

Functional health literacy in renal replacement therapy: an integrative review

Letramento funcional em saúde na terapia renal substitutiva: revisão integrativa
Alfabetización funcional en salud en terapia de reemplazo renal: revisión integradora

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Abstract

Objective: To analyze the instruments available to identify the functional health literacy level of patients submitted to renal replacement therapy.

Methods: Integrative review carried out by searching publications in the PubMed, Scientific Electronic Library Online, Cumulative Index to Nursing and Allied Health Literature, and Web of Science databases between October 2017 and January 2018. Full original articles in English, Spanish, or Portuguese made available from 2010 to the moment the search was performed were included. The descriptors used in the search were hemodialysis, peritoneal dialysis, transplantation, renal dialysis patient information, and health literacy.

Results: Sixteen out of the 4,286 studies found were included to be analyzed. It was observed that 12 different instruments were used, with the Rapid Estimate of Adult Literacy in Medicine and the Newest Vital Sign being the most frequently used tools, applied in four and three studies, respectively. Twelve instruments were applied in patients submitted to hemodialysis, three in those who underwent peritoneal analysis, and three were specific to patients who went through kidney transplant. The most recent tools have assessed social aspects, self-care, and management and understanding capacity in patients under renal replacement therapy.

Conclusion: The twelve instruments to measure functional health literacy in patients under renal replacement therapy show satisfactory psychometric properties, but only one is validated to be used in Brazil. The insufficient use of tools to evaluate literacy in patients undergoing peritoneal dialysis was noteworthy.

Resumo

Objetivo: Analisar os instrumentos disponíveis para a identificação do grau de letramento funcional em saúde dos pacientes submetidos a terapia renal substitutiva.

Métodos: Trata-se de uma revisão integrativa, realizada nas bases de dados PubMed, SciELO, CINAHL e *Web of Science*, entre outubro de 2017 a janeiro de 2018. Foram incluídos artigos originais completos, disponíveis a partir do ano de 2010 até o momento da busca e nos idiomas inglês, espanhol e português. Os descritores utilizados foram: *hemodialysis*, *peritoneal dialysis*, *transplantation*, *renal dialysis patient information* e *health literacy*.

Resultados: Dos 4.286 estudos encontrados na busca, 16 foram incluídos para análise. Doze instrumentos diferentes foram utilizados, sendo as ferramentas mais aplicadas o *Rapid Estimate Adult Literacy of Medicine* (REALM), utilizado em quatro pesquisas e o *Newest Vital Sign* (NVS), usado em três estudos. Doze instrumentos foram aplicados em pacientes submetidos a hemodiálise, três nos indivíduos em diálise peritoneal e foram encontrados três instrumentos específicos para transplantados renais. As ferramentas mais atuais têm avaliado aspectos sociais, autocuidado e capacidade de gerenciamento e entendimento dos pacientes em

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terapia renal substitutiva.

Conclusão: Os doze instrumentos para mensuração do letramento funcional em saúde para uso em pacientes em terapia renal substitutiva apresentam propriedades psicométricas boas, porém, apenas um está validado no Brasil. Ressalta-se a lacuna de uso de ferramentas que avaliem o letramento nos pacientes em diálise peritoneal.

Resumen

Objetivo: Analizar los instrumentos disponibles para identificar el nivel de alfabetización funcional en salud de los pacientes que realizan terapia de reemplazo renal.

Métodos: Se trata de una revisión integradora, realizada en las bases de datos PubMed, SciELO, CINAHL y *Web of Science*, entre octubre de 2017 y enero de 2018. Se incluyeron artículos originales completos, disponibles a partir de 2010 hasta el momento de la búsqueda, en los idiomas inglés, español y portugués. Los descriptores utilizados fueron: *hemodialysis, peritoneal dialysis, transplantation, renal dialysis patient information y health literacy*.

Resultados: De los 4.286 estudios encontrados en la búsqueda, se incluyeron 16 en el análisis. Se utilizaron 12 instrumentos diferentes y las herramientas más aplicadas fueron *Rapid Estimate Adult Literacy of Medicine (REALM)*, utilizado en cuatro estudios, y *Newest Vital Sign (NVS)*, utilizado en tres estudios. Se aplicaron 12 instrumentos a pacientes que realizaban hemodiálisis, tres a individuos en diálisis peritoneal y se encontraron tres instrumentos específicos para trasplantados renales. Las herramientas más actuales evaluaron aspectos sociales, autocuidado y capacidad de gestión y comprensión de los pacientes en terapia de reemplazo renal.

Conclusión: Los 12 instrumentos para medir la alfabetización funcional en salud de pacientes en terapia de reemplazo renal presentaron propiedades psicométricas buenas, pero solo uno está validado en Brasil. Se destaca un vacío en el uso de herramientas que evalúen la alfabetización de pacientes en diálisis peritoneal.

Introduction

Chronic kidney disease (CKD), which is increasing worldwide, is associated with the increase in the risk for hospital admissions and morbidities, contributing significantly to all the cardiovascular causes of death.^(1,2) It is estimated that over 2 million people are submitted to dialysis or kidney transplant, but this number might represent only 10% of the population that really needs these treatments to survive.⁽³⁾

The incidence of people under dialysis increased 37% approximately from 2007 to 2016 in patients under renal replacement therapy (RRT) in Brazil.⁽⁴⁾ Around 92.1% of the patients have the replacement performed with the application of hemodialysis, 7.9% with the use of peritoneal dialysis, and an estimated number of 29,000 people are in the waiting list to go through a kidney transplant.⁽⁴⁾

Given the prevalence and incidence of CKD in the population and the complexity of its treatment, shared decision-making and self-care management are essential characteristics to obtain success in the clinical outcomes of these patients.^(5,6) These factors can be considerably influenced by the level of functional health literacy (FHL) or health literacy, which consists in the capacity people have to obtain, process, and understand basic health information and services necessary for them to make pertinent decisions regarding health and health care.^(6,7)

Initial reading instructions and literacy are inseparable concepts from the educational point of view. The former means enabling a person to read and write, and the latter refers to the skills to use this system in reading and writing activities.⁽⁸⁾ The term “functional”, added to “literacy”, concerns people’s skills to apply reading, writing, and numeracy whenever it is necessary to carry out a certain activity or obtain new knowledge fundamental to personal development and the social context in which they are inserted.⁽⁹⁾

A recent metanalysis showed that inadequate FHL (43.47%) was more prevalent in people with diabetes mellitus⁽¹⁰⁾, and another study indicated that, among 137 patients with CKD, 26% had a limited FHL.⁽¹¹⁾ Similar findings in other studies are associated with a lower quality of life,⁽¹²⁾ lower adherence to drug treatment,⁽¹³⁾ insufficient attendance to medical appointments⁽¹⁴⁾, and lower hospital admission rates,⁽¹⁴⁾ which have a negative impact on the clinical outcome of these patients.

Specific instruments, which have been validated in Portuguese and adapted to the Brazilian reality, are necessary for nurses to assess the FHL level and select the result of their interventions. Consequently, identifying the available tools and knowing their characteristics and psychometric properties may help guide the selection conduct for their use in clinical practice and be the basis of fu-

ture studies focused on their translation and trans-cultural adaptation.

The objective of the present study was to analyze the instruments available to identify the FHL level in the population submitted to RRT.

Methods

This is an integrative literature review, which allows to investigate qualitative and/or quantitative studies and offers the possibility to examine several methods. The conclusions reported in the studies, when evaluated systematically and arranged orderly, can potentially be applied to clinical practice.⁽¹⁵⁾

The present study was developed according to the following steps: identification of the theme and selection of the hypothesis or research question, establishment of inclusion and exclusion criteria for studies and samples as well as for the search in the literature, definition of the information to be extracted from the studies and their categorization, evaluation of the included studies, interpretation of results, and presentation of the review and synthesis of the knowledge.⁽¹⁶⁾

The inclusion criterion applied in the search and selection of publications was full original papers in English, Spanish, or Portuguese available in databases from 2010 (the period in which the descriptor “health literacy” was made available) until the moment the search was carried out. The studies had to be indexed in at least one of the following databases: PubMed, Scientific Electronic Library Online, Cumulative Index to Nursing and Allied Health Literature, and Web of Science.

According to the terminology used on Health Science Descriptors, the studies had to be localizable by using the following terms: hemodialysis, peritoneal dialysis, transplantation, renal dialysis patient information, and health literacy. The Boolean operators “and” and “or” were used in the expression “peritoneal dialysis or renal dialysis or transplantation or hemodialysis and health literacy or patient education” to systematize the search in the literature. Repeated publications, monographs, dissertations, theses, and publica-

tions whose only section made available was the abstract were excluded.

Data collection occurred between October 2017 and January 2018 and was carried out by two independent researchers who, after selecting the articles, first evaluated their title, then their abstract and, in a last step, read the full text of the publication.

Results

The instruments that assess FHL can be general or specific, and the present study aimed to analyze the tools available to evaluate patients with CKD undergoing RRT. The search resulted in 4,286 publications, of which 16 were selected for analysis (Chart 1). It is important to emphasize that the Scientific Electronic Library Online database had only three publications, which were not pertinent to the scope of the present review.

Chart 1. Selection of scientific papers to be included in the integrative review

Search in databases	Publications: 4,286			
Application of inclusion and exclusion criteria	Not applicable to the guiding question of the study: 4,243	A duplicate was found in another database: 18	Excluded for being a letter to the editor or having only the abstract available: 7	Not available as full text: 2
Total number of selected papers	PubMed: 16 papers			

Twelve instruments were used to assess the FHL level of patients submitted to RRT. They are described in Chart 2.

Regarding the places where the studies were carried out, the United States showed a marked prevalence (n=11), followed by Australia (n=2), Canada (n=1), Singapore (n=1), and Taiwan (n=1). The first study about the subject was published in 2010⁽²⁸⁾ and there was an increase in the number of articles addressing this theme in 2015.^(19,21,22,25)

Examination of the level of evidence⁽³²⁾ of the studies showed that 12 were classified as belonging to level 6,⁽¹⁷⁻²⁸⁾ of which two refer to the design of instruments to measure literacy applied in patients submitted to hemodialysis⁽²⁰⁾ and those who received

Chart 2. Instruments to evaluate functional health literacy in patients under renal replacement therapy

Author(s)	Instrument	Evaluated aspects/classification	Known psychometric properties
Demian MN, et al. ⁽¹⁷⁾ Dodson S, et al. ⁽¹⁸⁾	<i>Health Literacy Questionnaire</i> (HLQ)	It evaluates skills necessary for health literacy: feeling understood and supported by healthcare providers; management of one's health; social support for health; navigating the healthcare system; understanding health information well enough to know what to do regarding health. Classification: 44 items, organized into nine domains, each one with four to six levels of agreement in a Likert scale. Higher scores indicate a higher health literacy level.	Cronbach's alpha from 0.77 to 0.90
Lambert K, et al. ⁽¹⁹⁾	<i>Health Literacy Management Scale</i> (HeLMS)	It evaluates skills necessary for health literacy: patients' attitudes and capacity to be proactive regarding their health; understanding of health information; social support; socioeconomic considerations for the access to healthcare services; accessing general practice healthcare services; communication with health professionals; and using health information. Classification: 29 items, organized into eight domains. The answers are scored in a 5-point Likert scale and dichotomized into no difficulty (score equal to 5 in the scale) and any difficulty level (score varying from 1 to 4 in the scale). Higher scores indicate a higher health literacy level.	Cronbach's alpha from 0.82 to 0.89
Chiu CH, et al. ⁽²⁰⁾	Health literacy in Chinese	It has 52 items, organized into two sections: health literacy (categorized into seven literacy constructs: functional, communicative, interactive, critical, basic health knowledge, advanced health knowledge, and patient safety) and demographic data. Classification: 1 point per correct answer in multiple-choice questions, with minimum and maximum scores of 0 and 26 points, respectively. Higher scores indicate a higher health literacy level.	Cronbach's alpha = 0.81
Cavanaugh KL, et al. ⁽²¹⁾	<i>Brief Health Literacy Screen</i> (BHLS)	It consists of three questions that evaluate patients' self-confidence, the frequency with which they need help to read documents related to their health, and the understanding they have of their health condition. Classification: Each question can receive a maximum score of 5 points and a minimum score of 1 point. The scores of the three questions are summed to produce a total score from 3 to 15 points, with a score ranging from 3 to 9 points indicating limited literacy and a score ranging from 10 to 15 points suggesting adequate literacy.	The area under the receiver operating characteristic curve for each question was 0.87, 0.80, and 0.76.
Kazley AS, et al. ⁽²²⁾	<i>Rapid Estimate of Adult Literacy of Medicine-Transplant</i> (REALM-T)	It brings 69 words that must be correctly pronounced out loud by patients. Classification: A score between 60 and 69 points to adequate health literacy; a score from 45 to 59 indicates marginal health literacy; and a score equal to or lower than 44 shows inadequate literacy.	Cronbach's alpha = 0.94
Kazley AS, et al. ⁽²³⁾ Escobedo W, et al. ⁽²⁴⁾	<i>Newest Vital Sign</i> (NVS)	It consists of two medical prescriptions and questions about each one of them, which make patients read, understand, and search for information. Classification: A score between 4 and 6 points to adequate health literacy; a score from 2 to 3 indicates marginal health literacy; and a score equal to 0 or 1 shows inadequate literacy.	Cronbach's alpha > 0.76 for the instrument in English and 0.69 for the version in Spanish.
Kazley AS, et al. ⁽²²⁾ Kazley AS, et al. ⁽²³⁾	<i>Decision-Making Capacity Assessment Tool</i> (DMCAT)	It has six questions that evaluate the knowledge and understanding of dialysis and the transplantation process. Classification: 3 points per correct answer, with the maximum score equal to 18. Higher scores indicate better knowledge.	Pearson's correlation coefficient between 0.56 and 0.73 and acceptable test-retest reliability and reliability between evaluators (0.65).
Jain D, et al. ⁽²⁵⁾ Green JA, et al. ⁽²⁶⁾ Green JA, et al. ⁽²⁷⁾ Cavanaugh KL, et al. ⁽²⁸⁾	<i>Rapid Estimate of Adult Literacy in Medicine</i> (REALM)	It brings 66 words that must be correctly pronounced out loud by patients. Classification: A score between 60 and 66 points to adequate health literacy; a score from 45 to 59 indicates marginal health literacy; and a score equal to or lower than 44 shows inadequate literacy.	*It shows a satisfactory correlation with other literacy tests and has high test-retest reliability.
Lai AY, et al. ⁽²⁹⁾	<i>Functional, Communicative and Critical Health Literacy</i> (FCCHL)	It has 14 items: five addressing functional literacy (evaluates basic reading and writing skills), five concerning communicative literacy (capacity to extract information from varied media), and four related to critical literacy (capacity to critically evaluate the information about one's own health). Classification: Likert scale with a score ranging from 1 to 4 (indicating never to often) for each item. The scores of the items in each subscale are summed and the result is shared by the number of items that make up the subscale. Higher scores indicate a higher health literacy level.	The Cronbach's alpha for functional, communicative, and critical literacies was 0.84, 0.77, and 0.65, respectively.
Brice JH, et al. ⁽³⁰⁾	<i>Single item literacy screener</i> (SILS)	It consists of a question that assesses the understanding that patients have when they read materials related to their health. Classification: Likert scale varying from 1 to 5, indicating from never to always. Higher scores indicate a higher health literacy level.	The area under the receiver operating characteristic curve was 0.67 (0.60 to 0.74).
	<i>Two-item literacy screener</i> (TILS)	It consists of two questions that evaluate the reading capacity and frequency of different materials. Classification: Likert scale varying from excellent to very bad.	The area under the receiver operating characteristic curve was 0.66 (0.59 to 0.73).
Brice JH, et al. ⁽³⁰⁾ Adeseun GA ⁽³¹⁾	<i>Short Test of Functional Health Literacy in Adults</i> (S-TOFHLA)	Patients are asked to choose one out of four options that fits best in the context of a sentence. This part of the instrument has 36 blank spaces to be filled out and aims to assess the reading understanding. The tool also has four cards (medical prescriptions and appointment schedules) that evaluate the numbering capacity. Classification: A score between 23 and 36 is considered adequate health literacy; a score from 17 to 22 indicates marginal health literacy; and a score between 0 and 16 shows inadequate literacy.	The Cronbach's alpha was 0.68 for the 36 reading items and 0.97 for the images of the instrument.

*The psychometric data of this paper were not available for evaluation

a kidney transplant.⁽²⁴⁾ Four publications were classified as belonging to level 4 and were cohort studies that aimed to evaluate the outcomes in patients under RRT according to the FHL level.^(29-31,33)

Most of the analyzed tools had English as their original language and did not go through a pro-

cess of validation and transcultural adaptation for other languages. The NVS^(23,24) and DMCAT^(22,23) tools are available in English and Spanish, and the REALM⁽²⁵⁻²⁸⁾ instrument, in addition to being found in these two languages, was translated into and validated for Brazilian Portuguese.⁽³⁴⁾

It must be stressed that the BHLS instrument⁽²¹⁾ was used by Dageforde et al.⁽³³⁾ but called Short Literacy Screen (SLS). The two tools are the same, but the cutoffs for literacy classification differ between them. Cavanaugh et al.⁽²¹⁾ used the instrument score according to the description reported in its validation study.

The REALM tool was the first used to evaluate literacy in this population, in 2010,⁽²⁸⁾ and it was also applied in other three studies included in the sample of the present review.⁽²⁵⁻²⁷⁾ The two more recent studies were published in 2016 and used the HLQ tool, which also assesses the subjectivity of patients regarding the information received in health services.^(17,18)

It must be emphasized that three specific tools that evaluate the FHL level in patients who underwent kidney transplantation were found: NVS in its version adapted for transplantation, which consists of interpreting two medical prescriptions; REALM-T, which assesses the reading and pronunciation of 69 health terms;⁽²²⁾ and the DMCAT, whose proposal is evaluating the capacity of patients to recognize the symptoms of terminal CKD and the dialysis and transplantation processes.^(22,23)

Discussion

The present study identified 12 instruments that have been used to assess patients' literacy in RRT. Initially, these tools had the objective of evaluating only the numerical capacity of patients and/or their ability to understand what they read, but more recent studies have introduced instruments that assess patients' general characteristics, such as their understanding of their disease and bureaucratic processes in health services.^(17,19,30)

Regarding the instruments used to evaluate patients going through dialysis, all the tools except SLS were applied in patients submitted to hemodialysis, possibly because this is the therapy with the highest prevalence and incidence in people with dialytic CKD. Only three out of the 12 studies included in the present review were applied in patients that undergo peritoneal dialysis, which points to the lack of investigations focused on examining

this population. However, it must be emphasized that this is the method in which patients depend on their understanding and self-care the most.^(18,19,25)

The REALM tool, the one used most often, was developed in the 1990s to be an instrument for quick screening in the identification of patients with limited reading skills. Other tools emerged afterwards, but many of them are based on that model, which is restricted to reading and pronunciation of terms without taking into account that patients can merely reproduce words that they usually hear at health services.

The first study that evaluated FHL in patients who had undergone kidney transplantation was published in 2013 and resorted to the NVS tool, which was designed based primarily on six questions about an ice cream nutritional label.⁽²⁴⁾ Although understanding written medical guidance is part of FHL, other aspects, such as knowledge of the disease, social support, and bureaucratic proceedings in health services are not assessed in this instrument. The DMCAT considers exclusively the knowledge of dialysis and of the transplantation process.^(22,23)

Currently, the importance of treating people in their disease process holistically has been emphasized, including not only the understanding of the received information but also the bond with healthcare professionals, self-care, and social support, among other aspects.⁽¹⁸⁾ As shown in more recent publications, the tendency is that FHL evaluation instruments encompass the items just mentioned, which can already be found in the HLQ^(17,18) and HeLMS.⁽¹⁹⁾

The HLQ is a self-report questionnaire with 44 items organized into nine domains with answers classified according to a 4-point Likert scale.⁽³⁵⁾ Its validation was carried out with patients who had heart disease and diabetes rather than with the population with kidney disease.⁽¹⁷⁾ This instrument assesses the active health management capacity, the social support to one's own health, health information, the capacity to actively interact with healthcare professionals, and the navigation in the healthcare system.⁽³⁵⁾

Similarly to the HLQ, the HeLMS tool is a self-report questionnaire, with eight domains, totaling 29 questions, and was validated in patients who had chronic diseases.⁽³⁶⁾ Five domains focus on people's skills (understanding of health informa-

tion, access to health services, communication with healthcare providers, proactivity, and use of health information) and three domains address more comprehensive factors, such as attitudes, social support, and socioeconomic characteristics.⁽¹⁹⁾

It is noteworthy that the only instrument translated into Brazilian Portuguese, adapted transculturally, and validated is an adapted version of the REALM, whose title was changed to Short Assessment of Health Literacy for Portuguese-speaking Adults (SAHLPA).⁽³⁴⁾ The S-TOFHLA has been translated and adapted, but it has not been validated, which is required for it to be used.⁽³⁷⁾

Taking into account the findings in the literature, it is important to stress that other characteristics were evaluated concomitantly to FHL, such as adherence to drug treatment in patients who submitted to a kidney transplantation,⁽¹⁷⁾ the quality of life of those who undergo hemodialysis,⁽¹⁸⁾ the evaluation of cognitive aspects by applying the mini-mental state examination^(21,28), and laboratory parameters, including phosphorus and serum albumin, to verify the association of the understanding capacity with the observance of a proper diet.^(18,28)

The instruments found in the present review show satisfactory psychometric properties, although most researchers evaluated internal reliability with Cronbach's alpha, which can be influenced by the number of items of the tool.⁽³⁸⁾ However, it is necessary to go beyond numerical evaluation and ponder about the complex meaning of FHL and which instrument would be suitable to measure it.

The present study is original, because it is the first literature review on this subject. Although the search for scientific papers included publications in English, considered the prevailing language in scientific literature, the fact that the search was limited to papers in only three idioms can be considered a limitation and may have prevented the inclusion of studies published in other languages.

Conclusion

There are different instruments that assess the FHL level, but none of them is validated to be applied in

Brazil in the population under RRT, except for patients submitted to kidney transplantation. Despite this fact, the results of the application of some of these tools can be compared in this population because, overall, the instruments evaluate similar aspects, such as recognition, reading, and pronunciation of words used in health services. Although the psychometric properties of all the tools identified in the present review are acceptable and indicate the instruments' reliability and validity, the authors recommend translation, transcultural adaptation, and validation in Brazilian Portuguese of the tools that evaluate comprehensive aspects of patients, especially those under RRT, for instance self-management and capacity to understand information, to optimize these people's treatment.

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