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.
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 publications 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.

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**

<table>
<thead>
<tr>
<th>Author(s)</th>
<th>Instrument</th>
<th>Evaluated aspects/classification</th>
<th>Known psychometric properties</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demian MN, et al.</td>
<td>Health Literacy Questionnaire (HLQ)</td>
<td>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.</td>
<td>Cronbach’s alpha from 0.77 to 0.90</td>
</tr>
<tr>
<td>Dodson S, et al.</td>
<td>Health Literacy Management Scale (HeLMMS)</td>
<td>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.</td>
<td>Cronbach’s alpha from 0.62 to 0.89</td>
</tr>
<tr>
<td>Lambert K, et al.</td>
<td>Health literacy in Chinese</td>
<td>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.</td>
<td>Cronbach’s alpha = 0.81</td>
</tr>
<tr>
<td>Chiu CH, et al.</td>
<td>Health literacy in Chinese</td>
<td>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.</td>
<td>Cronbach’s alpha = 0.81</td>
</tr>
<tr>
<td>Cavanaugh KL, et al.</td>
<td>Health Literacy in Chinese</td>
<td>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.</td>
<td>Cronbach’s alpha = 0.81</td>
</tr>
<tr>
<td>Green JA, et al.</td>
<td>Health Literacy in Chinese</td>
<td>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.</td>
<td>Cronbach’s alpha = 0.81</td>
</tr>
<tr>
<td>Jain D, et al.</td>
<td>Health Literacy in Chinese</td>
<td>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.</td>
<td>Cronbach’s alpha = 0.81</td>
</tr>
<tr>
<td>Kazley AS, et al.</td>
<td>Health Literacy in Chinese</td>
<td>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.</td>
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<td>Kazley AS, et al.</td>
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</tr>
<tr>
<td>Brice JH, et al.</td>
<td>Health Literacy in Chinese</td>
<td>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.</td>
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<tr>
<td>Lamberti K, et al.</td>
<td>Health Literacy in Chinese</td>
<td>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.</td>
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</tr>
</tbody>
</table>

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

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. Most of the analyzed tools had English as their original language and did not go through a process of validation and transcultural adaptation for other languages. The NVS and DMCAT tools are available in English and Spanish, and the REALM instrument, in addition to being found in these two languages, was translated into and validated for Brazilian Portuguese.
It must be stressed that the BHLS instrument\textsuperscript{(21)} was used by Dageforde et al.\textsuperscript{(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.\textsuperscript{(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,\textsuperscript{(28)} and it was also applied in other three studies included in the sample of the present review.\textsuperscript{(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.\textsuperscript{(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;\textsuperscript{(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.\textsuperscript{(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.\textsuperscript{(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.\textsuperscript{(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.\textsuperscript{(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.\textsuperscript{(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.\textsuperscript{(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\textsuperscript{(17,18)} and HeLMS.\textsuperscript{(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.\textsuperscript{(35)} Its validation was carried out with patients who had heart disease and diabetes rather than with the population with kidney disease.\textsuperscript{(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.\textsuperscript{(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.\textsuperscript{(36)} Five domains focus on people’s skills (understanding of health informa-
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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). The S-TOFHLA has been translated and adapted, but it has not been validated, which is required for it to be used.

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, the quality of life of those who undergo hemodialysis, the evaluation of cognitive aspects by applying the mini-mental state examination, and laboratory parameters, including phosphorus and serum albumin, to verify the association of the understanding capacity with the observance of a proper diet.

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. 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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