# The Relationship Between Health Literacy and Outcomes Before and After Kidney Transplantation

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**Background.** Limited health literacy (HL) is associated with decreased kidney function and death in patients with chronic kidney disease. Less is known about the impact of HL on kidney transplant (KT) outcomes. The aim of this study was to examine the relationship between HL and KT outcomes, including rates of waitlisting, healthcare utilization, acute rejection, renal allograft function, renal allograft failure, and death. **Methods.** We performed a retrospective review of HL data previously collected at our center. HL was assessed in a convenience sample of consecutive, English-speaking patients age ≥18 y who were evaluated for KT at Mayo Clinic in Minnesota between June 2015 and March 2017 as part of a practice improvement feasibility project (n = 690). HL was assessed using the 4-item Brief Health Literacy Screening Tool modified for the outpatient KT evaluation process. The 4 items assess confidence completing forms, reading comprehension, and oral literacy. **Results.** Overall, 30.4% of patients had limited or marginal HL. Patients with limited or marginal HL were less likely than those with adequate HL to be waitlisted for KT (hazard ratio = 0.62 and 0.69, respectively), even after adjusting for age, marital status, body mass index, Charlson comorbidity index, or dialysis dependency. Patient HL was not associated with post-KT healthcare utilization, acute rejection, or renal allograft function. Patients with limited or marginal HL appeared to experience a higher risk of renal allograft failure and post-KT death, but the number of events was small, and the relationship was statistically significant only for marginal HL. **Conclusions.** Inadequate HL is common in KT candidates and independently associated with decreased waitlisting for KT. We observed no statistically significant relationship between HL and posttransplant outcomes in our cohort. Further efforts to improve communication in patients with inadequate HL may improve access to KT.

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## INTRODUCTION

Health literacy (HL), the ability to obtain, understand, and use information to make informed decisions about one's health care, is a modifiable risk factor for adverse health outcomes.[1] Limited HL has been associated with medication errors, increased healthcare spending, inadequate self-management of chronic health conditions, and mortality.[1,2]

HL is such an important contributor to health outcomes that the United States Department of Health and Human Services identified HL as a public health priority in its Healthy People 2030 initiative[3] and has issued a National Action Plan to Improve Health Literacy.[4]

Our understanding of the impact of limited HL in patients with chronic kidney disease (CKD) outcomes is expanding. A systematic review demonstrated that approximately 25% of patients with CKD have limited HL, defined as a low score on

various HL instruments. Patients with limited HL experience lower kidney function,[5,6] earlier onset of CKD,[7] and increased mortality.[8] Limited data exist regarding the impact of HL in kidney transplant (KT) recipients. HL may be essential for this subgroup of patients who must navigate the highly complex process of obtaining and caring for a KT.[9] One study demonstrated that 9% of living donor KT recipients and 14% of deceased donor KT recipients have limited HL.[10] Limited HL has been associated with immunosuppression nonadherence.[11] Understanding the relationship between HL and KT outcomes is the first step toward developing effective interventions to improve HL in this high-risk patient population.

The primary objective of this study was to examine the relationship between HL and rates of waitlisting in KT candidates by performing a secondary analysis of data obtained during a practice improvement feasibility project. Secondary objectives included examining the relationship between patient HL and waitlist mortality, KT, post-KT healthcare utilization, rejection, allograft function, allograft failure, and post-KT death.

## MATERIALS AND METHODS

### Patient Population

We performed a retrospective review of HL data previously collected at our center. HL was assessed in a convenience sample of consecutive, English-speaking patients age ≥18 y who were evaluated for KT at Mayo Clinic in Minnesota between June 2015 and March 2017 as part of a practice improvement feasibility project. HL screening forms were distributed by desk staff to patients at the time of outpatient KT evaluation. Patients were asked to return their completed HL assessments at the end of their transplant center appointment. If the patient had limited HL, as indicated by the screening form, an additional appointment with a patient education specialist was added to the patient's evaluation appointment itinerary. The goal of the appointment with the patient education specialist was to confirm understanding of transplant-related health information and help patients organize any questions they had before their wrap-up visit with the transplant nephrologist. Clinical providers and the transplant center selection committee were not aware of patient HL scores. Likewise, they were not aware of whether the candidate met with a patient education specialist during their evaluation. The relationship between HL and KT outcomes was analyzed via secondary analysis of data generated from the practice improvement feasibility project. The goal of the practice improvement feasibility project was to determine whether HL screening and additional education for patients with limited HL could be integrated into routine clinical care.

Patients undergoing evaluation for a combined organ transplant or who did not provide Minnesota Research Authorization permitting access to their medical information for research purposes were excluded from the analysis. Clinical information, including education, marital status, smoking status, race, gender, and donor variables, were obtained from Mayo Clinic electronic databases. Comorbidities were obtained via ICD-10 codes. The study was approved by the Mayo Clinic Institutional Review Board, who waived the need for informed consent.

### HL

HL was assessed using the 4-item Brief Health Literacy Screening Tool (BRIEF) modified for the outpatient KT

**TABLE 1.**

**Health literacy assessment**

| Questions | Scale |
|---|---|
| 1. How confident are you filling out medical forms by yourself? | 1 = Not at all |
| | 2 = A little bit |
| | 3 = Somewhat |
| | 4 = Quite a bit |
| | 5 = Extremely |
| 2. How often do you have someone help you read materials you get from doctors or nurses such as booklets, forms, or instructions for medicine?[a] | 1 = All of the time |
| | 2 = Most of the time |
| | 3 = Some of the time |
| | 4 = A little of the time |
| | 5 = None of the time |
| 3. How often do you have problems learning about your medical condition because of difficulty understanding written information? | 1 = All of the time |
| | 2 = Most of the time |
| | 3 = Some of the time |
| | 4 = A little of the time |
| | 5 = None of the time |
| 4. How often do you have trouble understanding medical information spoken to you by doctors or nurses?[b] | 1 = All of the time |
| | 2 = Most of the time |
| | 3 = Some of the time |
| | 4 = A little of the time |
| | 5 = None of the time |

[a] Modified from original wording of BRIEF ("How often do you have someone help you read hospital materials?") to apply to this outpatient study population.
[b] Modified from originally wording of BRIEF ("How often do you have trouble understanding what is told to you about your medical condition?") to more explicitly note healthcare providers as the source of the spoken medical information.
BRIEF, Brief Health Literacy Screening Tool.

evaluation process (Table 1).[12,13] The 4 items assess confidence completing forms, reading comprehension, and oral literacy. We applied BRIEF scoring rules to create a total sum score ranging from 4 to 20 with lower scores indicating lower HL. The Cronbach alpha (a measure of internal consistency reliability) for the 4-study-specific screening items was 0.84, which supports combining the questions into a single score.[14] We also applied a priori BRIEF cut points to define limited HL as a score ≤12, marginal HL as a score of 13 to 16, and adequate HL as a score >16.[13] Better HL has consistently been shown to be associated with higher educational attainment.[15] A significant association between education and HL was also observed in our study ($P < 0.001$; Table 2), which supports the validity of the modified BRIEF HL scores in this sample.

### Clinical Outcomes

Pretransplant outcomes examined included waitlisting, waitlist mortality, and time to KT. Posttransplant outcomes examined included hospital length of stay following transplant surgery, rehospitalizations, acute rejection within the first posttransplant year, renal allograft function at 12 mo, renal allograft failure, and mortality. According to clinical protocols, KT recipients at our center routinely undergo surveillance renal allograft biopsies at 4 and 12 mo posttransplant. Indication allograft biopsies are performed at the discretion of the managing nephrologist based on evidence of renal allograft dysfunction. Rehospitalizations were defined as admissions within 30 d of transplant surgery. Cell and/or antibody-mediated acute rejection was diagnosed based on surveillance or indication biopsy according to Banff criteria[16,17] within the first posttransplant year. Glomerular filtration rate

**TABLE 2.**

**Characteristics of kidney transplant candidates at time of health literacy assessment[a]**

| Variable[a] | Limited patient health literacy (n = 65, 9.4%) | Marginal patient health literacy (n = 145, 21.0%) | Adequate patient health literacy (n = 480, 69.6%) | Total (n = 690, 100.0%) | P[f] |
|---|---|---|---|---|---|
| Age, y | 54.8 ± 13.4 | 55.5 ± 14.3 | 55.0 ± 13.3 | 55.1 ± 13.5 | 0.80 |
| | 57.1 (48.7–64.3) | 58.8 (45.1–66.3) | 57.2 (46.4–65.4) | 57.6 (47.0–65.6) | |
| Male sex | 45 (69.2%) | 98 (67.6%) | 282 (58.8%) | 425 (61.6%) | 0.06 |
| Race | | | | | 0.06 |
| White | 48 (73.8%) | 112 (77.2%) | 401 (83.5%) | 561 (81.3%) | |
| Black or African American | 3 (4.6%) | 10 (6.9%) | 38 (7.9%) | 51 (7.4%) | |
| Asian | 4 (6.2%) | 8 (5.5%) | 12 (2.5%) | 24 (3.5%) | |
| Other | 10 (15.4%) | 15 (10.3%) | 29 (6.0%) | 54 (7.8%) | |
| Cause end-stage renal disease | | | | | <0.001 |
| Glomerular | 15 (23.1%) | 38 (26.2%) | 172 (35.8%) | 225 (32.6%) | |
| Diabetes | 25 (38.5%) | 44 (30.3%) | 92 (19.2%) | 161 (23.3%) | |
| Polycystic kidney disease | 6 (9.2%) | 11 (7.6%) | 66 (13.8%) | 83 (12.0%) | |
| Hypertension/vascular | 0 (0.0%) | 10 (6.9%) | 28 (5.8%) | 38 (5.5%) | |
| Other/unknown | 19 (29.2%) | 42 (29.0%) | 122 (25.4%) | 183 (26.5%) | |
| Diabetes | 32 (49.2%) | 62 (42.8%) | 134 (27.9%) | 228 (33.0%) | <0.001 |
| Charlson comorbidity index | 3.0 ± 1.8 | 2.6 ± 1.2 | 2.7 ± 1.3 | 2.7 ± 1.3 | 0.37 |
| | 2.0 (2.0–3.0) | 2.0 (2.0–3.0) | 2.0 (2.0–3.0) | 2.0 (2.0–3.0) | |
| Preemptive at time of waitlist | 35 (53.8%) | 69 (47.6%) | 273 (56.9%) | 377 (54.6%) | 0.14 |
| Time on dialysis,[b] mo | 28.5 ± 28.3 | 33.5 ± 35.9 | 28.4 ± 36.2 | 29.6 ± 35.4 | 0.29 |
| | 22.2 (8.2–29.4) | 20.7 (7.5–48.4) | 16.1 (5.7–39.8) | 18.8 (6.4–40.3) | |
| Prior kidney transplant | 7 (10.8%) | 19 (13.1%) | 98 (20.4%) | 124 (18.0%) | 0.04 |
| Marital status | | | | | 0.18 |
| Married/life | 36 (55.4%) | 100 (69.0%) | 312 (65.0%) | 448 (64.9%) | |
| Divorced/separated | 6 (9.2%) | 10 (6.9%) | 53 (11.0%) | 69 (10.0%) | |
| Single/widowed | 23 (35.4%) | 173 (24.1%) | 115 (24.0%) | 173 (25.1%) | |
| Education[c] | | | | | <0.001 |
| High school or less | 39 (60.9%) | 59 (41.5%) | 105 (22.2%) | 203 (29.9%) | |
| At least some college | 22 (34.4%) | 69 (48.6%) | 287 (60.7%) | 378 (55.7%) | |
| Postgraduate | 3 (4.7%) | 14 (9.9%) | 81 (17.1%) | 98 (14.4%) | |
| Never smoker[d] | 30 (48.4%) | 69 (50.0%) | 250 (53.5%) | 349 (52.3%) | 0.62 |
| Body mass index,[e] kg/m² | 29.7 ± 6.7 | 31.3 ± 6.1 | 29.4 ± 6.0 | 29.8 ± 6.1 | 0.005 |
| | 29.8 (25.1–33.9) | 30.4 (26.8–35.2) | 29.0 (25.0–33.1) | 29.5 (25.5–33.7) | |

[a] Mean ± SD and medians and interquartile ranges for continuous variables; counts and percentages for categorical data.
[b] n = 313.
[c] n = 679.
[d] n = 667.
[e] n = 682.
[f] P values are from the chi-squared test or the Kruskal-Wallis test depending on whether or not the data are categorical or continuous, respectively.

was measured via iothalamate clearance. Renal allograft failure was defined as return to dialysis or relisting for KT.

**Data Analyses**

Means were compared using Kruskal-Wallis in case of heavily skewed data. Counts and proportions were compared using chi-square test. Survival analyses were performed using Kaplan-Meier estimation and Cox proportional hazards regression. Only patients with complete HL scores were analyzed. Missing data were handled using listwise deletion because, in all cases, the data missing ranged from 0% to 4%. When analyzing rates of waitlisting, the study was limited to individuals undergoing an initial KT evaluation. The relationship between risk factors available at baseline and limited HL was examined univariately and using stepwise logistic regression (α = 0.10 to enter) to determine a multivariable model. Time to event (waitlisting, death on the waitlist, KT, acute rejection, renal allograft failure, and post-KT death) was evaluated using Cox proportional hazards regression. In analyzing time to waitlisting, patients undergoing their initial evaluation were followed from evaluation to waitlisting or last follow-up; patients were censored at the time of death and at last follow-up. In analyzing time to waitlist mortality, individuals approved for KT were censored at the time of KT or last follow-up; in analyzing time to transplant while on waitlist, individuals were censored at death or last follow-up. In analyzing time to renal allograft failure, as well as post-KT death, individuals with a KT were censored at death and last follow-up (up to July 5, 2020). The relationship between HL and clinical outcomes was examined univariately and adjusted for baseline risk factors for all Cox proportional hazards models and for donor age, donor gender, and donor type for post-KT outcomes. Stepwise regression was run for multivariable models with a sufficient number of events, forcing HL into the modeling; for other outcomes (eg, renal allograft failure and post-KT death), risk factors were fit one at a time. All analyses were conducted in SAS, version 9.4.

## RESULTS

### Patient Characteristics

Of the 698 patients who underwent HL assessment during a KT evaluation at our center, 8 patients did not fully complete the HL assessment and were excluded from analysis. Among the overall patient cohort (n = 690), 139 (20.1%) underwent HL assessment during a waitlist reevaluation, whereas 551 (79.9%) underwent HL assessment during an initial KT evaluation. Mean time to transplant or last follow-up was 2.6 y. Of the 551 patients undergoing initial KT evaluation, 447 were subsequently waitlisted. Among the overall cohort (n = 690), 298 patients received a KT (Figure 1). Mean time to death or last follow-up after KT was 3.3 y.

Mean age of the overall patient cohort (n = 690) was 55.1 ± 13.5 y; 61.6% were male; 81.3% were White; 64.9% were married; 26.0% had a high school education or less; mean Charlson comorbidity index was 2.7 ± 1.3 (Table 2). Characteristics of the 298 patients who received KTs are outlined in Table 3. Of these 298 patients, 231 (77.5%) received a living donor KT.

### Patient HL

Among the overall patient cohort (n = 690), mean patient HL score was 17.4 ± 3.2. The prevalence of limited, marginal, and adequate HL among patients was 9.4%, 21.0%, and 69.6%, respectively (Table 2). HL was associated with education (P < 0.001); patients with limited or marginal HL were more likely to have a high school education or less than patients with adequate HL (60.9% versus 41.5% versus 22.2%, respectively). HL was also associated with body mass index (BMI) (P = 0.005) with patients with adequate HL having a lower BMI (29.7 ± 6.7, 31.3 ± 6.1, and 29.4 ± 6.0, respectively). Independent risk factors for limited HL included education level and race (**Table S1, SDC**, http://links.lww.com/TXD/A449). The odds of limited HL increased by over 4-fold for those with a high school education or less (odds ratio, 4.35; 95% confidence interval [CI], 2.55-7.43; P < 0.001) and by 73% for patients who were not White (odds ratio, 1.73; 95% CI, 0.94-3.18; P = 0.08).

### HL and Pretransplant Outcomes

Among those undergoing initial KT evaluation, patients with limited or marginal HL were significantly less likely than patients with adequate HL to be waitlisted (hazard ratio [HR], 0.62; 95% CI, 0.44-0.88; P = 0.004 and HR, 0.69; 95% CI, 0.54-0.88; P = 0.003) after adjusting for age at evaluation, marital status, evaluation BMI, Charlson comorbidity index,
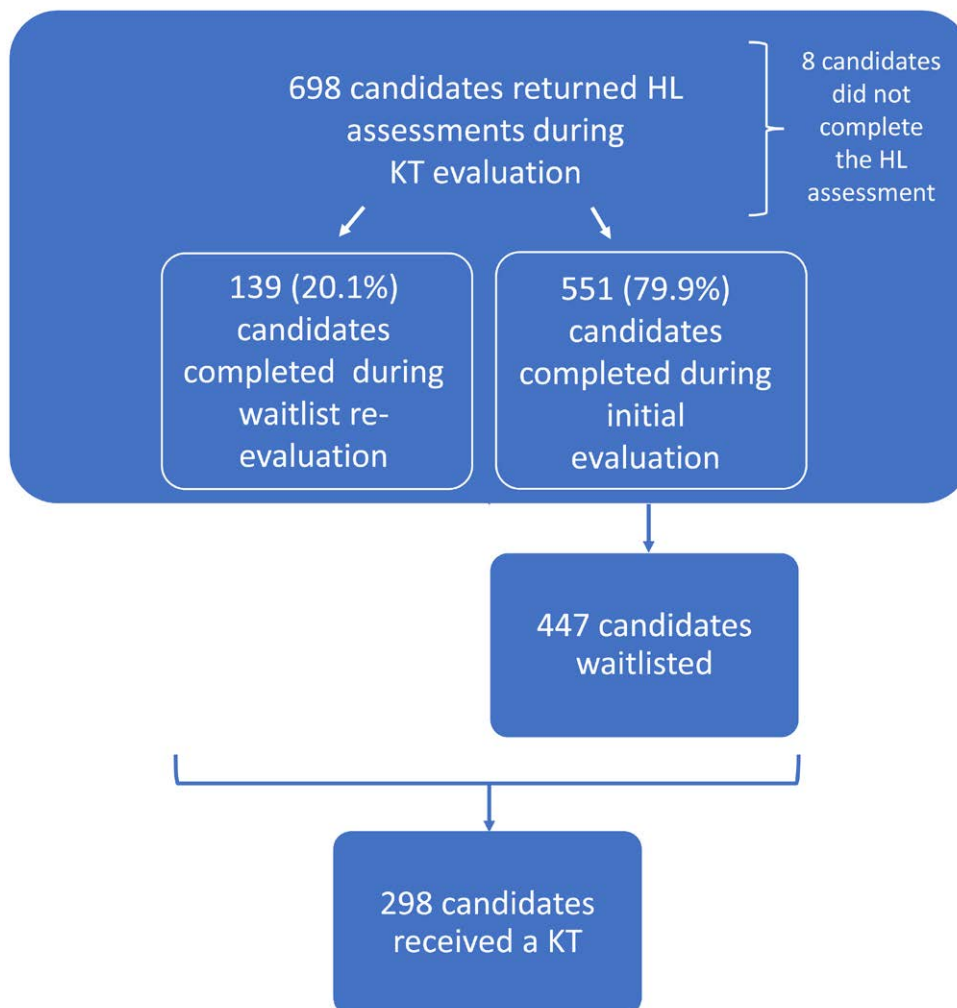


**FIGURE 1.** Study flow. HL, health literacy; KT, kidney transplant.

**TABLE 3.**

**Characteristics of patients at time of kidney transplantation**

| Variable[a] | Limited patient health literacy (n = 23, 7.7%) | Marginal patient health literacy (n = 51, 17.1%) | Adequate patient health literacy (n = 224, 75.2%) | Total (n = 298, 100.0%) | P[b] |
|---|---|---|---|---|---|
| Age, y | 52.3 ± 15.7 | 51.0 ± 15.4 | 53.7 ± 13.4 | 53.1 ± 13.9 | 0.59 |
| | 52.7 (46.0–64.2) | 51.4 (39.2–65.0) | 55.8 (44.8–64.5) | 55.2 (44.2–64.4) | |
| Male sex | 16 (69.6%) | 35 (68.5%) | 129 (57.6%) | 180 (60.4%) | 0.22 |
| Race | | | | | 0.04 |
| White | 19 (82.6%) | 43 (84.3%) | 205 (91.5%) | 267 (89.6%) | |
| Black or African American | 0 (0.0%) | 2 (3.9%) | 10 (4.5%) | 12 (4.0%) | |
| Asian | 1 (4.3%) | 1 (2.0%) | 5 (2.2%) | 7 (2.3%) | |
| Other | 3 (13.0%) | 5 (9.8%) | 4 (1.8%) | 12 (4.0%) | |
| Cause end-stage renal disease | | | | | 0.19 |
| Glomerular | 8 (34.8%) | 17 (33.3%) | 96 (42.9%) | 121 (40.6%) | |
| Diabetes | 6 (26.1%) | 9 (17.6%) | 27 (12.1%) | 42 (14.1%) | |
| Polycystic kidney disease | 2 (8.7%) | 5 (9.8%) | 41 (18.3%) | 48 (16.1%) | |
| Hypertension/vascular | 0 (0.0%) | 3 (5.9%) | 11 (4.9%) | 14 (4.7%) | |
| Other/unknown | 7 (30.4%) | 17 (33.3%) | 49 (21.9%) | 73 (24.5%) | |
| Diabetes | 6 (26.1%) | 17 (33.3%) | 35 (15.6%) | 58 (19.5%) | 0.01 |
| Charlson comorbidity index | 3.0 ± 2.6 | 2.5 ± 0.9 | 2.5 ± 1.4 | 2.6 ± 1.4 | 0.92 |
| | 2.0 (2.0–3.0) | 2.0 (2.0–3.0) | 2.0 (2.0–3.0) | 2.0 (2.0–3.0) | |
| Preemptive at time of transplant | 10 (43.5%) | 21 (41.2%) | 93 (41.5%) | 124 (41.6%) | 0.98 |
| Time on dialysis, mo | 35.8 ± 37.4 | 32.8 ± 36.2 | 31.2 ± 37.4 | 31.8 ± 37.0 | 0.58 |
| | 29.7 (12.6–41.4) | 23.3 (11.4–33.1) | 20.1 (7.0–42.0) | 21.4 (7.7–41.4) | |
| Prior kidney transplant | 2 (8.7%) | 5 (9.8%) | 37 (16.5%) | 44 (14.8%) | 0.33 |
| Donor age | 46.4 ± 12.6 | 42.5 ± 11.6 | 45.7 ± 13.5 | 45.0 ± 13.2 | 0.22 |
| | 48.0 (34.0–59.0) | 42.0 (36.0–51.0) | 46.0 (37.0–55.0) | 45.0 (37.0–55.0) | |
| Donor male | 9 (39.1%) | 27 (52.9%) | 95 (42.4%) | 131 (44.0%) | 0.35 |
| Living donor | 18 (78.3%) | 41 (80.4%) | 172 (76.8%) | 231 (77.5%) | 0.85 |
| HLA mismatch | | | | | 0.16 |
| 0 | 3 (13.0%) | 3 (5.9%) | 23 (10.3%) | 29 (9.7%) | |
| 1 | 1 (4.3%) | 2 (3.9%) | 8 (3.6%) | 11 (3.7%) | |
| 2 | 4 (17.4%) | 8 (15.7%) | 15 (6.7%) | 27 (9.1%) | |
| 3 | 3 (13.0%) | 13 (25.5%) | 46 (20.5%) | 62 (20.8%) | |
| 4 | 6 (26.1%) | 5 (9.8%) | 56 (25.0%) | 67 (22.5%) | |
| 5 | 6 (26.1%) | 12 (23.5%) | 42 (18.8%) | 60 (20.1%) | |
| 6 | 0 (0%) | 8 (15.7%) | 34 (15.2%) | 42 (14.1%) | |
| cPRA | | | | | 0.39 |
| 0 | 14 (60.9%) | 35 (68.6%) | 138 (61.6%) | 187 (62.8%) | |
| 1–25 | 2 (8.7%) | 9 (17.6%) | 27 (12.1%) | 38 (12.8%) | |
| 26–60 | 4 (17.4%) | 3 (5.9%) | 21 (9.4%) | 28 (9.4%) | |
| >60 | 3 (13.0%) | 4 (7.8%) | 38 (17.0%) | 45 (15.1%) | |
| Positive crossmatch | 0 (0%) | 2 (3.9%) | 5 (2.2%) | 7 (2.3%) | 0.57 |

*(Continued)*

**TABLE 3. Continued**
**Characteristics of patients at time of kidney transplantation**

| Variable[a] | Limited patient health literacy (n = 23, 7.7%) | Marginal patient health literacy (n = 51, 17.1%) | Adequate patient health literacy (n = 224, 75.2%) | Total (n = 298, 100.0%) | P[b] |
|---|---|---|---|---|---|
| ABO incompatible | 0 (0%) | 1 (2.0%) | 0 (0%) | 1 (0.3%) | 0.09 |
| Thymoglobulin induction | 7 (30.4%) | 13 (25.5%) | 59 (26.5%) | 79 (26.6%) | 0.97 |
| Maintenance | | | | | 0.70 |
| Tac/mycophenolate/pred | 13 (56.5%) | 31 (60.8%) | 147 (65.6%) | 191 (64.1%) | |
| Tac/mycophenolate | 10 (43.5%) | 19 (37.3%) | 71 (31.7%) | 100 (33.6%) | |
| Belatacept | 0 (0%) | 1 (2.0%) | 6 (2.7%) | 7 (2.4%) | |
| Marital status | | | | | 0.04 |
| Married/life | 13 (56.5%) | 35 (68.6%) | 151 (67.4%) | 199 (66.8%) | |
| Divorced/separated | 1 (4.3%) | 1 (2.0%) | 28 (12.5%) | 30 (10.1%) | |
| Single/widowed | 9 (39.1%) | 15 (29.4%) | 45 (20.1%) | 69 (23.2%) | |
| Education | | | | | <0.0001 |
| High school or less | 13 (56.5%) | 24 (47.1%) | 37 (16.5%) | 74 (24.8%) | |
| At least some college | 8 (34.8%) | 22 (43.1%) | 145 (64.7%) | 175 (58.7%) | |
| Postgraduate | 2 (8.7%) | 5 (9.8%) | 42 (18.8%) | 49 (16.4%) | |
| Never smoker | 11 (47.8%) | 25 (49.0%) | 126 (56.3%) | 162 (54.4%) | 0.52 |
| Body mass index, kg/m$^2$ | 28.3 ± 6.7 | 30.0 ± 5.7 | 28.7 ± 5.3 | 28.9 ± 5.5 | 0.20 |
| | 27.1 (23.8–33.0) | 30.2 (26.8–34.1) | 28.7 (24.5–32.6) | 28.8 (25.0–32.9) | |

[a] Mean ± SD or medians and interquartile ranges for continuous variables; counts and percentages for categorical data.
[b] P values are from the chi-squared test or the Kruskal-Wallis test depending on whether or not the data is categorical or continuous, respectively.
cPRA, calculated panel reactive antibody; pred, prednisone; tac, tacrolimus.
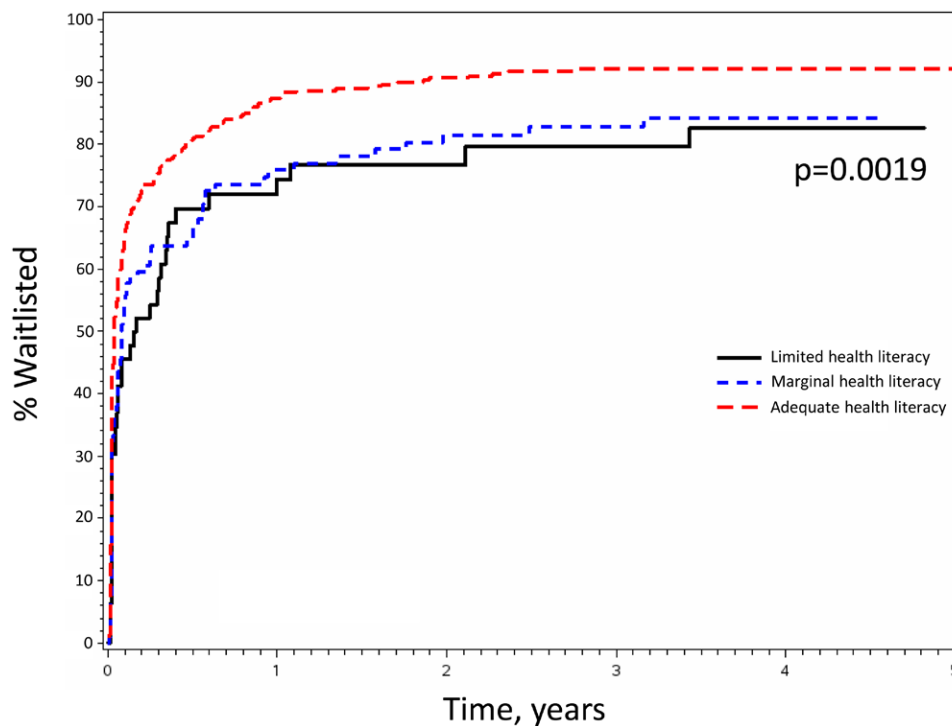
**FIGURE 2.** Relationship between patient health literacy and waitlisting.

and preemptive status at evaluation (Figure 2 [univariate] and Table 4). Specifically, by 6 mo after KT evaluation, only 69.7% of patients with limited HL had been waitlisted compared with 80.4% of patients with adequate HL ($P = 0.002$). Education level was not associated with being waitlisted (Table 4). No relationships between patient HL and rates of waitlist mortality (n = 37) or KT (n = 298) were observed (**Tables S2** and **S3, SDC**, http://links.lww.com/TXD/A449).

### HL and Posttransplant Outcomes

Among the 298 patients who received a KT during follow-up, the mean hospital length of stay following transplant surgery was $3.8 \pm 1.9$ d, 20.8% were rehospitalized (n = 62), and 26.6% experienced acute rejection within the first posttransplant year (n = 77). No relationship was found between patient HL and hospital length of stay, rehospitalizations, acute rejection during the first post-KT year, or 12-mo renal allograft function (Tables 5 and 6).

Among our cohort, 5.4% experienced allograft failure (n = 16), and 3.4% died (n = 10). Limited patient HL appeared to be associated with a >2-fold increase in the risk of graft failure when compared with adequate HL after individually adjusting for age (HR, 3.1; 95% CI, 0.6-15.6; $P = 0.15$), education (HR, 4.4; 95% CI, 0.8-23.4; $P = 0.08$), and diabetes (HR, 2.7; 95% CI, 0.5-13.8; $P = 0.22$), but these relationships did not reach statistical significance. Marginal patient HL appeared to be associated with a >5-fold increased risk of renal allograft failure when compared with adequate HL after individually adjusting for age (HR, 6.3; 95% CI, 2.2-18.5; $P < 0.001$), education (HR, 7.4; 95% CI, 2.5-21.6; $P < 0.001$), and diabetes (HR, 5.4; 95% CI, 1.8-16.0; $P = 0.002$) (Figure 3 and Table 6). Similarly, limited patient HL appeared to be associated with a >2-fold increase in the risk of post-KT death when compared with adequate HL after individually adjusting for age (HR, 3.2; 95% CI, 0.3-31.0; $P = 0.31$), education (HR,

4.3; 95% CI, 0.4-43.6; $P = 0.22$), and diabetes (HR, 2.5; 95% CI, 0.2-24.3; $P = 0.34$), but these relationships did not reach statistical significance. Marginal patient HL appeared to be associated with a >6-fold increase in the risk of post-KT death when compared with adequate HL after individually adjusting for age (HR, 9.5; 95% CI, 2.4-38.0; $P = 0.002$), education (HR, 10.6; 95% CI, 2.6-43.6; $P = 0.001$), and diabetes (HR, 6.8; 95% CI, 1.6-28.3; $P = 0.002$) (Figure 4 and Table 6).

### DISCUSSION

Our prospective study describes the prevalence and significance of HL in KT patients at our center. Inadequate HL was highly prevalent with nearly one third of individuals having limited or marginal HL. Patients with limited or marginal HL were significantly less likely than those with adequate HL to be waitlisted for KT (HR = 0.62 and 0.69, respectively). Patients with inadequate HL who were approved for KT and subsequently transplanted were not at increased risk of increased hospital length of stay, rehospitalization, acute rejection, or lower renal allograft function. Patients with marginal HL appeared to experience a 6.2-fold higher risk of renal allograft failure and a 8.6-fold higher risk of death than those with adequate HL. However, the number of patients experiencing these latter 2 post-KT events was small, and these relationships should be viewed as hypothesis generating.

Our finding that patients with inadequate HL are less likely to be waitlisted for KT is consistent with previously published studies. Warsame et al[18] found that the 8.9% of KT candidates at their center with limited HL were less likely to be waitlisted and more likely to experience waitlist mortality.[18] Likewise, Kazley et al[19] and Taylor et al[20] demonstrated that lower HL is associated with KT waitlisting and decreased rates of KT. The relationship between inadequate HL and decreased access to KT is likely multifactorial. Candidates with inadequate HL

**TABLE 4.**

**Relationship between patient health literacy and time to waitlisting**

| | Unadjusted hazard ratios (95% CI)[a] | | | Multivariable[b] adjusted hazard ratios (95% CI) | | |
|---|---|---|---|---|---|---|
| | Hazard ratio (95% CI) | P[a] | | | Hazard ratio (95% CI) | P[c] |
| Limited health literacy (n = 37)[d] | 0.62 (0.44-0.87) | 0.006 | Limited health literacy | 0.62 (0.44-0.88) | | 0.007 |
| Marginal health literacy (n = 86)[d] | 0.70 (0.56-0.89) | 0.004 | Marginal health literacy | 0.69 (0.54-0.88) | | 0.003 |
| Adequate health literacy (n = 324)[d] | 1.0 | | Adequate health literacy | 1.00 | | |
| Age at evaluation (per 1 y) | 0.98 (0.98-0.99) | <0.001 | Age at evaluation (per 1 y) | 0.99 (0.98-0.99) | | <0.001 |
| Male | 0.82 (0.68-0.99) | 0.04 | Male | | | |
| Married | 0.92 (0.83-1.03) | 0.15 | Married | 0.85 (0.75-0.96) | | 0.009 |
| Education | | | Education | | | |
| High school or less | 0.83 (0.62-1.12) | 0.22 | High school or less | | | |
| At least some college | 0.96 (0.73-1.25) | 0.74 | At least some college | | | |
| Postgraduate | 1.0 | | Postgraduate | | | |
| BMI at evaluation (per 1 kg/m²) | 0.98 (0.96-0.99) | 0.001 | BMI at evaluation (per 1 kg/m²) | 0.98 (0.96-0.99) | | 0.002 |
| Smoker (current or former) | 0.74 (0.61-0.89) | 0.002 | Smoker (current or former) | | | |
| Charlson comorbidity index at evaluation | 0.82 (0.75-0.89) | <0.001 | Charlson comorbidity index at evaluation | 0.86 (0.79-0.95) | | 0.002 |
| On dialysis at evaluation | 0.69 (0.57-0.84) | <0.001 | On dialysis at evaluation | 0.71 (0.58-0.86) | | <0.001 |
| Diabetes at evaluation | 0.62 (0.50-0.76) | <0.001 | Diabetes at evaluation | | | |
| Prior kidney transplant | 1.10 (0.85-1.44) | 0.44 | Prior kidney transplant | | | |

[a] Likelihood ratio P values; time to waitlisting in patients undergoing an initial kidney transplant evaluation (n = 551); number waitlisted = 447.
[b] Twenty-six people dropped out because of missing values (15 of whom were waitlisted).
[c] Likelihood ratio P value for marginal health literacy vs the referent (adequate health literacy); P for adjusting variables in multivariable model.
[d] Number waitlisted in each health literacy category.
BMI, body mass index; CI, confidence interval.

**TABLE 5.**

**Relationship between patient health literacy and posttransplant healthcare utilization and renal allograft function**

| | Limited patient health literacy (n = 23) | Marginal patient health literacy (n = 51) | Adequate patient health literacy (n = 224) | P |
|---|---|---|---|---|
| Hospital length of stay, mean ± SD, d | 4.0 ± 1.7 | 3.7 ± 1.3 | 3.8 ± 2.0 | 0.70[a] |
| Rehospitalization, n (%) | 2 (8.7%) | 11 (22.0%) | 49 (21.9%) | 0.33[b] |
| 12-mo corrected iothalamate clearance, mean ± SD, mL/min/BSA[c] | 59.6 ± 20.1 | 61.3 ± 18.8 | 57.1 ± 17.7 | 0.52[a] |

[a] Kruskal-Wallis P value.
[b] Chi-squared P value.
[c] n = 222.
BSA, body surface area.

may be less likely to complete the numerous steps required for listing because of lack of understanding of which tests and consultations are needed and how to obtain them, a lack of trust in transplant providers, and misperceptions regarding the risks of KT. Transplant centers may be less likely to approve candidates with inadequate HL because of concurrent socioeconomic barriers, including higher rates of unemployment and lower income.[21] These financial challenges may contribute to patient concerns about the costs associated with transportation and testing during the evaluation process.

Numerous possibilities for improving the evaluation process and path to waitlisting exist. For example, patients frequently receive written educational materials and written communications via patient portal.[22] These communication strategies may not be optimal for patients with inadequate HL. In fact, studies have shown that >90% of CKD educational materials are written above the average patient's literacy level.[23] Tailored educational materials for patients with limited or marginal HL that deemphasize written communication through the use of videos or animations may be preferable.[24,25] Furthermore, teaching transplant center providers better communication strategies,[26] including how to avoid medical jargon, repeat key messages,

use graphics, and ask patients to repeat back what they need to know or do, could improve the care of patients with limited or marginal HL.[1] Other promising interventions to improve HL in KT candidates include the use of patient navigators or community healthcare workers who can assist with communication between patients and transplant centers.[27,28] In our practice improvement feasibility project, we piloted an intervention in which patient education specialists met with candidates to discuss their understanding of KT-related information and to help formulate questions for their transplant care team. Despite this intervention, we still observed decreased rates of waitlisting in patients with inadequate HL. Our intervention may have been more beneficial if it involved (1) repeated appointments with the patient education specialists throughout the evaluation process, (2) content tailored to different HL levels,[29] and (3) emphasis on problem-solving skills.[30]

Few studies have examined the impact of HL on outcomes following KT. To our knowledge, ours is the first to examine the relationship between HL and post-KT length of stay, rehospitalizations, acute rejection, renal allograft function, renal allograft failure, and post-KT death. One cross-sectional study (n = 124) published in 2009 by Gordon and Wolf[31]

**TABLE 6.**

**Relationship between patient health literacy and posttransplant acute rejection, renal allograft failure, and death**

| | Hazard ratio (95% CI) | | | | |
|---|---|---|---|---|---|
| | Limited patient health literacy | $P^a$ | Marginal patient health literacy | $P^a$ | Adequate patient health literacy |
| Time to acute rejection | n = 6 | | n = 11 | | n = 60 |
| Health literacy alone | 0.9 (0.4-2.1) | 0.80 | 0.8 (0.4-1.4) | 0.38 | Reference |
| Health literacy adjusted for age at KT | 0.9 (0.4-2.1) | 0.79 | 0.7 (0.4-1.4) | 0.36 | Reference |
| Healthy literacy adjusted for education | 0.9 (0.4-2.1) | 0.80 | 0.8 (0.4-1.5) | 0.40 | Reference |
| Health literacy adjusted for diabetes | 0.9 (0.4-2.1) | 0.85 | 0.8 (0.4-1.5) | 0.45 | Reference |
| Time to allograft failure | n = 2 | | n = 8 | | n = 6 |
| Health literacy alone | 3.1 (0.6-15.3) | 0.17 | 6.2 (2.2-17.9) | <0.001 | Reference |
| Health literacy adjusted for age at KT | 3.1 (0.6-15.6) | 0.16 | 6.3 (2.2-18.5) | <0.001 | Reference |
| Healthy literacy adjusted for education | 4.4 (0.8-23.4) | 0.08 | 7.4 (2.5-21.6) | <0.001 | Reference |
| Health literacy adjusted for diabetes | 2.7 (0.5-13.8) | 0.22 | 5.4 (1.8-16.0) | 0.002 | Reference |
| Time to posttransplant death | n = 1 | | n = 6 | | n = 3 |
| Health literacy alone | 3.0 (0.3-28.9) | 0.34 | 8.6 (2.2-34.5) | 0.002 | Reference |
| Health literacy adjusted for age at KT | 3.2 (0.3-31.0) | 0.31 | 9.5 (2.4-38.0) | 0.002 | Reference |
| Healthy literacy adjusted for education | 4.3 (0.4-43.6) | 0.22 | 10.6 (2.6-43.6) | 0.001 | Reference |
| Health literacy adjusted for diabetes | 2.5 (0.2-24.3) | 0.34 | 6.8 (1.6-28.3) | 0.002 | Reference |

[a] Likelihood ratio P value for limited and marginal patient health literacy vs the referent (adequate patient health literacy).
CI, confidence interval; KT, kidney transplantation.
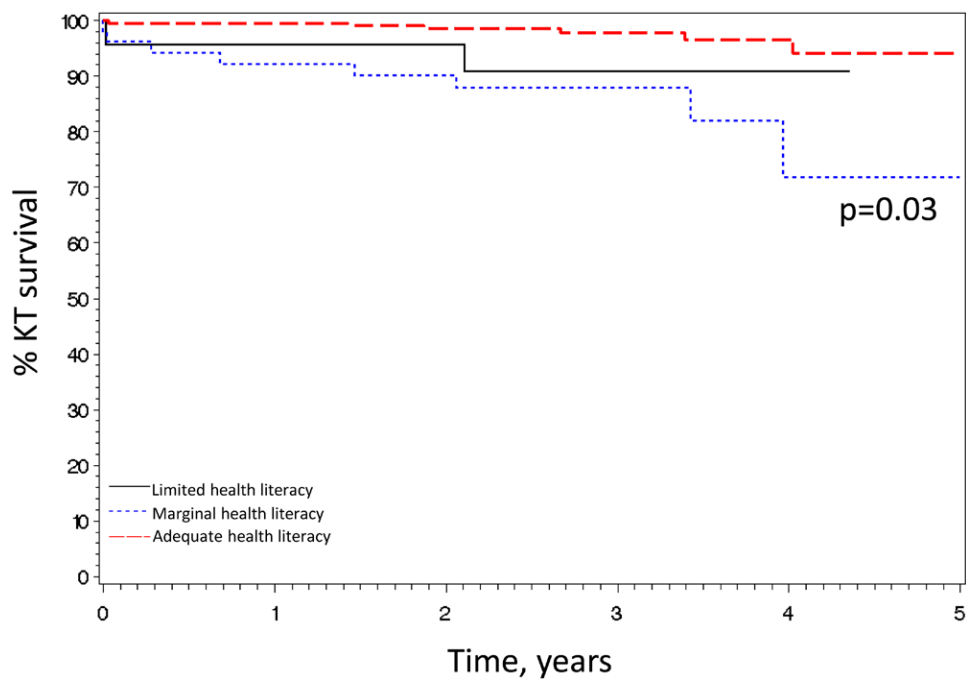


**FIGURE 3.** Relationship between patient health literacy and renal allograft survival. KT, kidney transplant.

found that patients with lower HL had higher creatinine levels approximately 4 y after KT. Several more recent studies have demonstrated that lower HL is associated with immunosuppression nonadherence following KT.[11,32] Although we did not observe a relationship between HL and acute rejection in the first posttransplant year, it is possible that lower HL over a longer period of time results in chronically impaired self-care behaviors and increased medication nonadherence, which would explain the possible relationship between HL and renal allograft failure and post-KT death in our cohort. The number of patients with inadequate HL who experienced renal allograft failure or post-KT death was small, and our findings need to be reexamined in a larger study.

Limitations of this study include its single-center design, high proportion of living donor KTs, and predominantly White participants, which may decrease generalizability to other patient populations. This lack of diversity may have affected the prevalence of limited HL in our study. Hispanic, Black, American Indian, and Alaska Native patients are more likely to have limited HL.[18,33] Because it was a practice improvement feasibility project, we do not have information regarding patients who did not complete the HL assessment. As a single educational session has previously been shown to increase HL scores,[34] it is possible that our patient education appointments improved HL and introduced bias into our study. However, given that our education appointments
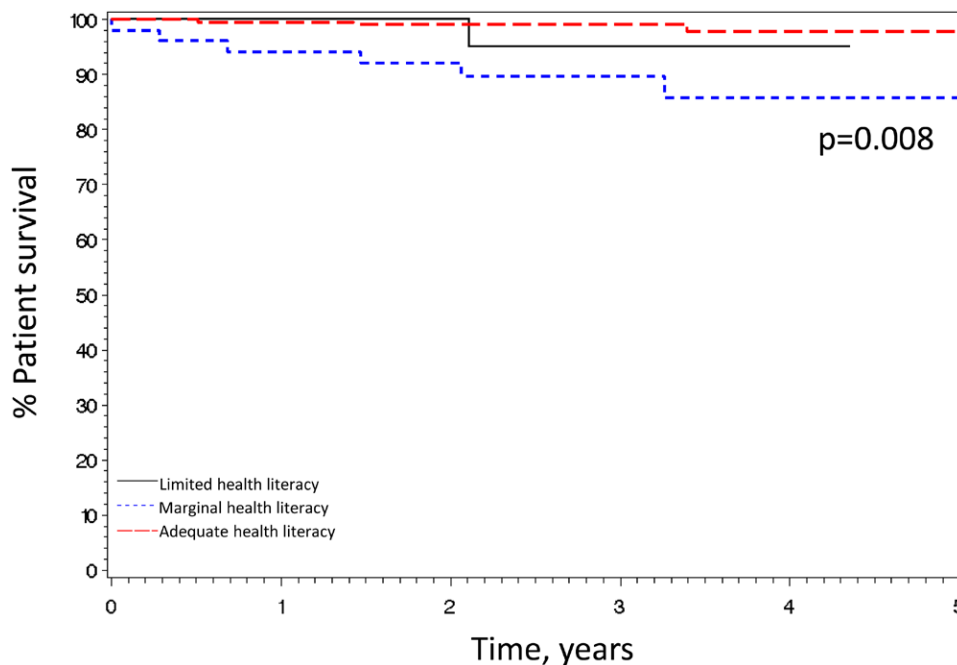
**FIGURE 4.** Relationship between patient health literacy and patient survival following kidney transplantation.

were focused on clarification of understanding of patient education materials provided during the patient's visit to our institution rather than an intensive teach-to-goal intervention, we anticipate the likelihood of meaningful bias to our study outcomes to be low. The small number of renal allograft failures and post-KT deaths observed in our cohort limited our ability to adjust for potential confounders. Thus, our findings should be replicated in future studies. We applied scoring cutoffs for the original BRIEF measure to a slightly modified version. However, the modified version displayed evidence of good psychometric properties in this sample, including internal consistency reliability and a highly significant association between the inadequate and adequate categories and with educational attainment (convergent validity). Lastly, we did not have access to insurance information in our cohort.

In conclusion, we found that inadequate HL was associated with decreased waitlisting for KT at our center. HL was not associated with healthcare utilization, acute rejection, or renal allograft function after KT. Our data suggest a possible relationship between marginal HL and reduced allograft and patient survival following KT, but the numbers were small and precluded multivariable analysis. Given the increasing prevalence of CKD and the concurrent organ shortage, improving the long-term survival of KTs is paramount. Improving communication with KT patients with lower HL may be one promising strategy to affect better outcomes. This study paves the way for future interventional studies to examine the role of improving post-KT communication on KT outcomes in patients with limited or marginal HL.

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