

Health Literacy and Access to Kidney Transplantation

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Background and objectives: Few studies have examined health literacy in patients with end stage kidney disease. We hypothesized that inadequate health literacy in a hemodialysis population is common and is associated with poorer access to kidney transplant wait-lists.

Design, setting, participants, & measurements: We enrolled 62 Black and White maintenance hemodialysis patients aged 18 to 75. We measured health literacy using the short form Test of Functional Health Literacy in Adults. Our primary outcomes were (1) time from dialysis start date to referral date for kidney transplant evaluation and (2) time from referral date to date placed on kidney transplant wait-list. We used Cox proportional hazard models to examine the association between health literacy (adequate *versus* inadequate) and our outcomes after controlling for demographics and co-morbid conditions.

Results: Roughly one third (32.3%) of participants had inadequate health literacy. Forty-seven (75.8%) of participants were referred for transplant evaluation. Among those referred, 40 (85.1%) were wait-listed. Participants with inadequate health literacy had 78% lower hazard of referral for transplant evaluation than those with adequate health literacy (adjusted hazard ratio [AHR] 0.22; 95% confidence interval 0.08, 0.60; $P = 0.003$). The hazard ratio of being wait-listed by health literacy was not statistically different (AHR 0.80, 95% CI, 0.39, 1.61), $P = 0.5$).

Conclusions: Inadequate health literacy is common in our hemodialysis patient population and is associated with a lower hazard of referral for transplant evaluation. Strategies to reduce the impact of health literacy on the kidney transplant process should be explored.

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The National Institutes of Health define health literacy as the “degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.” (1) Patients with inadequate health literacy are more likely to have difficulty understanding written health materials, processing oral communication, and navigating health care environments than those with adequate health literacy. Inadequate health literacy is common, found in one fourth to one third of previously studied populations, and has been linked to poorer health-related knowledge, more health care utilization, and worse outcomes (2–7).

There are few studies examining health literacy in patients with end stage kidney disease. Health literacy may be particularly important in the process of qualifying for and receiving toward kidney transplantation because that process requires patients to complete several steps. Alexander et al. (8) showed that blacks, the elderly, and the poor were less likely to complete each step in the process toward kidney transplantation. These demographic characteristics have been found to be associated with limited health literacy in several studies (3,4,9).

Therefore, variations in health literacy may be an important explanatory factor in linking patient characteristics to disparities in access to kidney transplantation. In addition to having more difficulty in navigating through the transplant process, patients with inadequate health literacy may be less likely to report wanting a transplant because of a lack of understanding of what transplantation entails. Furthermore, nephrologists may be less willing to refer, and transplant centers less willing to wait-list, patients with inadequate health literacy because of perceived patient inability to follow through with prescribed regimens necessary for transplanted graft survival. We hypothesized that inadequate health literacy in a hemodialysis population is common and is associated with poorer access to kidney transplant wait-list.

Materials and Methods

Study Setting, Participants, and Design

We enrolled 62 patients who were receiving maintenance hemodialysis. We recruited participants from five San Francisco Bay area outpatient dialysis units, including a university unit, a university-affiliated county hospital unit, a university-affiliated Veterans Affairs unit, and two privately owned units.

After dialysis unit staff obtained patient verbal consent for study recruitment, one of the authors (VG) approached potential participants as they were being dialyzed.

We included participants who self-identified as lack or white, were between 21 and 75 yr old, had been receiving dialysis for at least 9 mo, and who had never had a kidney transplant. We restricted race to black

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and white primarily to coincide with prior literature and to avoid confounding of health literacy measure attributable to non-native English proficiency. We restricted age to over 21 because access to transplantation among individuals who develop end stage renal disease in childhood may be confounded by parental health literacy. We restricted age to under 75 because transplant rates among those over 75 are very low (10). We restricted our study to those who had been receiving maintenance dialysis at least 9 mo as this is an agreed-upon time frame during which a patient can be expected to acclimate to dialysis and be referred for transplant evaluation (11). We restricted our study to patients who had never had a kidney transplant because they would not have successfully navigated the transplant process.

We excluded potential participants who had a Mini-Mental Status exam score less than 18 because we wanted to minimize confounding due to cognitive dysfunction distinct from health literacy (12). We also excluded potential participants whose vision was impaired (worse than or equal to 20/100 by pocket vision screener (Rosenbaum, Graham-Field Surgical Co, Inc, New Hyde Park, NY) because the tool we used for measuring health literacy was self-administered.

Interview

One investigator (VG) conducted all interviews between July 2007 and April 2008. The interview included an assessment of health literacy as well as ascertainment of demographic data. We measured health literacy using the well-established short form Test of Functional Health Literacy in Adults (s-TOFHLA) which is made up of 2 reading passages and is administered in 7 min and is scored 0 to 36 (13). An s-TOFHLA score above 22 is considered to represent adequate health literacy (13).

Participants were also asked questions about kidney transplant awareness (“Do you know what a kidney transplant is?” [yes/no]); prior discussion of transplant (“Has your doctor ever talked with you about kidney transplant?” [yes/no]); preference for kidney transplant (“Do you want to have a kidney transplant?” [yes/no/don’t know] and “How certain are you of that decision?” [very certain, fairly certain, not very certain, don’t know]); referral for kidney transplant (“Have you ever been referred to a transplant center to be examined to see if it appropriate for you to go on a transplant waiting list?” [yes/no/don’t know]); and completion of process required to be wait-listed (Have you completed the workup necessary to be considered for being placed on a transplant waiting list?” [yes/no/don’t know] and “Have you been told you were on a transplant wait-list?” [yes/no/don’t know]). Participants were also asked about having a support person (Who helps you with your medications and health care appointments? [spouse/significant other, adult children, relatives, other, i.e., friend/roommate, no one/I do it myself.]) Participants were given a \$20 grocery store gift card on completion of the interview.

Participant dialysis unit charts were audited immediately after interview completion for dialysis start date, comorbidity data from initial history and physical and from the Medical Evidence Form 2728, and documentation of referral and wait-listing dates. If documentation of referral and wait-listing dates was not available in the dialysis unit charts, area transplant center staff were contacted to obtain all missing information available.

Statistical Analyses

We hypothesized *a priori* that low health literacy would be common in our hemodialysis population and that inadequate health literacy would be associated with poorer access to kidney transplant wait-list. Health literacy, our primary predictor, was defined as a categorical variable of sTOFHLA score: inadequate (0–22) or adequate (23–36). To examine the impact of health literacy at each step in the process toward

kidney transplant wait-list, we defined access as: (1) time in months from date participant initiated maintenance dialysis to date of referral for transplant evaluation (referral date), and (2) time in months from referral date to date participant name was added to kidney transplant wait-list (wait-listing date). We therefore used Cox proportional hazards modeling to examine the independent association between health literacy and two outcomes: (1) time in months from dialysis start date to referral date, and (2) time in months from referral date to wait-listing date. Those not referred or wait-listed were censored at date of chart audit. We adjusted for race, gender, age at start of dialysis, annual income (less than \$30,000 or more than \$30,000), comorbid conditions (diabetes, hypertension, peripheral vascular disease, coronary artery disease, HIV, congestive heart failure, hepatitis C, depression, or drug abuse), and support (e.g., has someone to help with appointments or medications).

Results

Of 406 prevalent hemodialysis patients receiving maintenance dialysis in study sites, 238 (72%) self-identified as black or white and were approached for study participation as they received dialysis treatment. Of these potential participants, 73 (30.7%) refused to participate in the study and an additional 93 (39.1%) were not eligible for inclusion. Reasons for study exclusion are described in Figure 1.

Thus, 62 participants were included in our study. Their characteristics are shown in Table 1. Mean s-TOFHLA score overall was 25.6 (SD 9.4). Roughly one third (32.3%) of participants had inadequate health literacy (s-TOFHLA score less than 23). Mean health literacy scores were significantly lower among those over age 65, with incomes less than \$30,000 annually, and with lower education attainment (Table 2). Although mean health literacy score among blacks was lower than among whites, this difference did not reach statistical significance. Nearly all par-

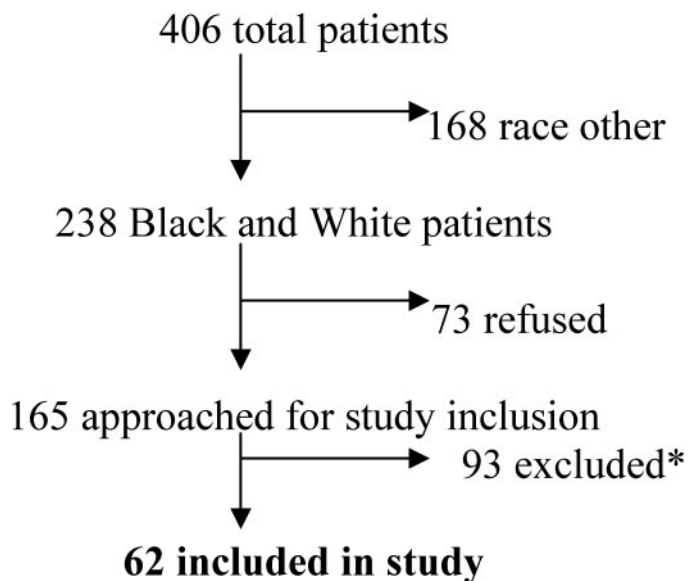


Figure 1. Flow diagram of study participants. *Reason excluded (n; % of excluded): age >75 (37; 39.8%), mini-mental status examination score <18 (16; 17.2%), dialysis <9 months (15; 16.1%), prior transplant (13; 14.0%), vision >20/100 (10; 10.8%), unable to complete interview (2; <0.1%).

Table 1. Participant characteristics

Characteristic	Value
White, n (%)	17 (27.4)
Black, n (%)	45 (72.6)
Male, n (%)	41 (66.1)
Age mean (SD)	52.4 (12.2)
Annual income, n (%)	
more than \$30 K	26 (41.9)
less than \$30 K	34 (54.8)
don't know/ refused	2 (3.2)
Education, n (%)	
more than high school	38 (61.3)
high school equivalent	16 (25.8)
less than high school	8 (12.9)
Median time on dialysis, mos. (min., max.)	29.6 (9.1, 206.5)
Comorbidities most commonly reported, n (%)	
hypertension	56 (90.3%)
diabetes	22 (35.5%)
hepatitis C	8 (12.9%)
congestive heart failure	6 (9.7%)
Insurance, n (%)	
Medicaid	7 (11.3)
Medicare	7 (11.3)
Medicare-Medicaid	26 (41.9)
private	8 (12.9)
private + Medicare	9 (14.5)
Veterans Affairs	5 (8.1)
Dialysis unit location, n (%)	
university	10 (16.1)
county hospital	11 (17.7)
Veterans Affairs	7 (11.3)
private (1)	19 (30.7)
private (2)	15 (24.2)

ticipants (90.3%) reported preference for kidney transplant, and most of those participants were very certain of that decision (83.9%). Adequacy of health literacy was not associated with preference for kidney transplant ($P = 0.7$) or certainty about that decision ($P = 0.5$)

Forty-seven participants (75.8%) were referred for transplant evaluation. Four (8.5%) of those participants' referral dates could not be obtained because of missing data from both dialysis unit chart and transplant center, so they were excluded from subsequent analysis. Each of these four participants had wait-list dates. Two participants with missing referral dates had adequate health literacy, and two had inadequate health literacy. Among those referred, the mean time from dialysis start to referral date was 17.8 (SD 41.7) months ($n = 43$) overall, 15.3 (SD 44.7) months for those with adequate health literacy, and 23.5 (SD 34.8) months for those with inadequate health literacy. There was no difference in mean time from dialysis start to referral date by health literacy ($P = 0.6$). All wait-list

Table 2. Differences in mean health literacy score by participant characteristics

Characteristic	Mean (SD)	P^a
Race		
white	29.9 (8.9)	0.08
black	25.3 (9.4)	
Gender		
male	27.6 (8.5)	0.2
female	24.6 (11.0)	
Age		
under 65	27.6 (9.3)	0.04
65+	20.7 (8.5)	
Annual income		
more than \$30K	30.3 (10.1)	0.01
less than \$30K	23.7 (7.1)	
Education		
more than high school	29.9 (7.3)	Reference
high school equivalent	23.5 (7.5)	0.01
less than high school	17 (13.8)	<0.0005

^at test for all dichotomous comparisons and linear regression for education attainment.

dates were available. Among those referred, 40 (85.1%) were wait-listed. The mean time from referral date to wait-list date was 3.6 (SD 6.5) months overall, 2.1 (SD 4.1) months for those with adequate health literacy, and 6.6 (SD 9.2) months for those with inadequate health literacy. There was a statistical difference in mean time from referral date to wait-list date by health literacy ($P = 0.05$).

Results of Cox proportional hazard model for time from dialysis start to referral date are shown in Table 3. Participants with inadequate health literacy had 78% lower hazard of referral for transplant evaluation than those with adequate health literacy after controlling for race, gender, age at start of dialysis, income, comorbid conditions, and support (adjusted hazard ratio 0.22; 95% CI: 0.08, 0.60; $P = 0.003$). Results of Cox proportional hazard model for time from referral date to wait-list date are shown in Table 4. The hazard ratio of being wait-listed if referred by health literacy was not statistically different (adjusted hazard ratio 0.80; 95% CI: 0.39, 1.61; $P = 0.5$).

Discussion

We found that inadequate health literacy in an adult population of patients on maintenance hemodialysis is common, being present in roughly one third of our study sample. Inadequate health literacy was associated with a lower hazard of being referred for transplant evaluation, but not for being wait-listed.

It is well accepted that transplantation affords improved survival when compared with maintenance dialysis for patients with end stage kidney disease (14–16). Furthermore, prolonged dialysis before transplant appears to have a detrimental effect

Table 3. Cox proportional hazard, time from dialysis start to referral date

Variable	Hazard ratio	95% CI	P
Health literacy			
adequate	1.0	Reference	
inadequate	0.22	0.08, 0.60	0.003
Race			
white	1.0	Reference	
black	0.79	0.23, 2.79	0.7
Gender			
male	1.0	Reference	
female	0.29	0.10, 0.86	0.03
Age at dialysis start (5-yr increments)	0.86	0.72, 1.02	0.09
Annual income			
more than \$30 K	1.0	Reference	
less than \$30 K	5.62	1.91, 16.51	0.002
Diabetes	4.37	1.38, 13.86	0.01
Hypertension	2.68	0.87, 8.31	0.09
Peripheral vascular disease	1.79	0.34, 9.41	0.5
Coronary artery disease	0.26	0.06, 1.13	0.07
HIV	0.73	0.15, 3.56	0.7
Congestive heart failure	0.60	0.15, 2.34	0.5
Hepatitis C	0.87	0.25, 2.97	0.8
Depression	0.57	0.14, 2.29	0.4
Drug abuse	1.05	0.27, 4.07	0.9
Support	1.45	0.63, 3.37	0.4

CI, confidence interval.

on post-transplant outcomes (17–19). Goldfarb-Rumyantzev *et al.* (17) found a 25% to 46% increase in graft failure for those transplanted after 6 mo to 5 yr of end stage kidney disease and 32% greater risk of death overall for those transplanted after 3 yr of end stage kidney disease. Therefore, it is important to identify factors associated with prolonged time in the process toward kidney transplantation.

Schaefer *et al.* (20) found a significant association between lower level of education and longer delay before being added to transplant wait-list, as well as time to first transplant, among a nationally representative sample of incident dialysis patients. However, educational attainment is considered a poor proxy for health literacy because quality of education is variable and most health materials are written at above 12th grade reading level (21). Ours is the first study to our knowledge to examine the association between health literacy and access to kidney transplantation.

Our finding of an association between health literacy and likelihood of referral for transplant evaluation may be attributable to nephrologists being less willing to refer patients they perceive as less equipped to follow the prescribed regimens necessary for transplanted graft survival. Alternatively, this finding may be attributable to various health complications, patient uncertainty over time, or a myriad of other unmeasured factors. Nevertheless, this finding points to the lack of stan-

dardized referral patterns in the current kidney transplant process and warrants further study.

Although we found no association between health literacy and time from referral date to wait-list date, it is conceivable that patients with inadequate health literacy would have difficulty completing the transplant evaluation process. Multimedia approaches and “teach-to-goal” methods have been cited as ways of overcoming inadequate health literacy (22). Furthermore, streamlining the transplant evaluation process to entail a short hospital stay rather than an outpatient procedure would overcome the difficulty some patients may have when trying to navigate a busy health care center.

The primary limitation of our study was sample size. Our small sample size was largely the result of the racially diverse patient population in our catchment area and left us underpowered to look for clustering differences by nephrologist and transplant center. A second limitation was that we retrospectively examined access to kidney transplant wait-list, rather than prospectively following incident hemodialysis patients. Therefore, those who were referred and received transplants very soon after initiating dialysis would have been removed from the maintenance dialysis pool. However, a prospective approach would be impractical because the wait for a cadaveric kidney transplant in our area is on average 5 to 7 yr, thus making it unlikely that many would have proceeded through

Table 4. Cox proportional hazard, time from referral date to wait-list date

Variable	Hazard ratio	95% CI	P
Health literacy			
adequate	1.0	Reference	
inadequate	0.80	0.39,1.61	0.5
Race			
white	1.0	Reference	
black	0.71	0.32,1.58	0.4
Gender			
male	1.0	Reference	
female	0.72	0.36,1.45	0.4
Age at dialysis start (5-yr increments)	0.84	0.73,0.96	0.01
Annual income			
more than \$30 K	1.0	Reference	
less than \$30 K	1.72	0.85,3.51	0.1
Diabetes	1.35	0.65,2.78	0.4
Hypertension	2.25	0.85,5.93	0.1
Peripheral vascular disease	0.96	0.20,4.48	1.0
Coronary artery disease	0.43	0.09,2.02	0.3
HIV	0.54	0.18,1.65	0.3
Congestive heart failure	0.80	0.34,1.92	0.6
Hepatitis C	1.00	0.44,2.30	1.0
Depression	1.78	0.52,6.10	0.4
Drug abuse	0.65	0.21,1.98	0.4
Support	1.33	0.68,2.59	0.4

CI, confidence interval.

the process so quickly. We did not have detailed information on why seven of the referred patients were not wait-listed. Another limitation is that we measured health literacy at the time of interview rather than at the time of referral, and health literacy level may have changed over time. Finally, although the s-TOFHLA is arguably the best tool currently available for measuring health literacy, it is inherently limited in that it includes measures only for written information. It does not account for other facets important to successfully navigating the health care system, such as understanding oral communication and comfort level in asking questions (1).

Despite these limitations, our study suggests that inadequate health literacy is common in the hemodialysis population and that it may play a potentially important and modifiable role in equitable access to kidney transplantation. It would be important to see whether these findings are replicable in other settings and how they fit into the larger context of factors contributing to disparities in kidney transplantation.

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Disclosures

None.

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