Predictors of health activation for patients with chronic kidney disease undergoing hemodialysis

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Abstract

Introduction: *the quality of self-care in patients with chronic kidney disease (CKD) is important to improve quality of life, increase survival and reduce complications. Self-care can be evaluated by measuring the health activation of these patients.* ***Objectives:*** *evaluating the health activation of patients with CKD undergoing hemodialysis (HD) compared to a normative group (health self-reported subjects), and to identify the social, demographic and clinical determinants that are associated with the health activation.* ***Method:*** *cross-sectional, analytical, descriptive and quantitative study approved by the local ethics committee and conducted in a public and a private outpatient hemodialysis clinic. Participants were patients with CKD on HD (focal group) and subjects on a normative group. All of them answered the questionnaire of sociodemographic and clinical characterization and the instrument "Patient Activation Measure" (PAM13). For scores comparisons were used the Mann-Whitney test. Regarding the evaluation of the linear effect of the variables of profile on PAM13, multiple linear regression was used, including the evaluation of the two groups and only for patients with CKD.* ***Results:*** *Regarding the characteristics of the CKD patients, there was a predominance of males (59%), incomplete high school or less (68%). Most of them too was from a private administration clinic (53%) and reported having already presented some type of complication stemming from CKD (57%). Regarding the evaluation of activation, the activation scores did not differ between the two groups (median of 56.4 in CKD patients and 56.4 in normative group, $p > 0.05$) and the activation scores of both groups corresponded to activation level 3 with 34.5% of prevalence ($p > 0.05$). When the two groups were analyzed together, schooling (Bi = 5.38; p= 0.002), practice physical activity (Bi = 4.2; p= 0.019) and the number of people who co-reside (Bi = -2.22; p= 0.001) influenced the activation score. In the CKD patients, independently, the variables that influenced the activation score were gender (Bi = -4.69; p = 0.050); schooling (Bi = 6.55; p = 0.008); type of clinic of origin (Bi = -5.48; p = 0.02) and the presence of complications related to CKD (Bi = -5.25; p = 0.026).* ***Conclusion:*** *activation scores did not differ between the patients with CKD on HD and the health subjects. Schooling, practice physical activity and number of people residing with the individual were predictors of health activation in both groups. For the CKD patients group, the variables that influenced positively the activation was schooling; and that influenced negatively was the gender, type of clinic of origin and the presence of complications related to CKD.*

Keywords: Renal Insufficiency, Chronic Disease; Quality of Life; Self-Care; Renal Dialysis.

1. Introduction

Chronic Kidney Disease (CKD) is an important public health problem in Brazil that worsens with late diagnosis and the presence of untreated comorbidities. It is defined by the progressive and irreversible reduction of the physiological functions of the kidneys, resulting from multiple causes and factors that alter its structure and function [1]. Between 2011 and 2014, in the United States, there was a prevalence of 14.8% of CKD in the adult population, with 124,144 new cases recorded in 2015 [2]. In Brazil, it is estimated that 3 out of every 100 inhabitants have some degree of CKD, and that the need for dialysis treatment would be necessary in five per 10,000 cases [3].

Dialysis treatment, or renal replacement therapy, has been the most widely used therapy for patients with end-stage CKD, with a significant increase in the survival rate of patients. Dialysis can be performed in two basic modalities, peritoneal and hemodialysis, according to the clinical indication of the patient [4]. Despite the great technological advances in treatment and the improvement in survival of these patients, these benefits were not accompanied with improvement in quality of life [5]. Its therapy and dismemberments negatively influence the biological, psychological, economic, social and quality of life dimensions [6].

CKD and its treatment impact the individual's life in several ways and cause negative repercussions on the individual's life, which include changes in habits and routine, including continuous use of medications, water restrictions, absence from work, physical, nutritional limitations, social and family life, and dependence on constant outpatient clinical follow-up. There is also sexual decline, existential conflicts and spiritual anguish, which aggravate physical and emotional symptoms, added to frequent trips to health units in search of care until hospitalization [7]. All these repercussions lead to impaired quality of life and directly interfere in the process of self-care and self-management of patients' health [8].

Self-care actions constitute the practice of activities that individuals deliberately perform for their own benefit with the purpose of maintaining life, health and well-being. They aim to contribute specifically to structural integrity, functioning and human development [9]. When the patient develops autonomy, he/she takes responsibility for decisions related to his/her health; he/she can incorporate actions for self-care [10]. Among these actions are, care with arteriovenous fistula [11], pharmacological treatment [12] and knowledge about the relationship between CKD and other chronic diseases [8].

Given so many attributions and commitments, it is of fundamental importance that the patient collaborates with treatment adhering to better health behaviors. This collaboration occurs with self-care and self-management in health, through health activation. Activation refers to the patient's understanding, ability and confidence in self-managing and developing practices related to their health [13]. One of the instruments for measuring activation is the Patient Activation Measure (PAM13), which assesses the patient's knowledge, ability and confidence for self-management [14]. The use of self-care action measurement instruments is a tool that collaborates in the evaluation of patients' responses to treatment, allows the comparison of data over time and allows the understanding and study of their associations observed [15]. Besides that, their use by health professionals can functioning as an quality indicator of

professional exercise.

Awakening or improve the activation of patients with CKD is a strategy directed to self-care, as it implies the implementation of improvements in health status and in the prevention of complications, which will have an impact on increasing survival and restoring the patient's health and well-being. Thus, stimulating the activation of patients with CKD can contribute to the entire patient health process, since it not only evaluates the relationship between the patient and the treatment, but also provides the health professional with new perspectives, allowing this to trace strategies and perform improvements in the maintenance and activation of these patients. Thus, it is desirable and necessary to diagnose the aspects of self-care in health harmed in this group of patients, so that it can guide interventions aimed at improving their level [16]. The data from this study will enable strategies for clinical and nursing interventions aimed at improving health outcomes, according to the real needs presented in these group of individuals.

This study aimed to evaluate the health activation of patients with CKD on hemodialysis and compare whether there is a difference in activation scores, between patients with CKD who undergo hemodialysis in relation to a normative group (healthy self-referred subjects). Besides that, desire identify the social, demographic and clinical determinants associated with health activation in individuals with CKD undergoing dialysis treatment in relation to a normative group.

2. Method

2.1 Type of study, place and ethical notes

Cross-sectional, analytical, descriptive, quantitative, correlational and comparative study. It was approved by the local Research Ethics Committee under number CAAE 67009117.0.0000.5152. After presenting the study objectives to the participants and before the necessary clarifications, the participants were requested to acquiesce, effected by signing a Free and Informed Consent Term. The study was carried out in the physical premises of two outpatient hemodialysis clinic. The first is a full public clinic inserted in a Federal public hospital. The second is private outpatient hemodialysis clinic contracted for public service by the Unified Health System - UHS (Sistema Único de Saúde in Portuguese – SUS), the public health system from Brazil.

2.2 Participants

In this study, two groups of participants were determined; one focal group the CKD patients on HD and one normative group represented by healthy self-referred participants. The sample was non-probabilistic, for convenience and consecutive. All individuals who met the inclusion criteria participated in the study, which are all subjects who had cognitive preservation. In the focal group, were included patients with CKD diagnosed in the period greater than six months, aged between 18 and 80, and regular outpatient clinical follow-up undergoing hemodialysis. In the second group, normative group, were included subjects who considered themselves healthy (without any comorbidity) and over 18 years old. Exclusion criteria for the focal group were individuals with a history of previous hospitalization in the last six months. For normative group, the exclusion criteria were people with a history of hospitalization or

previous infectious disease in the last 30 days.

2.3 Procedures

The data collection period of this study occurred between October 2017 and March 2018. The evaluation questionnaires (by the interview technique) were applied in a private environment. The time used to answer all questionnaires was around 30 to 35 minutes. The first evaluation was the screening of the cognitive state of the participant. The cognitive evaluation of the elected patients or subjects was performed with a questionnaire that evaluated the discriminatory capacity and mental orientation of the individual in time and space, as described by Pfeifer [17]. The questions that have been asked are as follows: (a) What is your full name? (b) What is your date of birth? (c) What day of the week are we on? and (d) What is the name of where we are right now? In this evaluation, the participant should answer correctly at least three questions to be included in the study. Patients who were considered cognitively fit by this evaluation took part in the other methodological stages of the study.

After the psychic and mental aptitude was obtained, the evaluative instruments were applied: Questionnaire for the characterization of sociodemographic data, a questionnaire with information on clinical data and the validated version for use in Brazil of the Patient Activation Measure instrument in the reduced version (PAM13)[13]. The PAM13 instrument is composed of thirteen items that evaluates the patient's activation in relation to the process of self-management of health. The Brazilian version was translated and culturally adapted by Cunha and collaborators [13]. It presented appropriate levels of validity and reliability (Cronbach's alpha coefficient greater than 0.8).

The calculation of the crude score of the reduced version (PAM13) is given by the sum of the values indicated by the answers in each item, represented in five options: Totally disagree (1 point), Disagree (2 points), Agree (3 points), Totally agree (4 points) and Do not apply (0 points). With this, the variable range of the instrument will be between 13 and 52 points. If there are items not marked or answered as "Does not apply" it is necessary to divide by the number of items answered and multiply by the total number of items of the instrument to reach the gross score [13]. The final values of the crude score must be transformed to an activation score ranging from 0 to 100 points through a conversion table contained in its user license. Through the crude score and the activation score the individuals were stratified in the levels of activation; the levels range from level 1 (low level of activation) to level 4 (high level of activation) [13].

2.4 Statistical treatment

The collected data was entered in a spreadsheet (Microsoft Office Excel®) and later transported to the IBM Statistical Package for the Social Sciences (SPSS) version 21.0 software, both run in Windows®. For all analyses, the significance of 0.05 was adopted.

As some of the qualitative variables with multiple levels presented a low sample in some levels (little representativeness of the same), dichotomization of some variables was chosen. The classifications adopted for dichotomization were municipality origin (1 - Uberlândia; 0 - other cities); marital status (1 - with partner; 0 - without partner); schooling (1 - high school complete or higher; 0 - high school incomplete or less); type of outpatient clinic origin (1 – public-public; 0 – private-public); gender (1 - female; 0 - male).

The qualitative data was presented in the form of absolute and relative frequency. The quantitative

data were presented as mean, standard error, minimum, maximum and median (depending on the distribution). The continuous data were tested for normality by Kolmogorov Smirnov Lilliefors test. For the comparison of the profile of the two groups, dichotomized data were compared using the Chi-Square independence test with continuity correction. For continuous and unpaired data, as they did not show normality, the Mann-Whitney test was applied to compare the medians. The profile was originally present, compared and discussed by Jesus et collaborators evaluating que quality of life from the two groups[18].

Regarding the evaluation of the linear effect of the profile variables in the crude and activation PAM13 scores, multiple linear regression analysis was used, including both groups and separately for hemodialysis patients. To obtain the most parsimonious model, the backward method for selection of variables was applied, based on the exclusion criterion of the model the Wald probability less than 0.10.

3. Results

The study included 200 individuals (100 in each group). Regarding the characteristics of the focal group participants, it was found that there was a predominance of males 59%, in 68% had incomplete high school education level, 55% reported not living conjugally with some company. The majority, 53% came from a private administration institution and 57% reported having some type of complication stemming from CKD. In relation to the general characteristics of the normative group, there was a predominance of females, 54%, in 56% had complete high school or more and 62% reported living conjugally. Only the qualitative variables marital status and schooling had statistical difference between the groups evaluated ($p < 0.05$; Table 1). Regarding the continuous variables, it was found that the study group was older (median = 54 years) compared to the normative group (median = 47 years) ($p = 0.004$). The normative group had a higher median than the study group for study time, individual and household income and number of minimal wages ($p < 0.05$).

The crude and activation scores did not differ between the normative groups and patients on hemodialysis. The median value from crude score were 39 and the median value from activation scores was 56.4 (Table 2). The both groups show the same distribution of activation according to the activation levels with no difference found (Chi-square = 1.64; $p = 0.649$, *d.f.* = 3; Figure 1). The activation scores of Level 3 were the most predominant in both groups with 34.5%, between the groups evaluated.

The variables that positively influenced the activation score were schooling (*Bi* = 5.38; $p = 0.002$); practice physical activity (*Bi* = 4.20; $p = 0.019$); and negatively influenced the activation was number of people living who co-reside (*Bi* = -2.22; $p = 0.001$). The same was observed by crude score, differently only the estimative of *Bi*. On the other hand, when considering only the focal group, CKD patients, the variables that influenced positively the activation score were schooling (*Bi* = 6.55; $p = 0.008$); and negatively was gender (*Bi* = -4.69; $p = 0.050$); type of outpatient clinic (*Bi* = -5.48; $p = 0.02$); and the presence of complications (*Bi* = -5.25; $p = 0.026$). The same was observed by crude score in the CKD patients, differently only the estimative of *Bi*. (Table 3)

Table 1 - Social and demographic profile of patients with chronic kidney disease (CKD) undergoing hemodialysis and individuals from a normative population (healthy self-referred).

Variable	Stratum	Group (%)*		p^1
		Hemodialysis	Normative	
Gender	Male	59	46	0.089
	Female	41	54	
Origin	Uberlândia	83	92	0.087
	Other cities	17	8	
Marital status	No mate	55	38	0.023
	With mate	45	62	
Schooling	Incomplete high school or less	68	44	0.001
	Complete high school or more	32	56	
Smoking	No	86	93	0.166
	Yes	14	7	
Physical activity	No	71	63	0.229
	Yes	29	37	
Institution	Public-Public	47		
	Private-Public	53		
CKD	No	43		
Complications	Yes	57		
Comorbidities	No	16		
	Yes	84		

Variable	Hemodialysis	Normative	p^2
	Average (Median)	Average (Median)	
Age (years)	53.59 (54)	47.79 (47)	0.004
Study time (years)	8.41 (9.5)	9.92 (11)	0.003
Individual income (Reals)	1584.56 (980)	1842.88 (1300)	0.018
Household income (Reals)	2712.52 (1980)	3441.60 (2800)	0.001
Minimum wages (number)	2.52 (2)	2.96 (3)	0.004
Home residents (number)	2.60 (2)	2.82 (3)	0.187
Session time (minutes)	220.25 (225)		
Hemodialysis time (month)	5.05 (4)		
Diagnostic time (month)	7.16 (5)		
Comorbidities (number)	1.57 (1.5)		

Source: Adapted from[18].

Legend: p^1 - probability based on the Chi-Square test, p^2 - probability based on the Mann-Whitney test. * n = 100 in each group, except for income variables (with n = 99 for the normative population).

Table 2 - Values of the Patient Activation Measure (PAM13) of patients with chronic kidney disease (CKD) undergoing hemodialysis and a normative population of healthy self-referred subjects (n = 100 patients per group).

Subjects group	Statistics	Crude Score	Activation Score
CKD patients on hemodialysis	Average ± standard error	39.43 ± 0.46	57.91 ± 1.23
	Minimum - Minimum (Median)	28.89 - 50 (39)	36 – 86.3 (56.4)
Normative (health self-referred subjects)	Average ± standard error	38.9 ± 0.5	57.03 ± 1.27
	Minimum - Minimum (Median)	23.4 - 52 (39)	28.4 - 100 (56.4)
p: probability based on Mann-Whitney test.		0.885	0.885

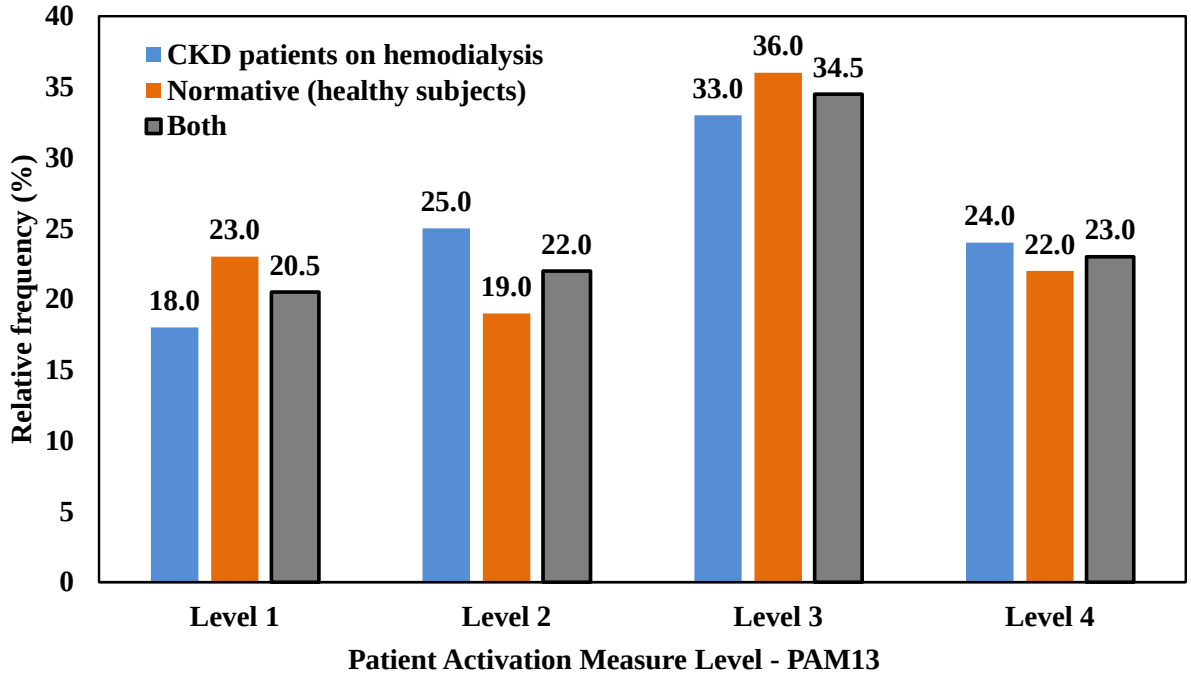
Table 3 - Multiple linear regressions for Patient Activation Measure (PAM13) score for patients with chronic kidney disease (CKD) undergoing hemodialysis and a normative sample of healthy self-referred subjects.

Hemodialysis and Normative Group					
PAM13 Score	**Predictor Variable [1]**	***Bi***	***SE***	***t***	***p***
Activation Score	Constant	59.76	1.96	30.54	< 0.001
	Schooling	5.38	1.67	3.22	0.002
	Practice Physical Activity	4.20	1.77	2.37	0.019
	Number Persons Who Co-Reside	-2.22	0.55	-4.04	< 0.001
Crude Score	Constant	40.41	0.76	53	< 0.001
	Schooling	2.12	0.64	3.29	0.001
	Practice Physical Activity	1.53	0.68	2.23	0.026
	Number Persons Who Co-Reside	-0.85	0.21	-4.01	< 0.001
Hemodialysis Group, independently					
Activation Score	Constant	66.69	3.01	22.13	< 0.001
	Schooling	6.55	2.43	2.69	0.008
	Gender	-4.69	2.36	-1.98	0.050
	Number Persons Who Co-Reside	-1.30	0,77	-1.67	0.098
	Type of Outpatient Clinic	-5.48	2.31	-2.37	0.020
	Presence of CKD Complications	-5.25	2.32	-2.26	0.026
Crude Score	Constant	41.75	0.97	42.82	< 0.001
	Schooling	2.27	0.93	2.43	0.017
	Gender	-2.11	0.87	-2.42	0.017
	Type of Outpatient Clinic	-2.04	0.88	-2.31	0.023
	Presence of CKD Complications	-2.15	0.88	-2.43	0.017

Legend: *Bi*: i-th estimate of model parameters; *SE*: standard error; *p:* probability based on Student's *t*-test .

[1] Coding of some predictor variables: Schooling (1 - complete or higher high school; 0 - incomplete or lower high school); Type of outpatient hemodialysis clinic origin (1 – public with public administration; 0 – public with private administration); Gender (1 - female; 0 - male); Presence of CKD complications (1 - yes; 0 - no).

Figure 1 – Patient Activation Measure (PAM13) activation levels of patients with chronic kidney disease (CKD), undergoing hemodialysis and a normative population of self-referred healthy subjects (Chi-square = 1.64; p = 0.649, $d.f.$ = 3).



3. Discussion

Self-management of health is an essential practice, today, for the maintenance and recovery of health. To this end, in this study, the application of the PAM13 instrument revealed that there are no differences in the self-care of patients in a group with CKD in HD in relation to a normative group. There is evidence of the benefits of self-care in the lives of these people with CKD. However, the negative repercussions of CKD on the biopsychosocial scope make it difficult to perform good health self-management practices [20].

CKD is a serious public health problem due to its high incidence and prevalence in the general population [21,22]. This problem is related to population aging, the advance in the number of cases of chronic diseases, such as hypertension and diabetes mellitus, as well as the increase in survival of chronic renal patients due to improved dialysis therapy and renal transplantation [21]. Despite being an indispensable treatment that makes it possible to prolong the life of chronic renal patients, hemodialysis implies negative impacts that affect physical, psychic and social changes. For the same population evaluated here also as observed prejudices in the quality of life[18]. Thus, the quality of life of these people is affected by several factors related to living with CKD, such as water and dietary restrictions, changes in appetite and weight, sleep disorder, decreased sexual interest, rigorous and continuous therapeutic regimens [23,24]. Often, CKD represents the loss of a healthy and active body, autonomy and changes in social and work activities (employment, economic stability, limitation of activities), change of family roles, changes in affective life, relationship of dependence (health professionals, family members, HD machine) [25].

Since CKD has an impact on the patient's quality of life and survival, preventing and decreasing complications of renal function replacement therapy has been a constant concern of health professionals [26]. The evaluation of the effects of chronic diseases and treatments on people's lives is of great importance in terms of public health [27]. Know their predictors also is essential, once that socioeconomic, demographic and clinical factors have a considerable impact on the quality of life of these people [18,28]. Knowledge of the profile of patients, risk factors, CKD diagnostic and treatment in the early stages, with the adoption of individualized and appropriate conducts can delay CKD evolution and avoid complications, improving the quality of life of patients and reducing treatment costs [29]. All these factors are considered when assessing self-care or self-management in health, since they are strategies that aim at gains in the health of this individual, because it reflects the greater willingness and aptitude of the individual to self-manage his/her chronic condition, to obtain better health results.

The difficulties in self-care were one of the problems most mentioned by patients[19]. Other study have found that there are challenges in self-management in health of people with different health conditions, such as diabetes mellitus and COPD [30] and need to be overcome. In the case of CKD, there is a lot of evidence of the benefits of self-care in the lives of these people. However, the negative repercussions of CKD on the biopsychosocial scope make it difficult to perform good health self-management practices [20].

Most of the participants in the study group were male and this is repeated in other studies conducted that talk about self-management of patients with CKD and other diseases [30-34]. The activation of patients was independently associated with the age and shows that in men self-care has a lower activation[35]. Here a different situation was found, with woman show lowers scores. The level of education was also a relevant factor, since most of the participants had incomplete high school. Other studies show that this influences the understanding and understanding of dismemberments of the individual's health condition, which consequently influences the patient's ability to self-manage his/her health [34]. In studies where participants have a higher level of education, it is possible to visualize the positive correlation with activation [36]. Thus, the expectation would be that the higher the level of education of the individual, the greater his/her ability to perceive the disease and its consequences, bringing more gains for its activation and health. The mean age of this study was lower than the study conducted by Zimbudzi and colleagues [35]. This study, conducted with patients with DM (Diabetes Mellitus) and CKD, found a relationship between advancing age with low activation of patients. In addition to showing that patients with DM have higher activation when compared to patients with CKD.

A study conducted in 2018 [33] showed that 44% of the population studying did not believe an important role in relation to their health care and 77% do not take care related to their treatment. This same study shows that the activation of CKD patients was low in relation to other chronic diseases. The authors used PAM13 and found that 44% of the patients had activation level 1, while at activation level 4; only 5% obtained this score. The combinations of dietary restrictions, strict medication control, and fluid control may explain the low activation of these patients.

In order to investigate the effects of self-management support on CKD progress, Chen et al. [32] found that patients who had greater training and knowledge about their health condition showed significant improvements in CKD delay. This research suggests that a support program can improve the search for

knowledge about CKD, encourage patients to develop a more active and collaborative role in their self-management and consequently reduce the rate of hospitalization.

The results of our study found activation scores of patients with CKD similar with a normative group, corresponding to activation level 3. This means that the individual studied understands the main factors that maintain or improve his/her health and with this begins to perform healthy behaviors. He/she is able to take action on maintaining lifestyles, with the aim of avoiding further problems in his/her health and handling symptoms. He/she is able to take action on maintaining lifestyles, with the aim of avoiding further problems in his/her health and handling symptoms. At this stage, it is necessary that the professional has an adequate communication with the patient, motivating the self-management of his/her [14,37].

The results found are evidence for health professionals to include the evaluation of this subjective construct in the clinical evaluation of patients with CKD and to seek strategies to improve the activation of these patients and reduce the risk of progression of CKD. A study shows that although the CKD patients do not present signs and symptoms of the disease that can be considered barriers to activation, the patient diagnosed with early CKD wants to self-manage his disease with the support of health professionals, which results in a delay in the progression of the disease [36]. This shows that the performance of the entire professional team is fundamental to increase the positive activation of these patients. All these strategies aim at gains in the health of this individual, based on the improvement of his self-care, the greater disposition and fitness of the individual in the self-management of his chronic condition, in order to obtain better health results.

Although this study reached the proposed objectives, there were some limitations, such as small sample size, lack of clinical intervention to improve the activation and the need for inclusion the more objective clinical variables and results of specific propaedeutic or laboratory tests related to CKD. On the other hand, these limitations can be overcome by conducting new, preferably longitudinal, studies based on the application of specific health interventions for this health condition. Even so, it was found that the results are quite important, because they add new evidence in the literature, which until then has been little addressed in the scientific community.

5. Conclusion

It was concluded that the activation scores from Patient Activation Measure (PAM13) of patients with chronic kidney disease in hemodialysis did not differ from those presented by the normative population (healthy self-referred subjects), corresponding to activation level 3. The time of formal education, the execution of physical activity and number of people living with the patient positively influence the activation score, when compared to both groups. The variables that positively influenced the activation of the chronic kidney disease patients in hemodialysis were be male, has higher education level, originated from public outpatient clinic with private administration and has no previous complications related to chronic kidney disease.

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