2.13)
CKD Load	1.0	1.06 (0.45-2.50)	0.47 (0.17-1.30)	2.37 (0.97-5.73)
Work Status	1.0	1.19 (0.48-2.91)	1.47 (0.54-3.93)	2.00 (0.83-4.84)
Cognitive Function	1.0	1.31 (0.55-3.11)	1.05 (0.39-2.76)	1.07 (0.71-4.03)
Social Interaction	1.0	0.61 (0.25-1.44)	0.60 (0.22-1.58)	1.21 (0.51-2.87)
Sexual Function	1.0	0.54 (0.8-3.36)	0.50 (0.07-3.54)	0.57 (0.09-3.40)
Sleep	1.0	1.94 (0.81-4.66)	1.71 (0.64-4.53)	1.71 (0.64-4.53)
Social Support	1.0	0.93 (0.38-2.27)	1.00 (0.37-2.71)	2.15 (0.82-5.63)
Dialysis Incentive	1.0	4.22 (1.60-11.0)*	0.66 (0.25-1.75)	2.1 (0.88-5.16)
Global Health	1.0	1.11 (0.46-2.63)	0.68 (0.25-1.86)	1.11 (0.46-2.63)
Patient Satisfaction	1.0	0.88 (0.37-2.07)	1.50 (0.56-3.95)	1.35 (0.57-3.18)
Physical Functioning	1.0	1.19 (0.48-2.91)	2.51 (0.93-6.73)	3.72 (1.51-9.18)*
Physical Function	1.0	0.71 (0.30-1.68)	0.80 (0.31-2.11)	1.09 (0.46-2.58)
Pain	1.0	1.43 (0.60-3.39)	0.91 (0.34-2.42)	1.85 (0.78-4.41)
General Health	1.0	2.18 (0.90-5.27)	0.96 (0.34-2.64)	3.72 (1.51-9.18)*
Emotional Well-Being	1.0	1.26 (0.52-3.05)	1.95 (0.73-5.18)	2.76 (1.14-6.68)*
Emotional Role	1.0	1.04 (0.44-2.45)	1.00 (0.38-2.60)	1.76 (0.73-4.21)
Social Role	1.0	0.91 (0.38-2.17)	0.80 (0.31-2.11)	1.90 (0.78-4.66)
Energy/Fatigue	1.0	2.07 (0.85-5.06)	1.89 (0.70-5.10)	4.62 (1.84-11.58)*
Physical Component	1.0	1.11 (0.46-2.63)	1.79 (0.68-4.73)	1.85 (0.78-4.41)
Mental Component	1.0	2.46 (1.006.00)*	1.89 (0.70-5.10)	3.82 (1.54-9.46)*

† Representation of the sample according to the quality of life components with scores above the 50th percentile. * p value < 0.05. Source: research data.

Table 5. Odds ratio of HRQOL components above the 50† percentile according to participants' activation level adjusted for confounding factors, Juiz de Fora, MG, Brazil, 2019.

	Setting 1*		Setting 2**	
	OR (95% CI)	Value p	OR (95% CI)	Value p
		Symptom		
Activation Level				
1	1.0		1.0	
2	2.19 (0.89-5.40)	0.086	2.26 (0.89-5.73)	0.085
3	1.70 (0.63-4.61)	0.293	2.05 (0.73-5.75)	0.169
4	2.99 (1.20-7.41)	**0.018**	3.11 (1.21-7.94)	**0.018**

† Representation of the sample according to quality of life components with scores above the 50th percentile. Symptom domain ≥ 81.25, n=84; Physical functioning ≥ 60, n=79; General health ≥ 65, n=79; Emotional well-being ≥ 75, n=79; Energy/Fatigue ≥ 65, n=81; Mental component ≥ 47.95, n=81. * Adjustment 1: Sex and Age. ** Adjustment 2: Sex; Age; Length of Hemodialysis; Number of Comorbidities; Hemoglobin and KTV. Source: research data.

Table 5. Continued...

	Setting 1*		Setting 2**	
	OR (95% CI)	Value p	OR (95% CI)	Value p
Physical Functioning				
Activation Level				
1	1.0		1.0	
2	1.28 (0.50-3.22)	0.597	1.03 (0.38-2.75)	0.949
3	2.58 (0.93-7.14)	0.068	3.07 (1.02-9.21)	**0.045**
4	3.94 (1.54-10.08)	**0.004**	4.48 (1.64-12.24)	**0.003**
General Health				
Activation Level				
1	1.0		1.0	
2	2.15 (0.90-5.25)	0.084	2.26 (0.91-5.61)	0.079
3	0.96 (0.35-2.60)	0.946	0.88 (0.31-2.50)	0.824
4	3.75 (1.52-9.26)	**0.004**	3.49 (1.39-8.75)	**0.008**
Emotional well-being				
Activation Level				
1	1.0		1.0	
2	1.30 (0.52-3.25)	0.572	1.24 (0.48-3.17)	0.643
3	1.98 (0.71-5.49)	0.186	1.98 (0.70-5.55)	0.191
4	3.13 (1.23-7.94)	**0.016**	3.12 (1.22-8.02)	**0.018**
Energy/Fatigue				
Activation Level				
1	1.0		1.0	
2	2.20 (0.88-5.48)	0.088	2.02 (0.79-5.14)	0.140
3	1.89 (0.69-5.17)	0.215	1.77 (0.62-5.01)	0.280
4	4.74 (1.85-12.10)	**0.001**	4.79 (1.82-12.55)	**0.001**
Mental Component				
Activation Level				
1	1.0		1.0	
2	2.53 (1.02-6.23)	0.043	2.31 (0.92-5.80)	0.074
3	1.87 (0.69-5.09)	0.216	1.81 (0.65-5.03)	0.252
4	3.88 (1.55-9.71)	**0.004**	4.33 (1.68-11.11)	**0.002**
Dialysis Incentive				
Activation Level				
1	1.0		1.0	
2	4.70 (1.73-12.75)	**0.002**	5.20 (1.86-14.53)	**0.002**
3	0.65 (0.24-1.78)	0.411	0.70 (0.25-1.90)	0.501
4	2.10 (0.85-5.18)	0.107	2.16 (0.86-5.14)	0.100

† Representation of the sample according to quality of life components with scores above the 50th percentile. Symptom domain ≥ 81.25, n=84; Physical functioning ≥ 60, n=79; General health ≥ 65, n=79; Emotional well-being ≥ 75, n=79; Energy/Fatigue ≥ 65, n=81; Mental component ≥ 47.95, n=81. * Adjustment 1: Sex and Age. ** Adjustment 2: Sex; Age; Length of Hemodialysis; Number of Comorbidities; Hemoglobin and KTV. Source: research data.

In KDOL-SF, the symptom is considered a domain to measure HRQOL, however, there are instruments that assess the presence of symptoms related to CKD. In this sense, the study of the United Kingdom Renal Association (2020)[4] analyzed the relationship between symptom burden, by means of 17 symptom measurement items of the POS-S instrument, and the activation of chronic renal patients. It was observed that the higher the activation, the lower the symptom burden. When considering each of the 17 items of the instrument individually and their overall burden, it also reinforces the finding of this study that higher activation is related to better HRQL in the symptom domain. This relationship can be justified by the fact that more activated people have better clinical indicators, such as adequate serum electrolyte levels.[29] These electrolytes, when increased in hemodialysis patients (for example, potassium, phosphorus, and sodium), cause symptoms such as cramps, nausea, diarrhea, and asthenia.

It is noteworthy that among the 17 symptoms assessed by the United Kingdom Renal Association (2020) and associated with patient activation, the symptom weakness or lack of energy was the most prevalent among respondents and the significance of this relationship corroborates the findings of this study. Patients with level 4 activation were more likely to have better HRQOL, considering the energy/fatigue domain, when compared to patients with level 1 activation.[4]

With regard to general health, people with activation level 4 were more likely to have better scores compared to people in level 1. Previous studies involving HD patients,[16] with chronic obstructive pulmonary disease, congestive heart failure, CKD (GFR<60 ml/min/1.73m^2) and type II Diabetes Mellitus,[30-31] also reiterate that the higher the activation, the better the self-reported health. A possible explanation for this relationship is that people with higher levels of activation have better clinical outcomes and present healthier behaviors than people with low activation, [22,29,32] and these variables interfere in the overall health of the individual.

Having level 4 activation increased the chances that HD patients would score better in the physical functioning domain of HRQOL. When considering that mobility is influenced by physical functioning, as previously described, there is evidence between the association of mobility with activation in patients with CKD,[4] which corroborates the findings of this study.

Regarding the associations between emotional well-being and activation, no other studies were found that explored this association in CKD patients. But in a research involving patients with severe obesity who underwent bariatric surgery, activation and emotional well-being were positively associated (B = 0.48, p<0.001). It is noteworthy that the authors measured emotional well-being by means of a specific instrument and not by means of a HRQOL domain.[33]

In a previous study measuring factors associated with activation in patients with comorbid diabetes and CKD, a worse burden of kidney disease was associated with worse HRQOL of patients in the low activation group (levels 1 and 2) when compared to the high activation group (levels 3 and 4),[16] differently from the findings of this study in which there was no association between the burden domain of CKD and the level of activation. This divergence may be justified by the fact that this study was restricted to patients on HD, while in the other study 305 people with CKD in stages 3 to 5 were included, and of these, only 59 were on dialysis.[16] In this regard, there is evidence that anxiety, worry and fear are more present in the early stages of CKD,[34] which may influence this HRQOL domain.

Given the above, the positive relationship between patient activation and HRQOL is evident. By considering that interventions in activation are able to improve quality of life,[35-36] health professionals should establish interventions that consider the level of activation of dialysis patients, aiming to strengthen the self-management of health in them and thus obtain better health outcomes such as HRQOL.[35]

CONCLUSION AND IMPLICATIONS FOR PRACTICE

This study related the level of activation with the HRQOL of hemodialysis patients and highly activated people (activation level 4) had higher chances of better HRQOL in the domains symptoms, physical functioning, general health, emotional well-being, energy/fatigue and mental component.

As this was a cross-sectional study, reverse causality cannot be ruled out, i.e., that a higher HRQOL can influence the level of patient activation, becoming a limitation of this investigation. In this sense, aiming to elucidate this causal relationship, longitudinal studies are suggested. In addition, another limitation was the type of convenience sampling, which makes it impossible to make inferences for other populations of hemodialysis patients.

As implications for practice, the level of activation is associated with HRQOL of patients on hemodialysis. Thus, health professionals can use this measure to implement strategies aimed at increasing the HRQOL of this population.

ACKNOWLEDGMENTS

We thank the Federal University of Juiz de Fora for granting the Post Graduate Monitor Program scholarship to Denise Rocha Raimundo Leone.

AUTHOR'S CONTRIBUTIONS

Study design. Acquisition, data analysis, and interpretation of results. Writing and critical revision of the manuscript. Approval of the final version of the article. Responsibility for all aspects of the content and integrity of the published article. Denise Rocha Raimundo Leone

Data analysis and interpretation of results. Writing and critical revision of the manuscript. Approval of the final version of the article. Responsibility for all aspects of the content and integrity of the published article. Gabriela Amorim Pereira

Data analysis and interpretation of results. Writing and critical revision of the manuscript. Approval of the final version of the

article. Responsibility for all aspects of the content and integrity of the published article. Arison Cristian de Paula Silva

Study design. Data analysis and interpretation of results. Writing and critical revision of the manuscript. Approval of the final version of the article. Responsibility for all aspects of the content and integrity of the published article. Aline Silva de Aguiar

ASSOCIATE EDITOR

Cândida Caniçali Primo

REFERENCES

1. Neves PDMM, Sesso RCC, Thomé FS, Lugon JR, Nasicmento MM. Brazilian Dialysis Census: analysis of data from the 2009-2018 decade. J Bras Nefrol. 2020;42(2):191-200. http://dx.doi.org/10.1590/2175-8239-jbn-2019-0234. PMid:32459279.
2. Pecoits-Filho R, Rosa-Diez G, Gonzalez-Bedat M, Marinovich S, Fernandez S, Lugon J et al. Renal replacement therapy in CKD: an update from the Latin American Registry of Dialysis and Transplantation. J. Braz. Nephrol. 2015;37(1):9-13. http://dx.doi.org/10.5935/0101-2800.20150002. PMid:25923744.
3. United States Renal Data System. USRDS Annual Data Report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases. Bethesda (MD): United States Renal Data System; 2019
4. The Renal Association. Transforming participation in chronic kidney disease [Internet]. Bristol: The Renal Association; 2019 [citado 2020 Ago 6]. Disponível em: https://www.thinkkidneys.nhs.uk/ckd/wp-content/uploads/sites/4/2019/01/Transforming-Participation-in-Chronic-Kidney-Disease-1.pdf
5. Macêdo IS, Macêdo GS, Pacheco ES, Mota MS, de Sousa ARR. Support and coping strategies used by chronic renal patients undergoing hemodialysis. RSD. 2020;9(9):e340996908. http://dx.doi.org/10.33448/rsd-v9i9.6908.
6. Zazzeroni L, Pasquinelli G, Nanni E, Cremonini V, Rubbi I. Comparison of quality of life in patients undergoing hemodialysis and peritoneal dialysis: a systematic review and meta-analysis. Kidney Blood Press Res. 2017;42(4):717-27. http://dx.doi.org/10.1159/000484115. PMid:29049991.
7. Wang R, Tang C, Chen X, Zhu C, Feng W, Li P et al. Poor sleep and reduced quality of life were associated with symptom distress in patients receiving maintenance hemodialysis. Health Qual Life Outcomes. 2016;14(125):125. http://dx.doi.org/10.1186/s12955-016-0531-6. PMid:27608683.
8. Centers for Disease Control and Prevention. HRQOL concepts [Internet]. 2020 [citado 2020 Out 25]. Disponível em: http://www.cdc.gov/hrqol/concept.htm
9. Oliveira APB, Schmidt DB, Amatneeks TM, Santos JC, Cavallet LH, Michel RB. Quality of life in hemodialysis patients and the relationship with mortality, hospitalizations and poor treatment adherence. J Bras Nefrol. 2016;38(4):411-20. http://dx.doi.org/10.5935/0101-2800.20160066. PMid:28001183.
10. Wright LS, Wilson L. Quality of life and self-efficacy in three dialysis modalities: Incenter hemodialysis, home hemodialysis, and home peritoneal dialysis. J Bras Nefrol. 2015;42(5):463-76, quiz 477. PMid:26591271.
11. Gonçalves FA, Dalosso IF, Borba JMC, Bucaneve J, Valerio NMP, Okamoto CT et al. Quality of life in chronic renal patients on hemodialysis or peritoneal dialysis: a comparative study in a referral service of Curitiba - PR. Braz. J. Nephrol. 2015;37(4):467-74. http://dx.doi.org/10.5935/0101-2800.20150074. PMid:26648496.
12. Blakemore A, Hann M, Howells K, Panagioti M, Sidaway M, Reeves D et al. Patient activation in older people with long-term conditions and multimorbidity: correlates and change in a cohort study in the United Kingdom. BMC Health Serv Res. 2016;16:582. http://dx.doi.org/10.1186/s12913-016-1843-2.
13. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the Patient Activation Measure (PAM): conceptualizing and measuring activation in patients and consumers. Health Serv Res. 2004;39(4 Pt 1):1005-26. http://dx.doi.org/10.1111/j.1475-6773.2004.00269.x. PMid:15230939.
14. Newland P, Lorenz R, Oliver BJ. Patient activation in adults with chronic conditions: a systematic review. J Health Psychol. 2021 jan;26(1):103-14. http://dx.doi.org/10.1177/1359105320947790. PMid:32830587.
15. Sánchez-Cabezas AM, Morillo-Gallego N, Merino-Martínez RM, Crespo-Montero R. Calidad de vida de los pacientes en diálisis. Revisión sistemática. Enferm Nefrol. 2019;22(3). http://dx.doi.org/10.4321/s2254-28842019000300003.
16. Zimbudzi E, Lo C, Ranasinha S, Fulcher GR, Jan S, Kerr PG et al. Factors associated with patient activation in an Australian population with comorbid diabetes and chronic kidney disease: a cross sectional study. BMJ Open. 2017;7(10):e017695. http://dx.doi.org/10.1136/bmjopen-2017-017695. PMid:29061622.
17. Van Bulck L, Claes K, Dierickx K, Hellemans A, Jamar S, Smets S et al. Patient and treatment characteristics associated with patient activation in patients undergoing hemodialysis: a cross-sectional study. BMC Nephrol. 2018;19(126):126. http://dx.doi.org/10.1186/s12882-018-0917-2. PMid:29859047.
18. Associação Brasileira de Empresas de Pesquisa. Critério de Classificação econômica Brasil-2018 [Internet]. São Paulo: ABEP; 2018 [citado 2020 Ago 8]. Disponível em: http://www.abep.org/criterio-brasil
19. Hays RD, Joel K, Donna M, Stephen C, Naseen A, William BC et al. Kidney Disease Quality of Life Short Form (KDQOL-SF ™), version 1.3: a manual for use and scoring [Internet]. Santa Monica, CA: RAND Corporation; 1997 [citado 2020 Ago 25]. Disponível em: https://www.rand.org/pubs/papers/P7994.html
20. Duarte PS, Miyazaki MCOS, Ciconelli RM, Sesso R. Tradução e adaptação cultural do instrumento de avaliação de qualidade de vida para pacientes renais crônicos (KDQOL-SF TM). Rev Assoc Med Bras. 2003;49(4):375-81. http://dx.doi.org/10.1590/S0104-42302003000400027. PMid:14963588.
21. Cunha CM, da Cunha DCPT, Manzato RO, Nepomuceno E, da Silva D, Dantas RAS. Validation of the Brazilian Version of the Patient Activation Measure 13. J Nurs Meas. 2019;27(1):97-113. https://doi.org/10.1891/1061-3749.27.1.97. PMID: 31068494.
22. Greene J, Hibbard JH, Sacks R, Overton V, Parrotta CD. When patient activation levels change, health outcomes and costs change, too. Health Aff (Millwood). 2015;34(3):431-7. http://dx.doi.org/10.1377/hlthaff.2014.0452. PMid:25732493.
23. Insignia Health. What the Patient Activation Measure® Reveals. USA: Insignia Health; 2017. TM Licence Materials.
24. Santos PR, Pontes LRSK. Mudança do nível de qualidade de vida em portadores de insuficiência renal crônica terminal durante seguimento de 12 meses. Rev Assoc Med Bras. 2007 ago;53(4):329-34. http://dx.doi.org/10.1590/S0104-42302007000400018. PMid:17823736.
25. Herdman M, Gudex C, Lloyd A, Janssen MF, Kind P, Parkin D et al. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). Qual Life Res. 2011;20(10):1727-36. http://dx.doi.org/10.1007/s11136-011-9903-x. PMid:21479777.
26. Brooks R. EuroQol: the current state of play. Health Policy. 1996;37(1):53-72. http://dx.doi.org/10.1016/0168-8510(96)00822-6. PMid:10158943.
27. Sousa L, Valentim O, Marques-Vieira C, Antunes AV, Severino S, José H. Association between stress/anxiety, depression, pain and quality of life in people with chronic kidney disease. Rev Port Enferm Saude Mental. 2020;23. http://dx.doi.org/10.19131/rpesm.0272.
28. Schmidt DB. Quality of life and mental health in hemodialysis patients: a challenge for multiprofessional practices. J Bras Nefrol. 2019;41(1):10-1. http://dx.doi.org/10.1590/2175-8239-jbn-2018-0227. PMid:31063179.
29. Hibbard JH, Mahoney ER, Sonet E. Does patient activation level affect the cancer patient journey? Patient Educ Couns. 2017;100(7):1276-9. http://dx.doi.org/10.1016/j.pec.2017.03.019. PMid:28330715.
30. Bos-Touwen I, Schuurmans M, Monninkhof EM, Korpershoek Y, Spruit-Bentvelzen L, Ertugrul-van der Graaf I et al. Patient and disease characteristics associated with activation for self-management in patients with diabetes, chronic obstructive pulmonary disease, chronic

heart failure and chronic renal disease: a cross-sectional survey study. PLoS One. 2015;10(5):e0126400. http://dx.doi.org/10.1371/journal.pone.0126400. PMid:25950517.

31. Hendriks M, Rademakers J. Relationships between patient activation, disease-specific knowledge and health outcomes among people with diabetes; a survey study. BMC Health Serv Res. 2014;14(393):393. http://dx.doi.org/10.1186/1472-6963-14-393. PMid:25227734.
32. Greene J, Hibbard JH, Sacks R, Overton V, Parrotta CD. When patient activation levels change, health outcomes and costs change, too. Health Aff (Millwood). 2015;34(3):431-7. http://dx.doi.org/10.1377/hlthaff.2014.0452. PMid:25732493.
33. Solberg H, Aarflot M, Skotnes LH, Graue M. Relationships between emotional well-being, patient activation and social support among adults with severe obesity who have undergone gastric bypass surger. Open J Nurs. 2015;5(7):596-604. http://dx.doi.org/10.4236/ojn.2015.57063.
34. Johnson ML, Zimmerman L, Welch J, Hertzog M, Pozehl B, Plumb T. Patient activation with knowledge, self-management and confidence in chronic kidney disease. J Ren Care. 2016;42(1):15-22. http://dx.doi.org/10.1111/jorc.12142. PMid:26537188.
35. Lin MY, Weng WS, Apriliyasari RW, Van Truong P, Tsai PS. Effects of patient activation intervention on chronic diseases: a meta-analysis. J Nurs Res. 2020;28(5):e116. http://dx.doi.org/10.1097/jnr.0000000000000387. PMid:32649394.
36. Nelson RG, Pankratz V, Ghahate D, Bobelu J, Faber T, Shah V. Home-based kidney care, patient activation, and risk factors for CKD progression in Zuni Indians: a randomized, controlled clinical trial. Clin J Am Soc Nephrol. 2018;13(12):1801-9. http://dx.doi.org/10.2215/CJN.06910618. PMid:30442864.