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REVIEW PAPER

Health Literacy of Candidates Undergoing or Submitted to Kidney Transplantation: An Integrative Literature Review

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ABSTRACT

Objective: To describe the repercussions of health literacy (HL) in patients with Chronic Kidney Disease (CKD) candidates for or undergoing kidney transplantation (TxR). **Methodology:** Integrative review, carried out with the systematic selection of articles in the PubMed, Portal BVS and SciELO databases in August 2021. 62 articles were identified, of which 17 were selected for synthesis. **Results:** Most of the analyzed studies developed an observational or qualitative design. The limited HL has several impacts on patients' decision-making processes, resulting in the postponement of insertion on the waiting list for TxR, refusal to perform this therapy and, in some situations, the death of the patient. Adequate HL is protective in several aspects of CKD patients' lives, especially in the psycho-emotional and cognitive domains. Educational strategies, provided in the form of routine recommendations in dialysis centers or in addition to them, are essential for increasing HL. **Conclusion:** Patients who were candidates for or submitted to TxR had a high prevalence of limited HL, negatively impacting decision-making processes. Complementarily, the appropriate HL is recognized as essential for the conscious and shared decision-making process of the patient, as it empowers and enables the development of self-management in health.

Descriptors: Renal Insufficiency Chronic; Kidney Transplantation; Health Literacy. Health Education.

Letramento em Saúde de Pacientes Candidatos ou Submetidos ao Transplante Renal: Revisão Integrativa da Literatura

RESUMO

Objetivo: descrever as repercussões do letramento em saúde (LS) em pacientes com Doença Renal Crônica (DRC) candidatos ou submetidos ao transplante renal (TxR). Revisão integrativa, realizada com seleção sistematizada de artigos nas bases de dados PubMed, Portal BVS e SciELO em agosto de 2021. Foram identificados 62 artigos, dos quais 17 foram selecionados para a síntese. **Resultados:** a maioria dos estudos analisados desenvolveu desenho observacional ou qualitativo. O LS em sua maioria foi limitado e causa diversos impactos nos processos decisórios dos pacientes, resultando em adiamento da inserção na lista de espera pelo TxR, recusa para realização desta terapêutica e, em algumas situações, a morte do paciente. O LS adequado tem efeito protetor em vários aspectos na vida dos pacientes com DRC, sobretudo no domínio psicoemocional e cognitivo. As estratégias educativas, fornecidas na forma de recomendações de rotina em centros de diálise ou adicionais a estas, são essenciais para o aumento do LS. **Conclusão:** pacientes candidatos ou submetidos ao TxR apresentaram elevadas prevalências de LS limitado, com impacto negativo nos processos decisórios. Complementarmente o LS adequado é reconhecido como essencial para o processo de decisão consciente e compartilhada do paciente, pois empodera e viabiliza o desenvolvimento do autogerenciamento em saúde.

Descritores: Insuficiência Renal Crônica; Transplante de Rim; Letramento em Saúde; Educação em Saúde.

INTRODUCTION

Health literacy (HL) is the individual's ability to use reading, writing and numerical skills to understand, interpret and apply written and/or spoken information for health self-management, health promotion, prevention of diseases and injuries assistance, care and treatment[1].

If satisfactory, HL can be associated with better health conditions and the application of prophylactic and/or therapeutic measures.[2] On the other hand, unsatisfactory levels are related to high rates of hospitalizations, lower adherence to the prescribed treatment, higher mortality, complications in the health-disease process and low quality of life.[3]

Chronic kidney disease (CKD) has a high prevalence and incidence in the population and requires complex treatment and adequate health self-management for a favorable follow-up.[4] Among renal replacement therapies, kidney transplantation is the treatment of choice for patients with CKD, stage five dialysis (CKD 5-D)[5]. Due to the high complexity of the procedure and self-care after kidney transplantation, patients with low HL and unsatisfactory self-management skills may become vulnerable to unfavorable outcomes, which include graft rejection.[6] Limited HL is associated with unfavorable clinical outcomes in managing patients with CKD, a condition that interferes with adherence to treatment, quality of life and therapeutic modality of these individuals.[4]

The patient's knowledge about the disease is commonly associated with the number of visits to the nephrologist. However, one study showed that patients with CKD in stages three and five, followed for an average of two years by nephrologists, reported limited knowledge about CKD and no therapeutic modalities.[7] In this context, it is understood that patients with CKD receive information about their clinical condition, which is often unsatisfactory, permeated with technical terminologies, results of unknown laboratory tests, and clinical procedures used to manage the difficult-to-understand disease.[8]

Many health professionals use technical approaches to transmit information in practice, as they overestimate patients' HL. However, it is known that essential reading and numeracy levels are necessary to understand such guidelines. From this understanding, the patient self-manages his health care; therefore, it is vital to identify his level of HL so that understandable health education actions are developed and interventions more effectively promote favorable clinical outcomes. It has been observed that individuals with CKD with low HL can demonstrate negligent attitudes in self-care, such as missing appointments, not performing tests and presenting suspicious responses when receiving written information, such as "I will read this at home" and, mainly, confusion about prescribed medications, prescriptions, schedule and administration of these.[9]

Thus, the health professional needs to understand the repercussions caused by HL in patients with CKD in the process of kidney transplantation, in the production of comprehensive care and contribute to a decision-making process shared with the patient and their family members. In addition, identifying intervening factors in the patients' HL may support the proposition of successful educational strategies that can positively impact quality of life and health prognosis. Thus, this study aimed to describe the repercussions of health literacy in patients with chronic kidney disease who are candidates for or undergoing kidney transplantation.

METHODS

The present is an integrative literature review, which sought to establish an analysis of publications on the topic "repercussions of HL in patients with CKD candidates for or undergoing kidney transplantation". An orderly systematization of the analyzed material was made possible, and new research was proposed to fill in the gaps identified about HL in transplanted CKD.[10,11] For its development, a protocol consisting of six steps was elaborated:[11] identification of the theme and selection of the research question; establishment and formulation of criteria for inclusion and exclusion; definition of the information to be extracted and its categorization; systematic evaluation of the studies included in the integrative review; interpretation of results; and presentation of the knowledge review/synthesis.

The formulation of the research question was based on the PICO strategy,[12] which refers to the acronym: population (P): patients with CKD candidates for or undergoing kidney transplantation; intervention (I): health literacy; comparison (C): not applicable because it is not about the development of clinical research;[13] and outcome or result (O): repercussions. Thus, the following research question was delimited: What are the consequences of HL in patients with CKD who are candidates or who undergo kidney transplantation?

The flowchart in the PRISMA model (Preferred Reporting Items for Systematic Reviews and Meta-analyses) was used to organize the identification, selection and inclusion strategies of studies within the proposed eligibility criteria. For the selection of studies, searches were carried out by two independent researchers in August 2021 in the databases Medical Literature Analysis and Retrieval System Online (MEDLINE/PubMed), from Biblioteca Virtual em Saúde (BVS) and the Scientific Electronic Library Online (SciELO). To resolve the differences between the two search engines, a third researcher was consulted to decide on the inclusion or exclusion of selected publications.[14]

The descriptors were selected using the Health Sciences Descriptors (DeCS) and their equivalents in English extracted from the Medical Subject Heading (MeSH). The search strategies were formulated by language, using the terms *Insuficiência Renal Crônica* (Renal Insufficiency, Chronic), *transplante de rim* (kidney transplantation) and *letramento em saúde* (health literacy), combined by the Boolean operator "AND".

The inclusion criteria were original articles, available in full, written in Portuguese, English and Spanish, without temporal delimitation. The following were excluded: publications that did not answer the research question, duplicate articles, theses, dissertations, monographs, annals of events, experience reports, research protocols, letters to the editor and editorials.

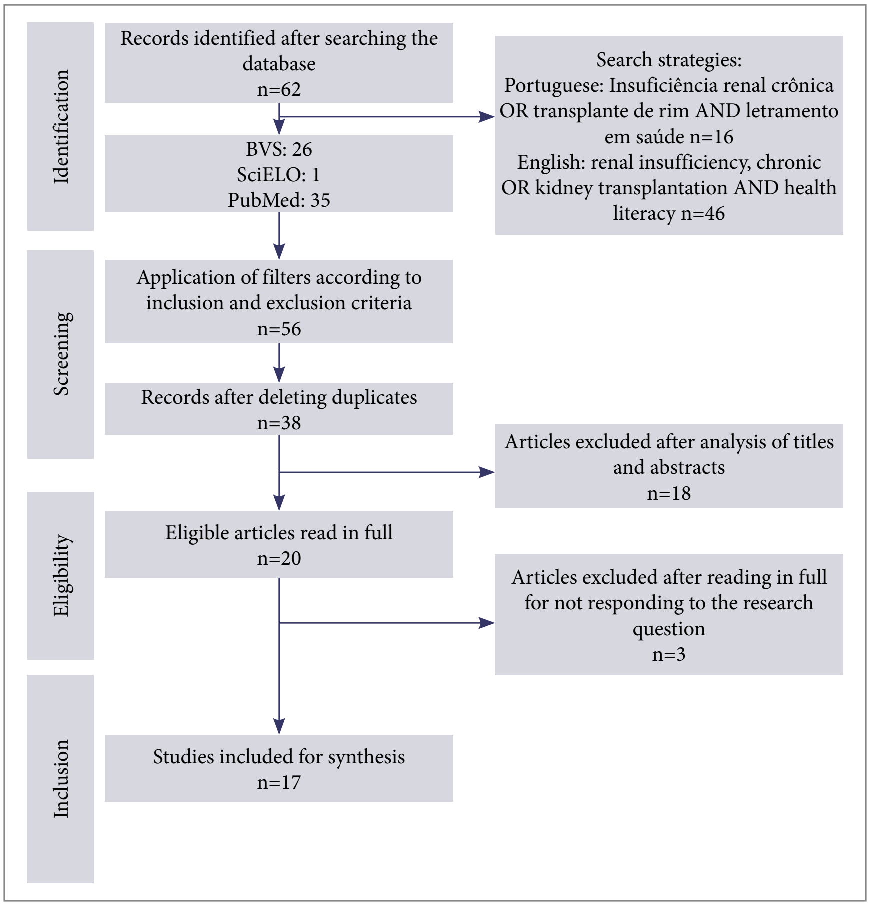
A data collection instrument was built with the variables database, journal, author/year, title, objectives, method and main results to organize the data extraction from the articles included in the review.

In the critical analysis of the studies identified in the databases, a screening was initially carried out by reading the titles and abstracts to exclude those unrelated to the theme or duplicated. Afterward, the eligible ones were read in full, and finally, only those answering the research question were included in the synthesis of the integrative review.

The precepts of Law 9.610/1988, which deals with copyright, were respected, attributing due credit to the authors of the publications.[15]

RESULTS

In the initial search in the selected research platforms, 62 publications were identified: 26 articles were found in BVS, 1 in SciELO and 35 in PubMed. Of these articles, six were eliminated for not meeting the inclusion criteria, 18 for being duplicated in the databases and 18 for not being related to the topic of interest based on the title and abstract. Thus, twenty articles were selected for reading in full, among which three were excluded for not answering the research question. Therefore, 17 articles were used for the synthesis of this integrative review. Fig. 1 shows the flowchart of the publication selection process.



Source: Elaborated by the authors.

Figure 1. Flowchart of the selection process of studies for the integrative review on Health Literacy of individuals with chronic kidney disease who are candidates for or submitted to kidney transplantation.

The summary of publications selected for this review is shown in Table 1. Most articles were published in English (94.1%; n=16) and only one in Portuguese (5.9%; n=1). These publications were predominantly from research with an epidemiological design (77.8%; n=14); there was a higher proportion of cross-sectional (44.4%; n=8), qualitative (22.2%; n=4) and prospective cohort studies (16.7%; n=3).

Regarding the objectives of the studies, there was a more significant proportion of publications that evaluated the prevalence of HL and associated factors in CKD candidates for or undergoing kidney transplantation (22.2%; n=4);[16–19] factors associated with the absence/withdrawal of patients in the steps to assess access to the waiting list for kidney transplantation (16.7%; n=3);[20–22] impacts of HL in patients with CKD who are candidates for or undergoing kidney transplantation (11.1%; n=2);[23,24] patient education practices (11,1%; n=2);[25,26] reasons for choosing/refusing kidney transplantation (11,1%; n=2)[27,28] and patient perception and expectations about kidney transplantation (11,1%; n=2)[29] (Table 1).

There was a greater predominance of those studies that involved candidate patients,[19,20–23,25,27,28,30–32], followed by those with candidates or transplant recipients as participants.[16–18,24,29] Most studies identified some degree of HL limitation among patients with CKD who were candidates for or underwent kidney transplantation.,[16–21,23,24,30,31] The prevalence ranged from 8,9%[19] up to 51,4%.[24]Limited HL was associated with male gender,[17] lower education levels[16,17,19,24,27] and income,[17,24,27] fragility,[19]comorbidity[19,27] and cognitive impairment[19] (Table 1).

Patients who had access and/or opted for kidney transplantation had a higher level of HL[28], and those with limited HL had a lower enrollment rate on the waiting list for a transplant,[19,21,23], regardless of whether the kidney comes from a deceased or living donor.[23] Also, in this list, higher mortality was identified for patients with limited HL.[19] Regardless of HL, it was found that patients on the waiting list were more likely to receive a living donor transplant[31] (Table 1).

It was found that adequate HL has a psycho-emotional protective effect and is associated with a better perception of quality of life in emotional aspects.[24] This finding is relevant, considering that patients on the transplant waiting list tend to have psycho-emotional and cognitive impairment[30] (Table 1).

Among the reasons given by patients with CKD for not seeking a transplant, the possible failure in the medical examinations necessary for the surgery, fear of the transplant, and financial difficulties in paying for the medications and the procedure stand out. These barriers can be attributed mainly to misinformation and limited HL.[22] On the other hand, it was observed that patients with CKD saw in kidney transplantation a possibility of cure[28], a stimulus that the appropriate HL can trigger since acquiring knowledge about the disease and the therapeutic possibilities can stimulate the willingness to perform the transplant (Table 1).

Regarding the educational activities carried out by professionals in the dialysis treatment centers, there were reports of unilateral verbal transmission of content, discussions with patients about transplantation, distribution of printed educational resources and use of intensive education approaches (intervention jointly consisting of exhibition transplant videos, providing information to share with potential living donors, offering the opportunity to speak with a kidney recipient, and providing transplant information in treatment center waiting rooms).[25,26] These last two educational activities contributed to greater adherence to the transplant waiting list.[26] Professionals with a higher level of knowledge about transplantation were more likely to use intensive education strategies, considered the most effective for increasing adherence to the transplant waiting list.[26] In addition, a study showed that additional strategies (educator-guided intervention through print, video and text messages or patient-guided intervention with telephone discussions with an educator) to those performed by treatment centers increase decision-making for transplantation, with a more significant effect on deceased donor transplants, followed by living donors[25] (Table 1).

The Knowledge Assessment of Renal Transplantation (KART) scale showed adequate psychometric validity, with a discriminatory capacity to measure the HL of patients who spent less than an hour or more in educational activities on kidney transplantation. As strategies used, dialogues with the medical team, reading of printed texts and access to information through digital media were included.[32] (Table 1).

Among the qualitative studies, thematic categories with manifest contents related to knowledge about transplantation and donor options (deceased or living) stood out,[29] communication difficulties and misinformation about the transplant,[27] low adherence of patients in decision-making processes regarding renal replacement therapies, dependence on physicians for these decisions[29] (Table 1).

Table 1. Synopsis of articles selected for the integrative review on Health Literacy of individuals with chronic kidney disease who are candidates for or submitted to kidney transplantation.

Author (year)	Objective(s)	Main results
	Cross-sectional study	
Escobedo and Weismuller (2013)[16]	To identify the level of health literacy in patients seen at a suburban transplant center.	Of the 44 participants, 18 (41%) had scores indicating a high likelihood of limited health literacy. An association was also found between limited health literacy and lower education levels. However, the assessment of educational level alone was not predictive of health literacy; eight participants (18%) had a high school education or higher but scored as having limited health literacy.
Lambert *et al.* (2015)[17]	To investigate the types and extent of health literacy deficits in patients with chronic kidney disease and to identify associations between patient characteristics and health literacy domains.	Inadequate health literacy was high among groups with chronic kidney disease – especially in domains related to meeting health needs, understanding health information, social support and socioeconomic factors. Male gender and lower education were significantly associated with inadequate health literacy. The type and extent of health literacy deficits varied among groups with chronic kidney disease; transplant patients had more deficits than other groups.
Grubbs *et al.* (2009)[21]	To examine health literacy in patients with end-stage kidney disease and the association with kidney transplant waiting list access.	Inadequate health literacy occurred in 32.3% of participants, and 75.8% were referred for transplant evaluation. Among those referred, 85.1% were on the waiting list. Participants with inadequate health literacy had a 78% lower risk of being referred for transplant evaluation than those with adequate health literacy.
Kazley *et al.* (2012)[22]	Identify barriers to kidney transplantation in patients who have not completed the necessary investigation to be added to the national transplant waiting list.	These were the main reasons patients gave for not seeking a transplant: they thought they would not pass the medical exams, were afraid of having the transplant, and could not afford the medicine or the procedure. These impediments may have resulted from unclear communication with the provider, incorrect information received from colleagues or other sources, misperceptions related to transplant surgery, or limited health literacy.
Rocha and Figueiredo (2019)[24]	To study the impact of the health literacy level of patients undergoing hemodialysis, peritoneal dialysis and kidney transplantation associated with cognitive aspects, medication adherence and quality of life.	Individuals with inadequate literacy had lower levels of schooling and monthly income. Those with adequate literacy had a higher score in the emotional aspects of quality of life.
Vilme *et al.* (2018)[31]	To characterize the interest and search for living donor transplantation among African Americans with varying levels of exposure to dialysis or transplantation treatments. Evaluate facilitators or barriers associated with the interest in and search for living donor transplantation among these populations.	Interest in transplantation among the three strata of the study was high (pre-dialysis, 62.9%; dialysis, 67.4%; and transplant waiting list, 74.2%). The dialysis and transplant waiting list strata sought living donations more readily than those not on dialysis. Interest and seeking were not associated with knowledge, health literacy, or confidence in medical care.
Vilme *et al.* (2018)[31]	To investigate the prevalence and associations of limited health literacy using UK transplant outcome measurement program data.	The prevalence of limited health literacy was higher in dialysis patients, followed by those on the waiting list and transplant recipients. Limited health literacy was independently associated with low socioeconomic status, low English fluency, and comorbidity.
	Qualitative study	
Devitt *et al.* (2017)[27]	To explore the views of indigenous patients with chronic kidney disease on transplantation as a treatment option.	Four interrelated thematic contents were apprehended: a very high level (90% of respondents) of positive interest in transplantation; patients experienced a range of communication difficulties and felt uninformed about the transplant; family involvement in decision-making was restricted by inadequate information; and patients needed to negotiate cultural and social sensitivities around transplantation.
Senghor (2019)[28]	To identify the reasons for choosing or refusing kidney transplantation as renal replacement therapy in patients with Chronic Kidney Disease.	The high level of health literacy predominated among patients who opted for kidney transplantation. Others saw kidney transplantation as a cure or a normal process. The patient's ability to understand the information received influences the decision-making process for transplantation.
King *et al.* (2020)[29]	To understand African American patients' knowledge of renal replacement therapy options and how patient, provider, and system factors contribute to knowledge and preferences.	Four themes were identified: (1) limited knowledge of home modalities and deceased donor options, (2) patients with chronic kidney disease paid little attention to choosing renal replacement therapy options, (3) patients with chronic kidney disease depended on physicians for treatment decisions and (4) while patients reported knowledge of live kidney donation transplants, it did not translate into receiving that type of transplant.

Continue...

Table 1. Continuation.

Author (year)	Objective(s)	Main results
Prospective cohort		
Warsame *et al.* (2019)[19]	To assess the prevalence of limited health literacy among 1,578 kidney transplant candidates.	Among kidney transplant candidates, 8.9% had limited health knowledge; risk factors included education less than higher education, frailty, comorbidity, and cognitive impairment. Candidates with limited health literacy had a 30% reduced probability of waiting list participation and a more than twofold increased risk of waiting list mortality.
Dageforde *et al.* (2015)[20]	To compare demographic, socioeconomic, and psychological factors among participants and those absent from the renal transplant evaluation visit.	Participants were 104 adults (61% male, 46% Caucasian, 52 ± 12 years old). Most participants (77%) had adequate health literacy. Financial concerns were the most prevalent. Previous evaluation at another transplant center and being on dialysis was significantly associated with absence. Frequency was associated with concerns about finding a living donor and a greater general perception of knowledge about transplantation. No differences in demographic, socioeconomic, or health literacy factors were found between groups.
Taylor *et al.* (2019)[23]	To investigate the relationship between limited health literacy and clinical outcomes, including access to kidney transplantation.	Limited health literacy was not associated with mortality, late presentation to nephrology, dialysis modality, vascular access for hemodialysis, or preventive kidney transplant list. Still, it was associated with a reduced probability of waiting for a deceased donor transplant, receiving a kidney transplant from a living donor or receiving a transplant from any donor.
Randomized clinical trial		
Waterman *et al.* (2019)[25]	To examine the effectiveness of two supplemental kidney transplant education approaches provided directly to patients.	In intention-to-treat analyses, patients randomly assigned to educator- and patient-guided interventions had more significant knowledge gains than standard-of-care patients who received transplant education provided by dialysis centers (control). Patients with educator- and patient-guided interventions could make informed decisions about initiating transplant evaluation, followed by deceased-donor and living-donor transplantation.
Interventional, non-randomized study		
Waterman *et al.* (2020)[26]	To identify the most common transplant education practices and barriers to education among dialysis units and examine the association of practices with increased transplant waiting list rates.	Of the educators, 52% orally recommended transplantation to patients, 31% had in-center discussions about transplantation with patients, 17% distributed printed educational resources, and 3% used intensive education approaches. The distribution of print education and the practice of intensive education were associated with increased waitlist rates. Educators with greater knowledge about transplantation were more likely to use intensive educational strategies, while those with poor communication with transplant centers were less likely to do so.
Retrospective, cross-sectional study		
Jesse *et al.* (2019)[30]	To report the frequency of psychiatric and cognitive pathologies and the corresponding psychiatric recommendations in a sample of patients actively listed for kidney transplantation.	Among the analyzed charts, 52.4% of the patients showed cognitive impairment, and 28.9% indicated limited health literacy.
Methodological study		
Peipert *et al.* (2019)[32]	To describe the development and psychometric performance of the Knowledge Assessment of Renal Transplantation (KART) scale.	Construct validity was supported by the ability of the KART psychometric test to distinguish between patients who spent less than 1 and 1 hour or more receiving different types of education about kidney transplantation, including conversations with physicians/medical staff, reading brochures, surfing the internet, and watching videos.

Source: Elaborated by the authors.

DISCUSSION

The main findings of this review showed a high prevalence of limited HL in patients with CKD who were candidates for or underwent kidney transplantation. Limited HL was associated with male gender, lower education and income levels, comorbidity and cognitive impairment. Patients with a higher level of HL opted for kidney transplantation, and those with limited HL had a lower enrollment rate and higher mortality on the transplant waiting list. Satisfactory HL acted as a psycho-emotional protective effect associated with a better perception of quality of life. Carrying out educational activities contributed to an increase in the HL level of patients with CKD and to shared decision-making about treatment, with repercussions on the choice to perform the transplant.

Appropriate HL is essential for people with CKD to have a greater ability to understand and reframe what they have learned and adopt concrete actions and changes in behavior based on the instructions they have received.[24] Thus, the high prevalence of limited HL requires attention from health professionals, and the level of HL must be evaluated and improved so that there is greater adherence to the decision to transplant and the success of the treatment as a whole. In addition, cognitive assessment of patients with CKD is also recommended [19,24,30] because the occurrence of comorbidities[19,27] can impact memory failures and action planning.[19,24,27] Using validated instruments with good psychometric performance, such as the KART scale[32] used in one of the selected studies, is recommended to develop a reliable measure of LH levels. Studies of cross-cultural adaptation and assessment of the psychometric performance of the KART scale in the Brazilian context were not identified, revealing the need for research to fill this gap in knowledge related to the measurement of HL in the country.

The evidenced relationship between lower HL and male gender[17] needs to be considered in the planning of health actions. Illness and self-care are little valued by men and are associated with sociocultural and institutional factors accentuating resistance to health care. Men, in general, are more exposed to the difficulty of recognizing their health needs, seeking health services and adhering to the necessary therapeutic measures.[33]

Similarly, the association of limited HL with lower levels of education[16–19,24,27] and income[17,24,27] are important predictive factors for kidney transplant failure. People with lower incomes may have greater difficulty accessing education with the quality necessary to develop cognitive, reading and numeracy skills to determine health literacy.[16] The simple fact of offering health education activities, whether verbal, printed or audiovisual, does not necessarily imply that the message will be captured and assimilated by the patient with CKD since there may be a lack of skills to understand them fully. One should also consider, as evidenced in this review,[27] that the assessment of HL cannot be restricted only to the individual's education since individuals with CKD may have a satisfactory level of formal education and, even so, not be able to understand health care guidelines in the context of the disease.[34]

Disparities in access to kidney transplantation, commonly measured by the extensive and lengthy waiting lists, are closely linked to HL. Patients undergoing CKD treatment with limited HL may have more difficulty navigating through the different pathways of the transplant process, especially within the scope of public services.[21] Also, they may be less likely to express their intention for the transplant due to their poor ability to understand what the treatment entails and what is necessary for it to happen, including having difficulty adhering to the required regimens and therapies prescribed for the survival of the transplanted graft.[21] Therefore, patients with CKD cannot be held responsible for these interventions, in addition to the low willingness of the multidisciplinary team to refer them to the transplant process and of the responsible centers regarding the waiting list.[21]

It was found that patients with CKD on the transplant waiting list were more willing to have it performed by a living donor.[31] Even if HL did not detect mediation, this is relevant information. The journey to the deceased and/or living donor transplant list differs, and adherence depends on communication and understanding between the health team and the patient with CKD to enable shared and assertive decision-making.[23] Once again, the effect of education on HL can be evoked to understand this finding, as a potential recipient and a potential donor, usually members of the same family, may have low education, being more susceptible to lower HL and sharing social disadvantages[23] and having resistance to receiving an organ from a deceased or even a living donor. The acceptance of the offer of a living or deceased donor is not unanimous. In most cases, the donors themselves or relatives of the patient with CKD must convince them to receive the donated organ.[35,36]

Evidence of better-perceived quality of life in CKD patients with better HL[23] endorses the need to strengthen HL strategies in health services, from primary health care, with health education and communication considered among the most effective. These patients better perceive emotional aspects related to quality of life due to their better ability to understand their health-disease process, prognosis and how transplantation and treatment help cope with CKD. The HL can promote a greater sense of well-being and reduce symptoms of depression and anxiety.[23]

Compared to the standard education provided in dialysis centers, providing additional systematic education empowers informed decision-making.[24] Therefore, several tools can be used for the literacy of patients with CKD and offered in dialysis centers, at home or anywhere patients can access them. These means include conducting team discussions with the participation of other patients and families, sending text messages, videos and printed materials[24,25] and encouraging an active search for information from available reliable sources.[24] It is also necessary for educators to improve their level of knowledge about transplants so that this translates into more encouragement to the patient in the decision to transplant the kidney.[24]

The barriers that distance patients with CKD from transplantation must be constantly overcome in health services. Although there are strict medical criteria for not including a patient on the kidney transplant list, patients should not exclude themselves from the process in the face of rumors about the ineligibility of their case.[21] The criteria for transplantation and the waiting list constantly evolve and vary from center to center. In addition, the influence and HL of the patient on an erroneous perception of contraindications for transplantation must be considered.[21]

Fear of transplantation should be discouraged in terms of surgery and subsequent follow-up. As much as there is a possibility that the transplant will not be effective or fail, it is essential to detail what the post-transplant life will be like. It is the responsibility of the transplant center to ensure that the patient has understood all the necessary information through questions related to the guidelines provided and the provision of educational material.[21]

The financial and bureaucratic issue was also evidenced as a reason for refusal or withdrawal from treatment.[21] In Brazil, to enter the single list system for transplantation, it is necessary to carry out specific biochemical and imaging tests, some of them costly, which must be scheduled by the Unified Health System (*Sistema Único de Saúde- SUS*). It takes time due to the long queue on the waiting list.[36] As many patients do not have enough financial resources to pay for the exams and speed up their entry on the list, they end up giving up the process.[37] It should also be considered that, after the transplant, medication will be necessary, which is not always provided by the SUS, financially burdening the patient and his family, in addition to the changes in lifestyle that are essential in this process.

The HL of patients with CKD can be improved by reliable information, formal and non-formal, and effective communication. Dialysis and transplant centers should implement educational strategies to reduce the impact of limited HL on the kidney transplant process.[20] During the evaluation of patients, professionals should assess HL, as this is a significant predictor of outcomes in kidney transplant patients.[21] For such, it is recommended to use validated instruments to measure HL and standardize the evaluation adequately.

The small number of publications related to HL of patients with CKD who are candidates for or have undergone kidney transplantation makes it clear that this is a neglected and little-studied topic. However, the epidemiological nature and theoretical-methodological rigor of the selected qualitative articles allowed us to understand critical points of intervening factors in the decision for kidney transplantation and its association with HL.

Longitudinal studies with probabilistic sampling and more robust analytical procedures must highlight the factors associated with limited HL in candidate patients undergoing TxR. In addition, analyzing factors that are mediators or confounders needs to be better explored. The identification of gender differentials is also a significant gap to be filled.

FINAL CONSIDERATIONS

This integrative review study showed that most research on HL in candidate patients or patients undergoing kidney transplantation recorded a high prevalence of limited HL, which presented as factors associated with its occurrence: male gender, lower levels of education and income, presence of comorbidities and cognitive impairment. It was identified that limited HL causes several impacts on the decision-making processes of patients, conditions that result in postponement of insertion on the transplant waiting list, refusal to perform this renal replacement therapy, and even the individual's death. On the other hand, it was shown that adequate HL has a protective effect in several aspects of the lives of patients with CKD, especially in the psycho-emotional and cognitive domains. Educational health strategies are prevalent in dialysis centers and are provided through routine service recommendations or, to a lesser extent, in addition to them, becoming essential for strengthening HL.

The review suggests that HL is essential for the decision-making process of the patient who is a candidate for a kidney transplant or has already been transplanted, as it empowers and enables the development of self-management in health. The scarce number of publications on kidney transplantation and health literacy demonstrates the invisibility of the topic within the scope of public policies and care production practices. It endorses the need to develop longitudinal studies for a more accurate investigation of HL's determining/conditioning factors in patients with CKD and its repercussions on decision-making for kidney transplantation and its outcomes.

CONFLICT OF INTEREST

Nothing to declare.

AUTHOR'S CONTRIBUTION

Substantive scientific and intellectual contributions to the study: Montelo MPM, Teixeira JB, Martins KA, Pereira ERS; **Conception and design:** Montelo MPM, Teixeira JB, Martins KA, Pereira ERS; **Data analysis and interpretation:** Montelo MPM; **Article writing:** Marcos Paulo Montelo MPM; **Critical revision:** Montelo MPM, Teixeira JB, Martins KA, Pereira ERS; **Final approval:** Pereira ERS.

DATA AVAILABILITY STATEMENT

All dataset were generated/analyzed in the current study

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