Original Article

Functional health literacy in chronic kidney disease patients: a challenge in the preventive approach

Letramento funcional em saúde em renais crônicos: um desafio na abordagem preventiva

Alfabetización funcional en salud en pacientes renales crónicos: un desafío en el enfoque preventivo

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Abstract

Objective: To identify the prevalence of functional health literacy and analyze the association between functional health literacy levels and clinical and sociodemographic variables in non-dialysis chronic kidney disease patients.

Methods: This is a cross-sectional study carried out with 167 chronic kidney disease patients being monitored at the nephrology outpatient clinic of a large city in the state of Minas Gerais, Brazil. For the interviews, a sociodemographic and clinical questionnaire and the Brazilian version of the Short Assessment of Health Literacy for Portuguese Speaking Adults (SAHLPA-18) were used to measure functional health literacy. Descriptive statistics were performed for sociodemographic and clinical variables, and correlation tests and linear regression models for association with functional health literacy.

Results: Most participants were older adults with a median age of 68 years, 33.3% (56 patients) were in stage 3B of chronic kidney disease and 53.9% (90 patients) had inadequate functional health literacy. There was no association between functional health literacy levels and clinical variables. The majority reported not using the internet and the more advanced stage of chronic kidney disease had lower literacy scores. Worse functional health literacy scores were also identified in those with lower income.

Conclusion: Most participants had inadequate functional health literacy. Clinical variables were not predictors of literacy scores. However, lower health literacy scores were identified in those with more advanced stage kidney disease, lower income and less internet use.

Resumo

Objetivo: Identificar a prevalência de letramento funcional em saúde e analisar a associação entre os níveis de letramento funcional em saúde e as variáveis clínicas e sociodemográficas em pacientes renais crônicos não dialíticos.

Métodos: Estudo transversal realizado com 167 renais crônicos em acompanhamento no ambulatório de nefrologia de um município de grande porte do estado de Minas Gerais, Brasil. Para as entrevistas foram utilizados questionário sociodemográfico e clínico e a versão brasileira do *Short Assessment of Health Literacy for Portuguese Speaking Adults* - SAHLPA-18, para mensurar o letramento funcional em saúde. Realizado estatística descritiva para variáveis sociodemográficas e clínicas; testes de correlação e modelos de regressão lineares para associação com letramento funcional em saúde.

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Conflict of interest: nothing to declare.

Resultados: A maior parte dos participantes era idosa com mediana de idade de 68 anos, 33,3% (56 pacientes) se encontravam no estágio 3B da doença renal crônica e 53,9% (90 pacientes) apresentaram letramento funcional em saúde inadequado. Não houve associação entre os níveis de letramento funcional em saúde e as variáveis clínicas. A maioria referiu não usar internet e o estágio mais avançado da doença renal crônica apresentou menores escores de letramento. Piores escores de letramento funcional em saúde também foi identificado naqueles com menor renda.

Conclusão: A maioria dos participantes apresentou letramento funcional em saúde inadequado. As variaveis clínicas não foram preditoras dos ecores de letramento. No entanto, escores mais baixos de letramento em saúde foram identificados naqueles em estágio mais avancado da doença renal, menor renda e menor uso da internet.

Resumen

Objetivo: Identificar la prevalencia de la alfabetización funcional en salud y analizar la asociación entre los niveles de alfabetización funcional en salud y las variables clínicas y sociodemográficas en pacientes renales crónicos no dializados.

Métodos: Estudio transversal realizado con 167 pacientes renales crónicos con seguimiento en consultorios externos de nefrología de un municipio de gran porte del estado de Minas Gerais, Brasil. Para las entrevistas se utilizó un cuestionario sociodemográfico y clínico y la versión brasileña del *Short Assessment of Health Literacy for Portuguese Speaking Adults* - SAHLPA-18, para medir la alfabetización funcional en salud. Se realizó estadística descriptiva para variables sociodemográficas y clínicas, pruebas de correlación y modelos de regresión lineales para asociación con alfabetización funcional en salud.

Resultados: La mayoría de los participantes eran personas mayores de 68 años de mediana de edad, el 33,3 % (56 pacientes) se encontraba en la etapa 3B de la enfermedad renal crónica y el 53,9 % (90 pacientes) presentó alfabetización funcional en salud inadecuada. No hubo asociación entre los niveles de alfabetización funcional en salud y las variables clínicas. La mayoría relató que no usaba internet y la etapa más avanzada de la enfermedad renal crónica presentó menor puntaje de alfabetización. Se identificaron peores puntajes de alfabetización funcional en salud en aquellos con menores ingresos.

Conclusión: La mayoría de los participantes presentó alfabetización funcional en salud inadecuada. Las variables clínicas no fueron predictoras de los puntajes de alfabetización. Sin embargo, se identificaron puntajes más bajos de alfabetización en salud en aquellos en etapa más avanzada de la enfermedad renal, con menores ingresos y menor uso de internet.

Introduction

Chronic health conditions play an important role in mortality rates in Brazil and around the world. Chronic kidney disease (CKD) is one of the chronic conditions with increasing prevalence and at a pace parallel to the increase in life expectancy. In Brazil, it is estimated that 13 million adults have some degree of CKD and most of them are unaware of this change in their health condition.[1–4]

As it is a chronic condition with a slow and insidious evolution, kidney disease must be identified as early as possible and managed in an integrated manner between health team and patients, in order to minimize progression to more serious phases.[5-7] It is known that, based on qualified education for self-care, patients' participation in decision-making and treatment is essential for autonomous choice and success in the proposed therapeutic approach.[8,9]

However, CKD self-management is closely influenced by adequate understanding of written and numerical instructions related to disease prognosis and its severity and also the importance of compliance with nephroprotective measures such as diet management and medication compliance.[10] People living with CKD need skills to perform basic reading and numerical tasks necessary to be functional in health settings, i.e., they need to have adequate functional health literacy (FHL) levels.[11]

As CKD progresses, the burden of disease management activity increases, while patients' ability to manage their health status may decrease due to increased symptoms, comorbidities, and reduced functional status. Thus, people with advancing health impairment associated with inadequate FHL levels are more vulnerable to worse outcomes.

In a recent systematic review on FHL in CKD, it was identified that hospitalizations, emergency room use, missed dialysis sessions, cardiovascular events and mortality were significantly associated with inadequate FHL.[10] However, studies with this focus are still scarce in Brazilian literature.[12–14]

In this sense, recognizing the importance of understanding the various contexts that involve care for chronic kidney disease patients and the ability to make assertive decisions in favor of their health, this study aimed to identify the prevalence of FHL and analyze the association between FHL and clinical and sociodemographic variables in non-dialysis chronic kidney disease patients.

Methods

This is an analytical cross-sectional study, developed in the nephrology outpatient clinic of a polyclinic of a large municipality in the Center-West of Minas Gerais/Brazil. To design the study, the cross-sectional studies proposed by Medronho *et al*. were used as a methodological framework.[4] Furthermore, the Strengthening Reporting of Observational Studies in Epidemiology Statement (STROBE) reporting guide was used as a way to identify compliance with all steps for a quality cross-sectional study. [15-17]

The eligible study population was made up of adult and older adult patients of both sexes, with an established diagnosis of CKD who were being monitored at the nephrology outpatient clinic. In addition to these characteristics, patients who presented adequate cognition assessed by the Mini Mental State Examination were included in the study,[18] whose score was equal to or greater than 27 points, which indicates the absence of cognitive decline and preserved senses (vision, hearing and speech), identified by the researcher at the time of invitation to participate in the research.

Patients who, at the time of collection, had neurological impairments were excluded, such as speech and reasoning limitations that prevented them from answering the questionnaire or even taking the Mini Mental State Examination, which is essential for participating in the research.

The sample size calculation was based on the total population of patients who began follow-up at the nephrology outpatient clinic in the period between June 2019 and June 2020, with a total of 262 people. For a 95% confidence level, 5% accuracy, 50% proportion for multiple outcomes, a sample of 157 patients was calculated.

Of the total of 181 people who attended the nephrology outpatient clinic during the study data collection period, 14 were excluded because they did not meet the inclusion criteria, as five did not have a confirmed diagnosis of CKD, seven did not reach the necessary score in the cognitive assessment by Mini Mental State Examination and two had hearing impairment. Thus, the study sample consisted of 167 people, with non-dialysis kidney disease and able to participate in the research.

Recruitment to participate in the study was carried out from March to June 2020, when patients attended a routine appointment scheduled at the nephrology outpatient clinic. Participants were approached in the waiting room and invited to answer the data collection questionnaires in a private location.

Data collection questionnaires prepared by the researchers were used for sociodemographic and clinical variables that are commonly described as factors that can influence CKD prognosis and management.[2,7] The Mini Mental State Examination was used for cognitive assessment as it is a simple and easy-to-apply instrument. The overall score is obtained by adding the items together, with a maximum value of 30 points. The reading of the results obtained with the sum varies according to the score: greater than or equal to 27 points suggests normal cognition; between 24 and 26 points suggests doubts regarding the decline in cognition; less than 24 points suggests cognitive decline; between 23 and 21 suggests a slight decline; between 20 and 11 suggests moderate decline; and less than 10 suggests serious decline.[13,15]

Investigating the cognitive status of people with kidney disease is an important clinical variable, since the decline in cognitive abilities can be evident even in patients who are still in the pre-dialysis phase.[19,20]

Thus, in order to minimize biases in the interpretation of FHL scores, cognitive function tracking was carried out as recommended in the literature.[21]

FHL was measured using the Short Assessment of Health Literacy for Portuguese Speaking Adults (SAHLPA-18), Brazilian version. The instrument contains 18 questions that assess individuals' ability to pronounce and understand medical terms used in clinical practice. The instrument score is obtained by adding the correctly pronounced and associated items, with each correct item corresponding to one point, ranging from 0 to 18 points. The FHL level is then classified as inadequate if the final score is less than or equal to 14 and adequate for scores greater than or equal to 15 points. The application

of SAHLPA-18 followed the instructions recommended by the authors.[21]

To characterize the population, a descriptive analysis of investigated variables was carried out, with the categorical variables presented using frequency distribution tables, and for continuous variables, position measures (median and quartiles) were used according to the normality distribution identified by the Shapiro-Wilk test.

For univariate analysis, the Mann-Whitney and Kruskal Wallis tests were performed with a post-test to identify the difference between the groups. Spearman correlation was also performed for continuous variables with asymmetric distribution. All variables that presented a p<0.20 were sent to multivariate linear regression analysis considering the continuous outcome of FHL. To ensure that the model had an adjustment without multicollinearities between the independent variables, the Variance Inflation Factor (VIF) measurement was checked: when 10 points were exceeded, the variable was excluded, even if it presented a good correlation with the response variable, since its result would be corrupted.

The significance level used was 0.05. Data analysis was performed using the Statistical Package for the Social Sciences (SPSS) version 21 software.

The research project was approved by an Institutional Review Board, Opinion 3.902.013 and CAAE (*Certificado de Apresentação para Apreciação Ética* - Certificate of Presentation for Ethical Consideration) 26414519.9.0000.5545.

Table 1. Association between sociodemographic characteristics and functional health literacy of patients with chronic kidney disease

Variables	Frequency (%)	FHL score median	Q1	Q3	p-value
Sex					
Female	83(49.7)	13.0	0.0	18.0	0.136*
Male	84(50.3)	15.0	3.0	18.0	
Religion					
Catholicism	115(68.9)	13.0	0.0	18.0	0.159*
Other	52(31.1)	17.0	0.0	18.0	
Education					
Illiterate	30(18)	-	-	-	≤0.001**
Incomplete elementary school (a)	78(46.6)	11.0	3.8	16.3	
Complete elementary school (b)	19(11.4)	17.0	16.0	18.0	
Incomplete high school to higher education (b)	40(24.0)	18.0	17.0	18.0	
Employed					
Yes	37(22.2)	18.0	14.5	18.0	≤0.001*
No	130(77.8)	9.5	0.0	17.0	
Family income					
Below 2 MW	148(88.6)	13.0	0.0	18.0	≤0.001*
From 2 MW to 3 MW	19(11.4)	18.0	15.0	18.0	
Used to reading					
Yes	36(21.6)	18.0	16.0	18.0	≤0.001*
No	131(78.4)	9.0	0.0	17.0	
Frequency of reading					
Always (a)	22(13.2)	18.0	15.5	18.0	≤0.001**
Sometimes (b)	15(9.0)	18.0	18.0	18.0	
Never (b)	130(77.8)	8.5	0.0	17.0	
What used to read:					
Newspaper (a)	17(10.2)	18.0	17.5	18.0	≤0.001**
Others (a)	19(11.4)	18.0	16.0	18.0	
Not used to reading (b)	131(78.4)	9.0	0.0	17.0	
Use internet					
Yes	61(36.5)	18.5	15.5	18.0	≤0.001*
No	106(63.5)	5.0	0.0	14.3	
Frequency of internet use					
Always (a)	55(32.9)	18.0	16.0	18.0	≤0.001**
Sometimes/rarely (b)	6(3.6)	13.5	10.3	16.5	
Never (b)	106(63.5)	5.0	0.0	14.3	

*Mann-Whitney test **Kruskal Wallis test with post-test. *MW: minimum wage: R$1,079.00 (US$215.80)/2020; *Q1-: first interquartile range **Q3: third interquartile range; Equal letters represent statistically equal groups (p > 0.05)

Results

Most participants were older adults, with a median age of 68 years, had a partner (55.4%) and self-reported white skin color. The sociodemographic and clinical characteristics of patients participating in the study and their associations with FHL are described in Table 1.

The median SAHLPA-18 score was 14 points (minimum of 0 and maximum of 18 points). More than half (53.9%) of individuals with CKD had an inadequate FHL level (score < 14 points). The correlation between age and FHL was significant and inverse (r2 - 0.575; p<0.001), indicating that the older the age, the lower the FHL skills. The association between clinical variables and FHL of people with CKD undergoing follow-up at a nephrology outpatient clinic is described in Table 2.

Finally, in linear regression, the variables frequency of internet use and family income remained in the final model. Frequent internet use had a negative coefficient, indicating that never having used the internet reduced the FHL score. Family income was higher, the higher the FHL scores, confirmed by the correlation with the positive coefficient (Table 3).

Table 2. Association between clinical variables and functional health literacy of patients with chronic kidney disease

Variables	Frequency (%)	FHL score median	Minimum	Maximum	p-value
Visit to the doctor in recent years					
Up to two	23(13.8)	5.0	0.0	17.0	0.023*
Appointment with nephrologist					
None	30(18)	15.5	0.0	18.0	0.732**
One or two	35(21.0)	10.0	4.0	17.0	
More than two	102(61.0)	14.0	0.0	18.0	
Stage of chronic kidney disease					
Stage 1 (a)	26(15.8)	18.0	15.8	18.0	≤0.001**
Stage 2 (a) (b)	21(12.7)	16.0	13.0	18.0	
Stage 3A (b) (c)	26(15.8)	13.5	0.0	18.0	
Stages 3B and 4 (c)	92(55.08)	6.5	0.0	17.0	

* Mann-Whitney test **Kruskal Wallis test with post-test. Equal letters represent statistically equal groups ($p > 0.05$).

Table 3. Final multiple linear regression model between frequency of internet use and family income with functional health literacy of people with chronic kidney disease

Variables	Coefficient	t	Sig.	VIF
Frequency of internet use	-0.222	-2.019	0.045	1.419
Family income	0.208	2.534	0.012	1.243

R2: 28.4%

Discussion

Naturally, the advancement of CKD requires more rigorous management, both by the multidisciplinary team and by the patients themselves to maintain balanced health.[22,23] However, simultaneously with this need, these patients often find themselves with a reduced general capacity to deal with their health condition.[24] This happens due to the clinical manifestation of disease increasing concomitantly with the progression of impairment of renal functions.[25] For this reason, interventions to improve FHL, i.e., to develop specific skills to manage prescribed activities, are often necessary to meet the immediate objectives of renal protection. In such circumstances, people need the knowledge and skills necessary to achieve results that are determined mainly by the multidisciplinary team.

However, the results of this study showed that more than half of people with CKD still in non-dialysis stages had inadequate FHL, as already evidenced in other studies.[22,23] In other words, they had limited abilities to obtain relevant information about their health, such as difficulty in following the guidelines prescribed by health professionals and even difficulty in using the health system.[26-28]

In this regard, the concern of this finding is highlighted here, as it is worrying to identify that the people involved in this study did not have the minimum FHL necessary to take care of themselves and preserve their kidney health. It is necessary to think about what would be the weak point of the entire care process that did not provide the development of basic skills for self-protection.

The answer is broad and difficult to describe. Perhaps the justification for this lack of knowledge on the part of patients is that sometimes these decisions are not assertive in favor of their health, which reinforces the warning for late diagnosis of CKD.[23] The health team does not approach these people preventively and refers them to specialized care late, and they themselves do not seek care early because they will only feel the clinical manifestations resulting from renal impairment when they have already lost more than 50% of the nephronic mass.[29,30] Therefore, it is understood that efforts must be made to promote health actions that aim to improve FHL levels, and consequently make people active in preserving their health.

These findings were also described in other national and international studies.[22,31,32] Among national studies, there was consensus on the predominance of the lack of adequate FHL when the population studied were people with non-dialysis CKD.[31,32] In these studies, inadequate FHL was associated with lower rates of adherence to drug therapies, less knowledge about CKD, and less ability to take care of oneself.

On the other hand, an American cross-sectional study, with a baseline from the Kidney Awareness Registry and Education (KARE) cohort study, showed that FHL was not uniformly associated with all self-care behaviors important for CKD management.[33] This points to the importance of more studies being carried out to better understand the association between FHL and self-care, in order to promote nephroprotective behaviors to delay CKD progression.[13]

In addition to identifying FHL levels themselves, this study sought to understand which factors could be associated with the low scores identified, in which it was evident that the frequency of

internet use and family income were independently associated with the worst FHL outcomes.

With regard to internet use, it would be plausible to say that the habit of reading precedes and facilitates it, which could improve the path to reaching the information provided by this technological resource as a way of improving the capture of knowledge and understanding of the information provided in the context of health care. However, 80% of people participating in this study did not have reading habits and 63.5% reported never using the internet.

These findings suggest a review of current preventive proposals implemented with the intention of improving patients' knowledge and skills to manage their health.[34]

Thus, the Brazilian society of nephrology has been investing emphatically in media and educational materials that are displayed on the internet with the aim of raising awareness among the entire population about the need to take care of their kidney health. The question, however, is: What is the real scope of this investment in changing people's attitude towards the disease in order to make assertive decisions in favor of their own health?[35,36] It is understood that these measures are very far from transforming the limited care scenario for chronic kidney disease patients in the non-dialysis phase and that new intervention proposals need to be thought of to, in fact, reach people with CKD in a transformative way.[37,38]

Another socioeconomic aspect that reflected in inadequate FHL was family income. Lower income had a negative impact on FHL, which was also observed in a study, in which people who had lower social conditions had lower FHL levels.[39,40] The authors drew attention to the fact that these results provide insights into the relationship between FHL and socioeconomic position in vulnerable groups. Therefore, it is necessary to think about guidelines for the development of equitable interventions that are equivalent to the socioeconomic conditions of patients. It is believed that people in unfavorable social conditions may have insufficient FHL and, consequently, are more susceptible to worse clinical outcomes.[41,42]

Proposals to enable equity in care provision need to be explored in order to identify effective and applicable interventions in different social contexts, with varying levels of reading and internet access to improve FHL and allow patients to be co-responsible for managing their health.

Finally, although the importance of the findings of this study is recognized, limitations must be mentioned. At first, not that this is a specific limitation of this study, but, when using a cross-sectional and unicentric design, it is assumed the impossibility of identifying the cause and effect relationship of the variables studied. However, even without this identification, carrying out a thorough discussion about the findings, both descriptive and the association worked with the Odds Ratio and its impact on clinical care, minimizes the fragility arising from biases inherent to the study design.

Furthermore, even though it is unicentric, the methodological rigor used made it possible to guarantee internal validity. The fact that the study sample sociodemographic characteristics are similar to others that explored FHL in people living with CKD contributes to the transposition of these results to have external validity. [43,44]

The study contributed to the literature in which it shows that even chronic kidney disease patients in the most advanced stage of the disease have difficulty understanding their health condition. This highlights the need for research that aims to assess and adapt the way in which educational health actions are carried out with chronic kidney disease patients, in order to strengthen communication between professionals and patients.

Therefore, it would be extremely necessary to strengthen the partnership between academia and clinical practice in order to develop robust studies that can generate reliable evidence and help guide decision-making, especially when assisting non-dialysis chronic kidney disease patients.

Conclusion

Most non-dialysis chronic kidney disease patients had inadequate FHL. Clinical variables were not pre-

dictors of literacy scores. Those with lower income and less internet use had lower abilities to perform basic reading and numerical tasks necessary for self-management of their health condition. We believe that the findings of this study brought an important warning regarding the need to review the format of the strategies adopted by the health team to offer information on preventive and protective measures to non-dialysis chronic kidney disease patients. Furthermore, it is necessary to explore health literacy beyond its functional aspect to have a better understanding of the barriers encountered by people with chronic kidney disease in accessing, understanding and using health information for themselves and others. It is also necessary to investigate how health services are prepared to meet the diverse health literacy conditions of this population.

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Collaborations

Ribeiro FHR, Cortez EN, Romano MCC, Pinto FM, Martins MAP, Morais FA, Moraes KL and Otoni A contributed to study design, data analysis and interpretation, article writing, relevant critical review of intellectual content and approval of the final version to be published.

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