



Health Literacy, Knowledge, and Patient Satisfaction Before Kidney Transplantation

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ABSTRACT

Background. Poor health literacy is associated with inferior outcomes in kidney transplant recipients, and knowledge remains suboptimal in this population. The goal of this study was to characterize the health literacy, kidney transplant knowledge, medication beliefs, and education satisfaction in a cohort of patients waiting to undergo kidney transplantation.

Methods. All patients on the wait-list in 1 Canadian center were invited to participate in the study. A research assistant administered the Short Test of Functional Health Literacy in Adults and its numeracy section, the Beliefs about Medicines Questionnaire, the Kidney Transplant Understanding Tool, and questions regarding satisfaction. Descriptive and univariate statistics were calculated between demographic variables and the assessments.

Results. Thirty-nine percent of patients (41 of 106) patients participated in the study. Overall, 95% and 86% were defined as having adequate health literacy and numeracy, respectively. The mean score on the Kidney Transplant Understanding Tool was 79%, and the majority (97.4%) had strong beliefs regarding the necessity of medication and little concern about adverse effects (73.8%). Participants with higher literacy scores had increased knowledge ($r = 0.52$; $P = .05$), understanding of why antirejection pills are necessary ($r = 0.38$; $P = .05$), and confidence about taking posttransplant medications ($r = 0.32$; $P = .05$). Overall, 30.7% were unsatisfied with their education regarding medications, and 22.5% were unsatisfied with what to expect after the transplant.

Conclusions. Before transplantation, health literacy, transplant knowledge, and scores on the Beliefs about Medicines Questionnaire were high in this cohort of patients. However, patient satisfaction regarding educational content remained suboptimal.

NINETY PERCENT OF PATIENTS WITH end-stage renal disease favor transplantation as their method of treatment [1]. Indeed, kidney transplantation provides superior outcomes compared with other renal replacement therapies [2]. This is not to say that transplantation is without challenges. In addition to the inherent risk of the transplant operation, posttransplant care is complicated and typically lifelong. Thus, improving patients' knowledge of their transplant treatments is often an important factor in achieving successful transplant outcomes. Ideally, patients should understand how to appropriately administer their transplant medications, how to monitor the health of their graft, and how to incorporate transplant-specific lifestyle

behavior changes. To be successful, they must be able to understand terminology and concepts relating to transplants [3]. In addition, patients must be empowered to actively participate in their own care [4] and to communicate effectively with their health care team [5].

Health literacy (HL) is the ability to access, comprehend, evaluate, and communicate information as a way to promote, maintain, and improve health in a variety of

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settings across the life course [6]. Low HL seems to be exceedingly common in Canada, affecting ~60% of adults and 88% of seniors [7]. The potential consequences of low HL include limited knowledge regarding medical conditions [8], poorer health status [9] and self-management skills [10], and increased nonadherence [11], hospitalizations [12], health care costs [13], and mortality rates [14]. These findings have remained consistent when adjusting for confounding sociodemographic factors [15].

Low HL is common among patients requiring renal replacement therapy, with studies indicating that limited HL may occur in up to 50% of these patients [16]. Low HL has been associated with increased blood pressure [17], more missed dialysis sessions, and frequent emergency visits [18] in patients receiving dialysis. The actual prevalence of limited HL specifically in patients listed and waiting for a kidney transplant, however, has not been established. Miller-Matero et al [19] discovered limited reading and math ability in 27.5% and 42.8% of patients being considered for various types of solid organ transplants, respectively. This study was conducted at the beginning of the transplant process (before listing), and these results may not be generalizable to other stages of the transplant process. Patients on the kidney transplant wait-list have completed a rigorous screening process to become listed for transplantation, and limited HL has been shown to be a significant predictor of both being listed for transplant and receiving a kidney [20].

The goal of the present study therefore was to determine the HL of the wait-listed patients. We also aimed to assess kidney transplant knowledge, medication beliefs, and patient satisfaction with current educational levels of information in this population. The results of this baseline analysis will be used to guide future educational initiatives and identify opportunities for targeting education in this population.

PATIENTS AND METHODS

The protocol for the study was approved by the regional ethics board (protocol number BEH-14-475). All patients on the kidney transplant wait-list between April 1, 2015, and September 30, 2015, were eligible to participate in the study. Potential participants were mailed a letter describing the study; ~2 weeks later, they were contacted by a research assistant to ask about participation, obtain consent, and to schedule a face-to-face appointment for patients wishing to participate in the study. The research assistant administered a 4-part questionnaire to consenting participants during a dialysis treatment or clinic visit to the Saskatchewan Transplant Program in Saskatoon or Regina. The 4-part questionnaire consisted of a knowledge questionnaire (the Kidney Transplant Understanding Tool [K-TUT]), the Education Satisfaction Assessment, the Beliefs about Medicines Questionnaire (BMQ), and the Health Literacy and Numeracy Assessment, which are further described in the following sections. A Tim Horton's \$15 coffee card was provided as incentive for participation.

HL and Numeracy Assessment

HL was assessed by the trained research assistant using the Short Test of Functional Health Literacy in Adults (S-TOFHLA) [21].

The S-TOFHLA, which has similar reliability and validity to the full version [22], is more practical because of the shorter completion time of 7 to 10 min [21]. We scored the S-TOFHLA as follows: scores <16 represented inadequate literacy, scores of 17 to 22 represented marginal literacy and scores ≥ 23 indicated adequate health literacy. Because renal transplant recipients must be capable of comprehending numerical directions (eg, to interpret laboratory information, adjust doses of medications), the numeracy section of the original TOFHLA [22] was also used in this study. During this section of the test, cue cards of prescription labels were supplied, and the patient was asked to respond to corresponding questions. Scores of 0 to 9, 10 to 12, and 13 to 17 represented inadequate numeracy, marginal numeracy, and adequate numeracy, respectively. The health numeracy assessments were audio-recorded and, to ensure anonymity, the numeracy and literacy results were verified by an additional research assistant who was blinded to patient identity.

Kidney Transplant Knowledge Assessment

After an exhaustive search of the literature, the K-TUT was developed by the research team because no validated tool currently exists to assess knowledge of kidney transplantation. To gather evidence of face and content validity, the instrument was reviewed by ~40 members of the Saskatchewan Transplant Program and Saskatoon Health Region, including 3 nephrologists, 3 surgeons, 16 nurses, and 3 pharmacists with extensive knowledge of transplantation. The measure was subsequently reviewed by 10 transplant recipients, and small modifications were made. The final version of the instrument consisted of 9 true or false questions and 14 multiple-choice questions (each with >1 potential answer, equating to a potential score of 69) regarding immunosuppressive medications and lifestyle recommendations necessary for optimal transplant outcomes. One point was given for each correct answer chosen. Because the present analysis was the first formal examination of the tool in a study, determination of adequate knowledge was not identified at this juncture.

BMQ Analysis

The BMQ, as developed by Horne et al [23], is an 18-item instrument used to measure cognitive representation of medication of a patient's own medication and beliefs about medication in general. It has been validated for use in patients with chronic illnesses and has been shown to predict adherence to treatment in certain populations, such as those with asthma, rheumatoid arthritis, severe mental disorders, and (more recently) kidney transplantation [24–26]. The first part of the questionnaire (BMQ-specific) evaluates the patient beliefs about their own medications, and the second part (BMQ-general) assesses the patient beliefs of medicines in general. The BMQ-specific has 2 themes; the first assesses perceptions of medication importance (BMQ-specific necessity), and the second theme describes the patients' potential concern for harm and adverse effects (BMQ-specific concern). Each theme generates a score ranging from 5 to 25. Likewise, the BMQ-general consists of 2 domains, with the BMQ-general overuse scale assessing patient concern regarding overuse of medications and the BMQ-general harm domain assessing patient beliefs about the harmful nature of medication in general. The scores in this section of the questionnaire range from 4 to 20, with a higher score indicating a more negative perception about medicines in general.

A BMQ necessity-concerns differential was also calculated as the difference between the BMQ-specific necessity and BMQ-specific

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