

Development and testing of a disease-specific health literacy measure in kidney transplant patients

Context—Health literacy affects a patient’s ability to navigate through the system of care for late-stage kidney disease, including evaluation, waiting, and recovering from kidney transplant.

Objectives—To develop and provide a preliminary evaluation of a knowledge and decision-making capacity tool, which is a component of health literacy.

Design—Cross-sectional design with purposive sampling.

Setting—Vascular access, dialysis, and outpatient transplant clinics.

Methods—A Decision-Making Capacity Assessment Tool (DMCAT) was developed and administered to 127 adults at different stages in the kidney care process.

Results—The DMCAT tool is positively and significantly correlated to the other 2 previously validated instruments and accounts for more variance than the other 2 tools in the regression models. We found significant differences in patients’ health literacy and decision-making capacity related to their stage of care. Decision-making capacity appeared to be an important component of health literacy and should be considered as health care providers tailor care to meet patients’ needs. (*Progress in Transplantation*. 2014;24:263-270)

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doi: <http://dx.doi.org/10.7182/pit2014958>

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The Institute of Medicine has defined health literacy as “the degree to which individuals have the capacity to obtain, process, and understand the basic health information and services needed to make appropriate decisions.” The 1993 National Adult Literacy Survey showed that approximately 90 million adults in the United States had some difficulty understanding or using health information.¹ The emerging body of literature since the Institute of Medicine’s report has consistently found health literacy to be associated with health care knowledge, behavior, utilization, decision making, and outcomes²⁻⁵ and to be a more robust predictor of health status than are other sociodemographic characteristics (eg, age, income, education, employment).⁶

Despite the emergence of health literacy as an important focus of empirical study, surprisingly few

studies have been done to examine health literacy in the context of kidney transplant.⁷ In a study using the Short Term of Functional Health Literacy in Adults (S-TOFHLLA) and the Rapid Estimate of Adult Literacy of Medicine-Transplant (REALM-T), Gordan and Wolf⁸ found that approximately 91% of 124 kidney transplant recipients had adequate health literacy, although 81% were unfamiliar with at least 1 kidney transplant-related term. A similar study⁹ used the S-TOFHLLA to assess correlations between low health literacy and the demographic variables sex, race, age, type of transplant, and years since transplant in a small sample (n=36) of kidney transplant recipients. Age was the only demographic variable that resulted in a significant correlation with health literacy ($r=-0.399$, $P=.008$). Within this small sample, 72% of the patients were categorized

as having marginal or low health literacy on the basis of their S-TOFHLA scores.⁹ Other health literacy assessment tools previously used include the Newest Vital Sign (NVS) and the original REALM. Such tools measure certain aspects of health literacy such as language and comprehension, but health literacy is a more complex construct that also includes the ability to use information to make decisions. Beyond understanding health information, making care-related decisions requires the ability to make decisions on the basis of that information. This skill is a competency that represents a different dimension of health literacy that may demand additional health literacy measures.

The purpose of this study was to develop and pilot test a new tool for measuring the health literacy levels of patients with end-stage renal disease (ESRD) who are navigating the care process. We chose to use a purposive sample that included patients from different parts of the ESRD care process. We recruited patients who were currently undergoing dialysis, or are pretransplant, posttransplant, and being assessed for vascular access (dialysis/preemptive dialysis). This newly developed instrument was designed to measure knowledge of terminology relevant to the ESRD health care process as well as capacity to make decisions about choices/actions required to navigate this process for ESRD patients. Our research questions were as follows: (1) What are the variations in knowledge of renal failure, (2) what are the variations in decision capacity observed for ESRD patients who are currently in the renal failure care system, (3) What are the validity characteristics of the data collection instrument we developed to measure these factors?

Methods

Scenario Development

The need for an instrument to assess aspects of health literacy of patients with renal failure became apparent after we analyzed charted responses of patients to a set of questions that our transplant coordinators routinely asked clinic patients to gauge their knowledge of kidney failure and their ability to make informed decisions about their care. The nurses were asking “renal failure health literacy” questions as part of probing to ensure that their patient education efforts were successful. When we examined currently available health literacy instruments, we found that very few of the questions in the instruments probed the issues that were judged to be important by our clinicians for assessing knowledge and decision-making capacity of patients with renal failure. We reviewed the literature on health literacy and presented the results for discussion at clinical and research team meetings.

After extensive discussion, consensus was reached that the most promising approach would be to develop

a renal failure scenario that that could be used to frame individual questions to measure knowledge about renal failure and decision capacity of patients. Two experienced clinicians volunteered to develop scenarios. These were presented and discussed in group meetings. They were then combined, and the combined scenario was edited by team members individually. The edited scenarios were then discussed again in a group setting and the final scenario was approved. This scenario was presented for cognitive pretesting to 2 clinicians who were not members of the scenario development group, and the final scenario was edited for clarification. Questions were then developed that were based on the scenario. The scenario and questions were pretested in a group of 8 patients and revised for clarity. Based on the pretest responses, a scoring scale was developed for the final scenario and questions. Responses could be scored from 0 to 3, with a 0 score earned for no response or a “do not know” response, a score of 1 for responses that were vague or nonspecific, a score of 2 for correct but limited responses, and a score of 3 for correct and comprehensive responses. The scoring guide is provided in Table 1.

Interrater reliability was tested on a sample of 30 responses (see Results). The institutional review board provided approval for data collection with 2 previously validated health literacy instruments and the newly developed instrument. A purposive sample of 120 patients with renal failure was prospectively identified from the clinic’s scheduling system. Patients were approached to be interviewed, and informed consent was obtained. Patients were enrolled in the study with the goal of having approximately 30 patients from different parts of the ESRD care process.

Health Literacy Assessment Tools

The surveys administered to the study sample contained 3 different assessment tools. Two of the instruments, the REALM-T and the NVS, have been validated and used in research; the NVS had previously been modified slightly to create a more relevant tool with regards to the targeted population of transplant patients. The REALM-T and NVS both measure health literacy. The development of the third assessment tool, the Decision-Making Capacity Assessment Tool (DMCAT) was described in the preceding section.

REALM-T. The REALM-T is a modified version of the original REALM that is used to assess the health literacy of the transplant population. This instrument had been validated by Gordon and Wolf.⁸ The test consists of 3 lists, totaling 69 words. Participants are asked to say the words aloud and are assigned a score that is based on the number of the words that they pronounce correctly.

Table 1 Scoring guide for the Decision-Making Capacity Assessment Tool

Question	Literacy knowledge and decision-making dimensions	Example			
		Incorrect or no answer = 0	Vague/nonspecific response = 1	Good but limited response = 2	Good comprehensive response = 3
1	Knowledge of kidney failure symptoms: What do you think might be wrong?	I don't know	Could be many things, she could have a bladder infection	Mentions 1 symptom linked to kidney failure	Mentions 2+ symptoms linked to kidney failure
2	Decision to recommend: What should your friend do?	Don't know, I do not tell friends what to do	Well I am not sure, but I would be worried and talk to [relative/friend]	Go see her doctor	Make an appointment to see her doctor to have her kidneys tested
3	Knowledge of kidney failure treatments: Friend's options for treating kidney failure?	Don't know	Wait and see if it goes away	One correct option: dialysis or transplant	Both correct options: dialysis or transplant
4	Decision capacity related to dialysis: Tell friend of advantages and disadvantages of dialysis	Don't know	I don't like dialysis or Dialysis is OK	Responds with 1 good thing OR 1 bad thing about dialysis	List 1 or more good things AND 1 or more bad things about dialysis
5	Decision capacity related to transplant: Tell friend of advantages and disadvantages of transplant	Don't know	Irrelevant: I knew a woman in church who had a transplant	Responds with 1 good thing OR 1 bad thing about transplant	List 1 or more good things AND 1 or more bad things about transplant
6	Decision capacity to recommend: Which treatment would you tell your friend to get?	Don't know	It does not matter	Dialysis	Transplant
7	Knowledge of how to access care: If he wanted to, how would friend start [treatment in question 6]?	Don't know	Vague or irrelevant: talk to someone who knows about this	Wrong medical contact/limited answer: example, go to emergency department	Give 1 or more entry point into transplant or dialysis process: physician referral, dialysis center, transplant center

NVS. The original NVS also measures health literacy and numeracy skills but is not specific to any particular area of medicine. The NVS was previously modified and validated by the original authors to create a more specific assessment tool for patients who are preparing for transplant. The questions assess the participants' ability to read, understand, and find necessary information on a medication prescription label by asking specific questions. The modified version of the NVS used consists of 2 prescription labels, 1 for amoxicillin and 1 for fluocinolone acetonide. Patients' scores depended on the number of questions answered correctly.

DMCAT. The DMCAT is a questionnaire specific to transplant. It was created for the current study to assess a person's decision-making capacity. The test consists of a scenario and 7 questions to evaluate the participant's knowledge and understanding of dialysis and the transplant process. The survey administrator reads a short scenario about a person who presents with symptoms common to patients with ESRD and chronic kidney disease and then asks the questions. The questions address the participant's knowledge of

the dialysis and transplant process and poses questions that require patients to make a decision. Each of the questions is open ended, and each answer is worth up to 3 points. Therefore, the highest possible overall DMCAT score is 21. Each answer is consistently graded depending on the relevance and accuracy of the participant's response (see Table 1).

Study Sample and Data Collection

The targeted populations of patients were English-speaking patients who were being treated with dialysis before transplant, were kidney transplant recipients, or were undergoing vascular access procedures and dialysis. A total of 127 patients participated in the study. Each group of patients was surveyed at the Medical University of South Carolina's clinics except for the patients undergoing dialysis, who were surveyed in local dialysis clinics. The study was approved by the institutional review board at the Medical University of South Carolina.

Data on patients' literacy were collected by using the 3 instruments just described. The REALM-T was administered first, followed by the NVS and finally the DMCAT. Demographic data were gathered through

patients' reports and hospital databases and included age, dialysis clinic attended, date of waiting list registration and date of transplant if applicable, sex, race, marital status, and primary insurance.

Assessment of Instrument Validity

Construct validity of the DMCAT was evaluated by assessing the correlation between the patients' responses to the knowledge questions of the DMCAT and their responses to the global response scores on the REALM-T and the NVS as well as the overall correlation between the total scores for the instruments. Convergent validity of responses within the DMCAT was assessed by examining the correlation between the knowledge question and the decision questions of the instrument as well as by comparing respondents' distributions with thirtiles (high, moderate, and low) for the knowledge and decision questions. Discriminant validity could not be assessed because DMCAT does not contain questions that are clearly unrelated. Internal consistency was examined by assessing correlations between all questions in the DMCAT instrument. Measurement precision was explored by test-retest reliability and by interrater reliability measures.

Statistical Analysis

Descriptive summaries of each of the variables were calculated and are provided. Differences between groups for continuous variables were tested by using a *t* test or Wilcoxon test as appropriate for the distribution of the data. Pearson correlation was used to examine correlation between scores, and χ^2 test was used to assess differences between groups. Multivariable regression modeling was used to assess the association between patients' characteristics and the literacy scores. Tests of normalcy of the distribution of the data and multicollinearity assessment were performed beforehand to inform modeling choices. Patients' characteristics were recoded for some analyses too. Sex was specified as male (=1) and female (=0). The race variable was coded as African American (=1) or not African American (=0) because of the paucity of other minority groups in our data. The age was recoded as a categorical measure with a value of 0 if the patient was less than 65 years of age, and otherwise 1. Individual insurance status binary variables were constructed for Medicare, Medicaid, private insurance, and self-pay.

Results

Demographics of Patients

The sample included 127 patients with a minimum of 30 patients from each stage of care ranked from the lowest to highest time exposure/familiarity with the care process for renal failure: (1) vascular access, (2) dialysis, (3) pretransplant, and (4) post-transplant. Thirty patients undergoing vascular access

Table 2 Patients' demographics

Characteristic ^a	All patients (N = 127)
Age, mean (SD), y	53.2 (18.6)
Male sex	61 (48.4)
Married ^b	45 (35.9)
African American	89 (69.5)
Medicare	95 (74.2)
Medicaid	8 (6.3)
Private Insurance	24 (18.8)
Self-pay	1 (0.8)
Vascular access clinic	30 (23.6)
Dialysis	36 (28.3)
Pretransplant	31 (24.4)
Posttransplant	30 (23.6)
REALM-T score, mean (SD; range)	53.8 (19.7; 0-69)
NVS score, mean (SD; range)	4.5 (2.0; 0-6)
DMCAT score, mean (SD; range)	13.4 (5.0; 0-18)

Abbreviations: DMCAT, Decision-Making Capacity Assessment Tool; NVS, Newest Vital Sign; REALM-T, Rapid Estimate of Adult Literacy of Medicine-Transplant.

^a Values in second column are No. (%) of patients unless otherwise stated.

^b Information was missing for 11 patients.

were between 18 and 80 years old, 12 were male and 18 were female, and 4 were white and 26 were African American. Thirty-six patients undergoing dialysis were between 18 and 80 years old, 15 were male and 21 were female, 7 were white and 29 were African American (1 patient was Hispanic). The 31 pretransplant patients were between 18 and 80 years old, 16 were male and 15 were female, 15 were white and 16 were African American. Thirty posttransplant patients were between the ages of 18 and 80 years, 18 were male and 12 were female, 11 were white and 19 were African American (Table 2).

Validity of the DMCAT Measure

Construct validity of the DMCAT was assessed by examining the correlation between the knowledge and decision-making subscores as well as the correlation of the total DMCAT score with patients' scores on the REALM-T and the NVS. All correlations were significant with *P* values less than .001. The correlation coefficients for the measures varied between 0.430 and 0.707. The lowest correlation was between the REALM-T and the DMCAT scores. The results provide support for the DMCAT having acceptable or good construct validity in this population (Table 3).

Convergent validity of the DMCAT was assessed by examining correlation between responses to individual questions and by comparing respondents for

Table 3 Correlations among the instruments^a

	Total DMCAT	REALM-T	NVS	DMCAT knowledge subscore	DMCAT decision subscore
Total DMCAT	1				
REALM-T	0.401	1			
NVS	0.727	0.619	1		
DMCAT knowledge subscore	0.961	0.401	0.684	1	
DMCAT decision subscore	0.893	0.392	0.716	0.893	1

Abbreviations: DMCAT, Decision-Making Capacity Assessment Tool; NVS, Newest Vital Sign; REALM-T, Rapid Estimate of Adult Literacy of Medicine-Transplant.

^a All have $P < .001$.

low, medium and high scores across the questions in the instrument. The individual correlation coefficients for the question ranged between 0.56 and 0.73 and were all significant ($P < .001$). The mean respondent scores by low, medium, and high total DMCAT score are shown in Figure 1. The results of this analysis indicate that the DMCAT has good convergent validity.

Test-retest reliability and interrater reliability of the DMCAT were assessed and found acceptable. We assessed test-retest reliability in a sample of 47 individuals who took the DMCAT again within approximately 1 hour of the original test. The total score had a κ value of 0.65, indicating acceptable reliability. As expected, the reliability of the individual score for question 3 was low ($\kappa = 0.24$) because patients who did not recognize renal failure symptoms during the initial test received an explanation and clarification of the symptoms, which would affect their second test response. The κ values for the rest of the questions were between 0.54 and 0.95, indicating acceptable to excellent reliability. Interrater reliability was assessed by scoring responses from 29 individuals independently by 2 study team members (A.K. and K.N.S.). We found good interrater reliability (weighted $\kappa = 0.71$) for the total DMCAT scores. The interrater agreement plot is provided in Figure 2. Agreement for the individual scores ranged from a κ of 0.51 for question 3 to 0.90 for question 7.

Descriptive Multivariable Modeling of DMCAT and Health Literacy Scores

We used multivariable modeling to describe how the summary health literacy scores for the DMCAT differed by respondents' characteristics. Our goal for this analysis was to describe the individual patient characteristics that systematically affected total scores on the instrument in our population. Of the 127 patients, 11 were excluded from the multivariable models because the marital status variable was missing. The range of REALM-T scores was from 50.21 to 61.69: patients undergoing vascular access scored the lowest, followed by patients who were undergoing dialysis,

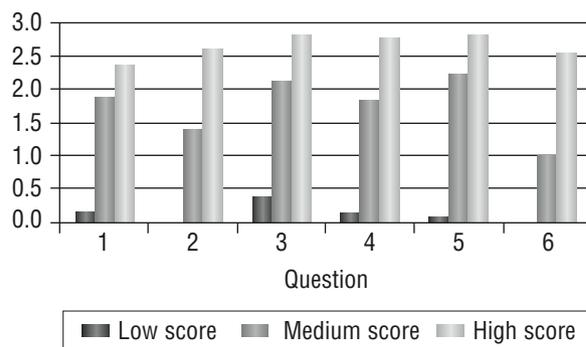


Figure 1 Mean individual responses to questions on the Decision-Making Capacity Assessment Tool (DMCAT) by low, medium, and high scores on the DMCAT.

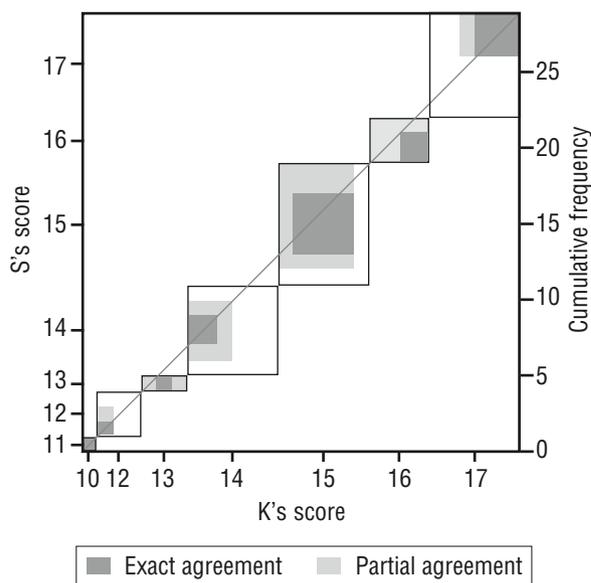


Figure 2 Interrater agreement on total score on the Decision-Making Capacity Assessment Tool between raters K and S.

pretransplant patients, and posttransplant patients. For the NVS, the scores ranged from 4.12 to 5.62: the lowest scores were in patients undergoing dialysis, then patients from the vascular access clinic, then

Table 4 Mean scores on health literacy tests by patient group

Patient group	Mean score		
	REALM-T (range 0-69)	NVS (range 0-6)	DMCAT (range 0-18)
Vascular access clinic	50.21	5.00	13.34
Pretransplant	59.61	5.03	16.32
Posttransplant	61.69	5.62	16.52
Dialysis	50.57	4.12	12.15

Abbreviations: DMCAT, Decision-Making Capacity Assessment Tool; NVS, Newest Vital Sign; REALM-T, Rapid Estimate of Adult Literacy of Medicine-Transplant.

pretransplant patients, and posttransplant patients. Finally, the range of scores for the DMCAT was from 12.15 to 16.52: the lowest scores were exhibited by dialysis patients, followed by vascular access, pretransplant, and posttransplant patients (Table 4).

Strong positive correlations were found between the 3 health literacy tools. The DMCAT tool was correlated with *P* values less than .001 with both the REALM-T and the NVS with correlations of 0.430 and 0.797. Such strong correlations indicate that the DMCAT is a valid and strong tool for measuring the decision-making aspect of health literacy and holds positive predictive value for patients' performance on the other 2 health literacy assessment tools.

REALM-T

In the REALM-T, the overall model was found significant and explained 28% of the variance. Significant predictors of the score included patients' status, race, and age. Posttransplant patients had the highest level of health literacy, followed by pretransplant patients; however, no statistically significant difference was found in health literacy between dialysis and vascular access patients. Males scored lower than females in health literacy, and African Americans and older patients also scored lower than non-African American and younger patients, respectively (Table 5). Overall, 18.9% (n=24) had low/inadequate health literacy, 24.4% (n=31) had marginal health literacy, and 53.5% (n=68) had good/adequate health literacy. Four patients (3.1%) did not complete the REALM-T.

NVS

In the NVS, the DMCAT was significant overall and predicted 25% of the variance based on patients' status, race, and age. For patient status, only dialysis patients were significantly different from the other groups, with lower scores on this measure (Table 5). Males and older individuals also performed significantly lower on this measure of health literacy. Overall, 4.7% (n=6) had low health literacy, 8.7% (n=11) had marginal health literacy, and 78.0% (n=99) had

good/adequate health literacy. The remaining 11 patients (8.7%) could not be included in the analysis because data on their marital status were missing.

DMCAT

In the DMCAT, the model explained 41% of the variance and was significant overall. Significant predictors of decision-making capacity include patient status, with pretransplant and posttransplant patients scoring higher than both dialysis patients and vascular access patients. No significant difference was found in the scores of dialysis and vascular access patients (Table 5).

Discussion

ESRD is a costly and prevalent disease, and the optimal treatment for ESRD is kidney transplant. Despite life years gained and increased quality of life made possible through kidney transplants, a large number of patients are lost to follow-up and do not complete the necessary evaluation to receive a kidney transplant. The southeast United States in particular has one of the lowest rates of entering patients on waiting lists for a kidney transplant, with only 18% of patients on dialysis and less than 70 years old in the Southeast listed, as opposed to 24% nationally. The transplant center at a major health sciences institution has implemented several strategies to reduce the number of patients that do not continue for follow-up. These include the use of patient navigators in community nephrologist offices; regional educational classes; the redesign of materials to be more patient friendly; and reminder phone calls and letters sent to patients, dialysis units, and the referring nephrologist. Despite these efforts, a number of patients continue to be lost to follow-up.

Use of the DMCAT in this study provided a useful and significant measurement as an important component of health literacy and access to care by assessing decision making. The DMCAT is highly sensitive and helps explain a larger portion of the variance, potentially identifying an area of focus for improving the patient's experience in the treatment of ESRD. Previous studies have examined control preferences related to decision-making capacity in renal failure and cancer patients, indicating various levels of preferences for information related to diagnosis, prognosis, treatment options, and side effects as well as for involvement in decision making related to their treatment.¹⁰⁻¹² These various preferences for information and participation in decision making may explain an important related component of health literacy given that some patients desire understanding of their illness. Clinicians should thus attempt to assess these preferences and tailor care accordingly. Although previous research has shown variance in health literacy by using the

Table 5 Multivariable models predicting total instrument scores after controlling for patients' characteristics

Characteristic	DMCAT model (score 0-18)		REALM-T model (score 0-69)		NVS model (score 0-6)	
	β	<i>P</i>	β	<i>P</i>	β	<i>P</i>
Intercept (vascular access group)	13.7	<.001	57.8	<.001	5.7	<.001
Pretransplant	2.7	<.001	7.5	.07	-0.3	.52
Posttransplant	3.0	<.001	9.8	.02	0.4	.34
Dialysis	-1.1	.14	4.2	.28	-0.9	.02
Male	-0.5	.26	-3.0	.29	-0.2	.36
African American	-0.2	.68	-10.0	.002	-0.8	.01
Married	-0.3	.62	-5.1	.08	-0.5	.09
Young	0.7	.16	7.6	.01	0.5	.05
Private insurance	0.5	.41	6.3	.07	0.2	.46
Model <i>R</i> ²	0.41		0.28		0.25	

Abbreviations: DMCAT, Decision-Making Capacity Assessment Tool; NVS, Newest Vital Sign; REALM-T, Rapid Estimate of Adult Literacy of Medicine-Transplant.

NVS in transplant,¹³ this study explores an additional element in decision-making capacity through the development and use of a new tool.

The results indicate a relationship between the demographic status of patients and health literacy. This finding is important because it is possible that patients with a higher level of health literacy are more easily able to navigate the system and thus are more likely to receive a transplant than are other patients with lower levels of health literacy. On the other hand, it is possible that health literacy is increased through the evaluation and treatment process and that patients increase their understanding by necessity to undergo the complex evaluation system that is required to receive a transplant.

Other factors also affect health literacy, including race, marital status, and age. Racial health disparities, most likely related to health literacy in ESRD, transplant, and other areas, have been explored in previous research and must be considered when providing care.¹⁴ Specific strategies such as patient navigators, targeted print materials, and videos of diverse patient testimonials may assist in reducing these disparities. Likewise, the role of marriage in health literacy is probably a function of who makes the health care decisions in families. For many men, their wives are the primary health care decision makers, and thus the wives should be included in discussions and directions for evaluation and care. Finally, age may relate to health literacy because a great deal of health-related information is currently available online. It is possible that younger people are more apt to use these online resources, or it is possible that they are more interested in actively pursuing treatments that will improve their quality of life because they are still young, and thus they attain or maintain the health literacy needed to make related decisions.

Given that posttransplant patients must maintain strict adherence to medication and other monitoring for good outcomes, providers must maintain a careful balance between ensuring that patients can understand and comply with the complex follow-up instructions for successful graft survival and increasing access to information and evaluation for patients with reduced health literacy who seek treatment. Health literacy and decision-making capacity are complex constructs that are most likely related to education, socioeconomic, cultural, and personal factors. Providers are most likely best suited to provide multifaceted approaches to provide complex information about the illness and process of treatment to allow more equitable access to transplants for all patients in ways that can be understood. These approaches may include information sessions, the opportunity to ask questions of clinicians, video information, pamphlets at the appropriate reading level, and access to a patient navigator or coordinator who can answer questions and assist in completing the needed components of care for evaluation and transplant.

Our study does have several limitations. A diverse group of patients from only 1 transplant program and 1 geographic area were recruited, thus limiting the generalizability of our findings. Second, our analysis does not allow identification of relationships of causality, leaving questions of whether health literacy is increased by the treatment process or whether health literacy is necessary to navigate through the treatment and evaluation process.

Future studies are needed to assess interventions that address significant health literacy issues and tailor care to patients on the basis of their existing health literacy. Practitioners may wish to assess patients' health literacy and decision-making capacity formally or informally and take it into account when designing

educational materials and programs for patients who are in the treatment process for ESRD and/or kidney transplant.

Financial Disclosures

This work was funded by a grant (R01 DK06259) from the National Institutes of Health/National Institute of Diabetes and Digestive and Kidney Diseases "A Program to Increase Living Donations in African Americans."

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