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Health literacy in kidney disease: Review of the literature and implications for clinical practice

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Abstract

Health literacy is the capacity of an individual to understand information related to a disease in order to make an informed decision. In patients with kidney diseases, studies have reported increasing impact of limited health literacy on health outcomes. Our paper discusses current literature on health literacy in kidney diseases.

Key words: Health literacy; Kidney diseases; Rapid estimate of adult literacy in medicine; Hemodialysis; Peritoneal dialysis; Chronic kidney disease

Core tip: Health literacy is an increasing recognized cause of suboptimal care and management of chronic diseases in patients. Our paper reviews the current literature on its prevalence and impact in the population with kidney diseases. More studies are needed in patients with kidney diseases to better understand the effect of limited health literacy.

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BACKGROUND

According to the Institute of Medicine, health literacy is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make informed health decisions"[1]. It is a complex phenomenon including diverse communication skills of individuals beyond simply being able to read. It also involves oral understanding (speaking and listening skills), numeracy, and cultural and conceptual knowledge. The prevalence of limited health literacy is higher amongst the elderly, minorities, and those with lower socioeconomic status including income and education[2].

Health literacy is particularly important in the large

and growing number of patients with chronic kidney disease (CKD) due to the complexity of the disease, which requires a high level of patient involvement and self-management skills. Patients with kidney disease must follow appropriate dietary restrictions, adhere to complex medication regimens, make decisions about dialysis, and keep up with multiple appointments in the health care system. Despite having data on methods to delay disease progression, kidney outcomes are suboptimal in part related to patient factors. Of these, there is increasing evidence that health literacy plays an important role in the care of patients with kidney disease[3,4]. We present currently available health literacy screening tools, studies of health literacy in patients with kidney disease, and strategies to address health literacy in clinical practice.

HEALTH LITERACY MEASURES

There are a variety of health literacy screening tools available, many of which have been studied in patients with kidney disease. One of the most commonly used tools is the Rapid Estimate of Adult Literacy in Medicine (REALM), which is a 66-item word recognition test. Scores are based on the total number of words a patient can correctly identify and pronounce, categorized by grade-equivalent reading level. Scores range from 0 to 66 with lower scores representing more limited health literacy (0 to 18 = less than 4th grade reading level; 19 to 44 = 4th to 6th-grade reading level; 45 to 60 = 7th to 8th-grade reading level; > 60 = 9th-grade reading level or above). Limited health literacy is defined as a REALM score < 60. The REALM takes about three minutes to administer[5]. It has been studied in patients with chronic kidney disease and kidney failure, including transplant, hemodialysis, and peritoneal dialysis patients[6,7]. A kidney transplant specific version is also available, the REALM-T[8].

Another commonly used health literacy screening tool is the Test of Functional Health Literacy in Adults (TOFHLA). This test uses the modified cloze procedure, where every fifth to seventh word is omitted from reading passages and subjects select the correct word from among a set of four options. The full version involves 50 reading comprehension items in 3 passages and 17 numeracy items, and takes about 22 min to complete[9]. The shortened version (S-TOFHLA) includes 36 reading comprehension items and takes about 7 min to complete[10]. Scores are categorized into inadequate, marginal, and adequate health literacy. Both versions are available in Spanish.

Routine use of the REALM and TOFHLA has been largely limited by administration time; therefore, shorter literacy screening instruments are increasingly being used. A 3-item brief health literacy screen (BHLS) is available[11], which uses the following self-report questions: (1) How confident are you filling out medical forms by yourself? (2) How often do you have someone help you read hospital materials? and (3) How often do you have problems learning about your medical condition because of difficult understanding written information? Answers are scored on a 5-point Likert scale. The BHLS takes approximately 1 min to complete and has been validated against the REALM and the S-TOFHLA in the hemodialysis population[12]. The areas under the receiver operator curves comparing BHLS were reported as 0.71 (95%CI: 0.61-0.80) for the REALM, and 0.73 (95%CI: 0.59-0.88) for the S-TOFHLA. The use of a single item version using just one of these questions (confidence with forms) has been validated against the REALM in patients on peritoneal dialysis[13].

The newest vital sign (NVS) is another instrument that can be used to assess health literacy. This test uses a nutrition label from a pint of ice cream and requires patients to answer six questions related to the information on the label[14]. A score of 4 or more indicates adequate literacy, a score of 2-3 indicates possible limited literacy and a score of 0-1 indicates high likelihood of limited literacy[15]. Devraj *et al*[16] have used this tool in the CKD population to examine the association between health literacy and kidney function. More recently, this tool has been used to assess literacy outcomes in the kidney transplant population[17,18].

HEALTH LITERACY IN CHRONIC KIDNEY DISEASE

Despite the increased awareness of the importance of health literacy in kidney care[19], there have been few studies examining health literacy in patients with chronic kidney disease not on dialysis. Wright *et al*[20] reported an 18% prevalence of limited health literacy in a single cohort of 401 patients with CKD stage 1-5 in an outpatient study. In this study, limited health literacy based on the REALM was associated with poorer CKD knowledge. Another study of 2340 patients with mild-moderate CKD reported a prevalence of limited health literacy of 28% in non-Hispanic Blacks and 5% in non-Hispanic Whites. This study used the S-TOFHLA as a tool to measure health literacy[21]. The investigators reported that participants with limited health literacy had lower estimated glomerular filtration rate (eGFR) (34 mL/min *vs* 42 mL/min per 1.73 m^2); higher urine protein/24 h (0.31 g *vs* 0.15 g); a higher self-reported cardiovascular disease (61% *vs* 37%); and were less likely to have blood pressure < 130/80 mmHg (51% *vs* 58%). Finally, Devraj *et al*[16] also found an association of limited health literacy with kidney function. In a small study of 150 patients with CKD stages 1-4, every unit increase in the Newest Vital Sign score was associated with a 1.9% increase in eGFR. Further studies are needed of health literacy in patients with earlier stages of kidney disease, since their care and needs are different than those with more advanced disease.

HEALTH LITERACY IN DIALYSIS

There has been more research on the impact of health

literacy in the dialysis population compared to those with earlier stages of kidney disease. In peritoneal dialysis, three studies have reported the prevalence of limited health literacy ranging from 6% to 50%[6,7,13,22]. In previous studies by us, the prevalence of limited health literacy was similar in peritoneal dialysis[13] and hemodialysis[23] study populations. In addition, limited health literacy was not associated with an increased risk of infectious complications or hospitalizations. This suggests that the presence of limited health literacy should not preclude consideration of peritoneal dialysis for renal replacement therapy, provided patients receive appropriate hands-on training that is tailored to their individual literacy needs[7].

In the hemodialysis population, the largest study by Cavanaugh *et al*[24] examined health literacy in 480 incident hemodialysis patients using the REALM. They reported a prevalence of 32% of limited health literacy in their cohort, which is similar to what was reported by Grubbs et al in their study of 62 hemodialysis patients using the S-TOFHLA[25]. On the other hand, Green et al reported a prevalence of limited health literacy of 16% in their analysis of 260 patients on maintenance hemodialysis using the REALM[23]. Variations in prevalence of limited health literacy may be due to differences in patient populations or the use of alternative health literacy assessment tools. In all these studies, limited health literacy was seen more often in non-white people and those with lower educational status and lower income levels[23,24,26].

In terms of outcomes, Green *et al*[26] reported that limited health literacy was independently associated with an increased incidence of missed dialysis treatments, emergency department visits, and dialysis related hospitalizations. Another study of 72 patients on hemodialysis reported that people with limited health literacy had worse blood pressure control than those with adequate health literacy[27]. Moreover, limited health literacy has been associated with an increased risk of death in hemodialysis patients[24].

HEALTH LITERACY IN KIDNEY TRANSPLANT

Limited health literacy may be a barrier to kidney transplantation. Grubbs et al reported that the access to kidney transplantation is reduced in patients with inadequate health literacy. They reported, in a cohort of 62 dialysis patients, that participants with inadequate health literacy had 78% lower hazard of referral for transplant work up than those with adequate health literacy (AR = 0.22; 95%CI: 0.08-0.60; P = 0.003)[25].

In another study by Dageforde *et al*[28], living kidney donors and recipients were compared with the deceased donor recipients. They reported that the deceased donor kidney transplant recipients were more likely to have moderate or low health literacy than living donor kidney transplant recipients (OR = 1.911; P = 0.022). They also found that the living donors had a higher level of health literacy.

More recently, Kazley *et al*[17] examined health literacy and its impact on kidney transplant outcomes. They used the REALM-T (REALM modified for the transplant population), NVS and Decision Making Capacity Assessment Tool (DMCAT). They reported that each of these tools significantly predicted whether or not a patient was listed for transplant. However, the NVS and DMCAT tool significantly predicted whether a patient actually received a transplant.

Table 1 Clinical "red flags" for limited health literacy

Patient registration forms that are incomplete or inaccurately completed
Non-adherence with medications or treatments
Frequently missed appointments
Lack of follow-through with labs, imaging tests, or referrals
Unable to name medications, explain what medications are for, or explain timing of medication administration
May offer excuses to deflect reading tasks
"I forgot my glasses"
"Let me bring this home so I can discuss it with my children"
Seldom have questions
Seek help only when illness is advanced
Have difficulty explaining medical concerns

IMPLICATIONS FOR CLINICAL PRACTICE

There is now convincing evidence that limited health literacy is common in patients with kidney disease and associated with a variety of adverse outcomes. In clinical practice, providers can consider routinely screening for health literacy in order to identify at-risk patients who may need more tailored care. In fact most studies till date have looked at the impact in chronic kidney disease and dialysis population. The data in population with acute kidney injury is sparse and it will be interesting to see future studies looking at prevalence and influence of health literacy in this subset of patients with renal failure. However, consideration must be given to time constraints and the potential to induce shame[29]. Clinical "red flags" can also be used to predict which patients may have limited health literacy (Table 1)[30], but it is important to note that many patients who struggle with understanding may not exhibit any of these signs. A better approach recommended by most experts is to implement the use of health literacy "universal precautions", which encourages the systematic use of clear health communication principles to promote better understanding for all patients[31,32]. Key clear health communication principles are shown in Table 2. Communications skills training have been shown to be effective at increasing the use of a variety of these skills[33]. A health literacy universal precautions toolkit is available online at http://nchealthliteracy.org/toolkit. Additional resources include an online plain language medical dictionary (www.lib.umich.edu/plain-

Table 2 Clear health communication techniques

Explain things clearly in plain language
Avoid medical jargon (for example, state "long-term" rather than "chronic")
Avoid vague terms such as "negative" test result
Slow down
Focus on 1-3 key points or messages - and repeat
Confirm understanding using teach-back
"I want to be sure that I explained your medication correctly. Can you tell me how you are going to take this medication?"
Effectively encourage patients to ask questions
"What questions do you have?" rather than "Do you have any questions"
Use analogies and pictures
Use patient friendly educational materials
4^{th}-6^{th} grade reading level
Picture-based
Write down important instructions

language-dictionary) and readability formulas (www.readabilityformulas.com) to target written materials at the appropriate reading level (4^{th}-6^{th} grade). Several recently published reviews of the readability of patient education materials in chronic kidney disease are also available[34,35].

CONCLUSION

In summary, health literacy is an important consideration in kidney disease care. Tools are available to help providers address health literacy in clinical practice. Collective efforts are critically needed to reduce the impact of limited health literacy and improve the quality of care and outcomes of this high-risk population[36].

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