Candidate Comprehension of Key Concepts in Kidney Transplantation

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Background: Although kidney transplant candidates receive education regarding transplantation and donation, little is known about the extent of their comprehension. We aimed to identify factors that affect patient comprehension of important concepts regarding kidney transplantation.

Material/Methods: We performed a cross-sectional survey of consecutive adult kidney transplant candidates seen at our center between July 2013 and October 2013 for initial evaluation (n=100) or for reevaluation (n=117). The main outcome measure was a Knowledge Assessment Questionnaire completed by patients. We assessed factors affecting patient understanding of key kidney transplant concepts as measured by mean knowledge score.

Results: Mean knowledge scores of those at evaluation (72±21) and those at reevaluation (70±20; p=0.4769) were similar; therefore the entire cohort was analyzed as a single group. Compared to the high-scoring group, low-scorers (<75%; median value) were significantly more likely to be older, Hispanic, with lower education attainment, and have end-stage renal disease due to hypertension or diabetes rather than other etiologies. On multivariate analysis, independent risk factors for low-scores were increasing age (aOR 1.03 (95% CI 1.01–1.06) and educational level (less than high school; aOR 4.23, 95%CI 1.82–9.80; high school or GED aOR2.85, 95% CI 1.43–5.70 compared to some college or technical school). Of 139 candidates that consented to receive ECD and 152 consenting to CDCHR kidneys, 52% and 27%, respectively, answered the high-risk-specific question incorrectly.

Conclusions: Educational level and older age are independent risk factors for poor comprehension. Kidney candidate knowledge of organs with increased risks is suboptimal despite previous consent to receive such organs.

MeSH Keywords: Comprehension • Education • Kidney Transplantation

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Background

Patient comprehension about kidney transplantation and donor options is a key component in optimizing access to transplantation. Low patient education or low transplant knowledge have been shown to be risk factors for disparities in access to and completion of the transplant evaluation [1–7]. In general, educated kidney patients are more likely to comply with their treatment and participate in healthcare decisions impacting their treatment and outcomes [7–11]. Prior studies have suggested that minorities have decreased access to transplant because of lower awareness of transplantation, and that disparities are alleviated among patients with higher education [6]. Little research has quantitatively examined risk factors for transplant candidates’ comprehension of key concepts about kidney transplantation.

Several concepts are important for candidates to comprehend in order to optimize access to transplantation. For example, understanding key concepts regarding live-donor kidney transplantation may impact the identification of a living donor [8,9]. Understanding the survival benefit derived from transplantation over dialysis may increase motivation towards evaluation completion and acceptance of kidney offers. Knowledge of average waiting times and the option of multiple listing may impact motivation for discussing and accepting potential living donors or pursuing multiple listing. Comprehending the meaning of active versus inactive status on the list may impact motivation to comply with testing and reevaluation schedules. Lastly, perceptions of kidneys with increased risks, such as expanded criteria donor kidneys (ECD) and Centers for Disease Control high-risk kidneys (CDCHR) may impact decision making against the acceptance of these types of kidneys, leading to longer waiting times and reduced quality of life. Alternatively, the trade-off of shorter waiting-times with either reduced graft survival in the case of ECD or increased risk of infection in the case of CDCHR kidneys may not be fully understood by patients consenting to receive these types of organs [12–14].

The goal of our study was to identify risk factors amongst kidney transplant candidates for poor knowledge of transplant concepts that are important for optimizing access to transplantation. Additionally, since patients must specifically consent to receive organs with increased risks of infection and graft failure (CDCHR and ECD, respectively) we specifically aimed to determine comprehension levels of those who consented to these types of organs.

Material and Methods

Study design and participants

Consecutive adult (≥18 years) kidney transplant candidates who were seen at our center from July 2013 through October 2013 for either initial evaluation (n=100) or for reevaluation (n=117) were included. At initial evaluation candidates attended a 45-minute transplant education lecture given by the transplant coordinator about the transplant, risks, benefits, and alternatives, as well as donor types, including the option of accepting organs from ECD and CDCHR donors. At re-evaluation, candidates received one-on-one education with the transplant coordinator regarding ECD and CDCHR donors only. All candidates were seen by a nephrologist, social worker, and financial advisor. Candidates at initial evaluation were additionally seen by a surgeon. Education was reinforced by each discipline at patient encounters. At the conclusion of the evaluation, candidates were approached in the transplant center to take a Knowledge Assessment Questionnaire consisting of 8 multiple-choice questions (a Spanish version provided when applicable).

The questionnaire was developed in a stepwise fashion by the clinical team. We conducted content review of kidney knowledge questionnaires and convened experts in various areas of kidney candidate care, including nephrologists, nurses, social workers, and research personnel. Through an iterative process the items of the survey were reviewed for face and content validity, and redundancy, and reduced to a parsimonious set of questions. Approximately 10 pre-transplant patients were asked to comment on clarity and content. The Questionnaire was constructed with simple sentences in a multiple-choice fashion or as true/false statements (Figure 1). It was administered in person by either a medical student (SA, NS) or a master’s-level transplant scheduler (SB). For questions that were answered incorrectly the candidates were given the opportunity to answer the question in their own words (e.g., “In your own words, what is an expanded criteria donor kidney?”) to determine if incorrect answers were due to poor test-taking skills or lack of knowledge; these results were separately recorded. Lastly, all incorrect answers were discussed with the candidate in order to reinforce learning. All approached candidates participated except for 2 who declined. Questionnaire administration and discussion lasted approximately 20 minutes.

Patient-level covariates

Patient demographic, clinical, and follow-up data were obtained from the electronic medical records. Covariates collected included age, race (Black, Hispanic, or other), sex, etiology of end-stage renal disease (hypertension, diabetes, other), time on dialysis (none, ≤1, 1–3, or ≥4 years), education (less than high school, high school completion or GED, or at least some college or technical school), ABO (A, B, AB, or O), the presence of family or friend at the evaluation (occasionally used as a health literacy indicator), previous kidney transplantation, consent to ECD or CDCHR kidneys, poverty rate according to census tract income by ZIP code of candidate residence (1, 0–14.9%; 2, 15–30%, 3 >30%) of patients living in this zip code have
incomes below the poverty level), and health insurance (non-private vs. other) at the time of evaluation. The poverty rate was defined as the percentage of population in a county or census tract below the poverty level [15]. Insurance status and domicile zip code are often used as surrogate markers of SES [16]. The appropriate functional form of model covariates was determined by exploratory data analysis in unadjusted models and perceived impact on clinical meaningfulness. To determine which variables would be in the final model predicting low knowledge, univariate analyses of each variable of interest and the outcome were examined.

**Outcomes**

The primary outcome was to assess (a) risk factors for low knowledge score. Secondary outcomes were to (b) evaluate knowledge score with respect to consent for increased-risk donor kidneys.

**Statistical analysis**

Univariate factors associated with knowledge score were examined using the chi-square test for categorical variables and the t test for continuous variables whose distributions approximated normality. Knowledge score was calculated as the number of correct answers divided by the number of total questions (range 0–100%) and was dichotomized by the median value. The odds of low knowledge score was assessed using a logistic regression model. Any variable associated with the outcome of a p<0.05 significance level was included in the multivariable model.

All statistical analyses were conducted using the SAS system version 9.2 (SAS Institute, Inc., Cary, N.C.). Statistical significance was identified by a p-value of less than 0.05 and all confidence intervals also used a 95% threshold. All p-values are 2-sided. The Institutional Review Board of the Albert Einstein College of Medicine approved this study.

**Results**

Of 219 individuals approached, 217 (99%) participated. At the time of questionnaire administration, 100 candidates were attending initial evaluation and 117 were attending reevaluation. Of those at initial evaluation (72±21) and those at reevaluation (70±20; p=0.4769); therefore, the entire cohort was evaluated at the time of questionnaire administration, 100 candidates were at- tended at least some college or technical school, a less than high school education was associated with a 4.2-fold increased odds of low score (aOR 4.23, 95%CI 1.82–9.80) and high school or GED was associated with a 2.9-fold increased odds of low score (aOR2.85, 95% CI 1.43–5.70) compared to those with at least some college or technical school education.

**ECD and CDCHR specific knowledge**

There were no differences between the groups in terms of the proportion consenting to receive ECD or CDCHR organs – 67% of low-scorers and 62% of high-scorers consented to ECD (p=0.4033); 73% of low-scorers versus 72% of high-scorers consented to receive CDCHR kidneys (p=0.6736). Of 139 candidates that consented to receive ECD organs, 52% answered the ECD-specific question incorrectly. Of 78 patients that did not consent to receive ECD organs, 51% answered the question incorrectly. Of 152 patients that consented to receive CDCHR organs, 27% answered the CDCHR-specific question incorrectly. Of 62 candidates that did not consent to receive CDCHR organs, 40% answered the specific question incorrectly.

**Discussion**

We found that kidney transplant candidate educational level is an independent risk factor for low comprehension of key concepts about kidney transplantation. Compared to candidates that attended at least some college or technical school, a less than high school education was associated with a 4.2-fold increased odds of poor comprehension, and completion of high school or GED was associated with a 2.9-fold increased odds of poor comprehension. The top 3 concepts that were most misunderstood were knowledge regarding ECD kidneys, waiting-list status (active vs. inactive), and living donation. Of those consenting and not consenting to receive ECD and CDCHR organs, rates of incorrectly answering the disease-specific question were not optimal.
Our finding that the level of educational attainment is independently associated with comprehension of key concepts about kidney transplantation has several implications. Comprehension is not only important for adequate informed consent but may also impact the likelihood or expediency of being transplanted.

Lack of patient education about kidney disease and the renal transplant process has been identified as one explanation for disparities seen in the completion of the transplant evaluation [1–3]. Higher education level has also been found to be independently associated with greater placement on the list [7], shorter time to listing [5,16–18], higher likelihood of completing evaluation, and (7) and shorter time to kidney transplantation [16,19]. Suggested reasons for lower rates of wait-listing amongst patients with lower education are patient non-adherence, communication barriers, candidate comprehension, educational level, potential confounding by comorbidity, health provider discrimination, and low candidate interest in transplantation. Once patients have been placed on the waiting list, their position on the list is less prone to clinician

A
1. Chose the true statement about ECD kidneys
   - A. The waiting time is longer  20.8%
   - B. The chance of getting infections is high  12.7%
   - C. These kidneys are from older donors  47.2%
   - D. ECD kidneys are more likely to function longer  19.3%

B
2. Chose the false statement about kidney from living donors
   - A. Only a blood relative can donate a kidney  54.8%
   - B. Likely to function immediately  10.5%
   - C. Usually last longer than kidneys from donors who have died  12.9%
   - D. Can be transplanted before I have to go on dialysis  21.9%

C
3. The waiting time for a kidney in NY is?
   - A. 1–2 years  2.8%
   - B. 3–4 years  8.8%
   - C. 5–6 years  87.6%
   - D. Less than one year  0.9%

D
4. I can only be listed at one transplant center in the US?
   - A. True  26.4%
   - B. False  73.6%

E
5. Choose the true statement about CDC high risk kidneys
   - A. They are more likely to fall  6.6%
   - B. The chance of getting an infection is very high  13.7%
   - C. The waiting time is longer  6.6%
   - D. These kidneys can come from prostitutes and drug abusers  73.1%

F
6. Most people who get kidney transplants live longer than on dialysis
   - A. True  82.2%
   - B. False  16.8%

G
7. Transplant recipients must take immunosuppressive medications for the life of the transplant
   - A. True  94.8%
   - B. False  5.2%

H
8. A person who is on the waiting list as “inactive” status can be offered a kidney transplant from a deceased donor
   - A. True  40.7%
   - B. False  59.3%

Figure 1. Knowledge Assessment Questionnaire Responses.
bias, but could be affected by biological factors, such as the burden of comorbid conditions and willingness to accept organs with increased risks.

Improved education may influence the prospect of being transplanted among those on the waiting list, especially for those who choose to accept ECD or CDCHR organs (now termed KDPI ≥85% and PHS increased-risk, respectively). A common strategy to increase the number of available kidneys is to offer candidates kidneys that come from donors with increased risks of shorter graft longevity in the case of ECD [22], or that have an increased risk of disease transmission (of human immunodeficiency virus, Hepatitis B, and Hepatitis C) in the case of CDCHR donors [23]. ECD kidneys comprise approximately 10% of all US deceased organ donors [24] and CDCHR kidneys are nearly 9% of all non-ECD donors [25]. The Organ Procurement and Transplantation Network (OPTN) policy mandates informed consent from recipients who accept kidneys with increased risks (http://optn.transplant.hrsa.gov/). The mechanism of disclosure and informed consent are decided by each transplant center. Despite efforts to educate and inform candidates, it is unknown how well candidates actually comprehend the donor-specific risks. We found that in our population, of those consenting to receive ECD and CDCHR organs,

Table 1. Baseline characteristics by group.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Low score &lt;75% (n=100)</th>
<th>High score ≥75% (n=117)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Re-evaluation</td>
<td>54</td>
<td>63</td>
<td>0.7673</td>
</tr>
<tr>
<td>Age, years</td>
<td>55±12</td>
<td>50±13</td>
<td>0.0059</td>
</tr>
<tr>
<td>Race,</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>African-American</td>
<td>44</td>
<td>59</td>
<td>0.0067</td>
</tr>
<tr>
<td>Hispanic</td>
<td>47</td>
<td>27</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>9</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Sex, Female</td>
<td>42</td>
<td>51</td>
<td>0.1721</td>
</tr>
<tr>
<td>Listed primary ESRD etiology</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Diabetes</td>
<td>48</td>
<td>43</td>
<td>0.0255</td>
</tr>
<tr>
<td>Hypertensive nephrosclerosis</td>
<td>35</td>
<td>25</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>17</td>
<td>32</td>
<td></td>
</tr>
<tr>
<td>Education*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Below High School</td>
<td>36</td>
<td>14</td>
<td>0.0199</td>
</tr>
<tr>
<td>High School or GED</td>
<td>44</td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>Some college or technical school</td>
<td>20</td>
<td>48</td>
<td></td>
</tr>
<tr>
<td>Recipient dialysis duration</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>22</td>
<td>28</td>
<td></td>
</tr>
<tr>
<td>≤1 year</td>
<td>21</td>
<td>19</td>
<td>0.3328</td>
</tr>
<tr>
<td>1–3 years</td>
<td>31</td>
<td>29</td>
<td></td>
</tr>
<tr>
<td>4–9 years</td>
<td>26</td>
<td>24</td>
<td></td>
</tr>
<tr>
<td>ABO</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>24</td>
<td>26</td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>22</td>
<td>19</td>
<td>0.8027</td>
</tr>
<tr>
<td>AB</td>
<td>6</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>O</td>
<td>48</td>
<td>53</td>
<td></td>
</tr>
<tr>
<td>Poverty rate</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 (0–14.9%)</td>
<td>22</td>
<td>27</td>
<td>0.3411</td>
</tr>
<tr>
<td>2 (15–30%)</td>
<td>34</td>
<td>38</td>
<td></td>
</tr>
<tr>
<td>3 (&gt;30%)</td>
<td>44</td>
<td>35</td>
<td></td>
</tr>
<tr>
<td>Family or friend present at evaluation</td>
<td>41</td>
<td>40</td>
<td>0.8530</td>
</tr>
<tr>
<td>Previous kidney transplantation</td>
<td>13</td>
<td>9</td>
<td>0.2881</td>
</tr>
<tr>
<td>Non-private insurance</td>
<td>78</td>
<td>70</td>
<td>0.2112</td>
</tr>
</tbody>
</table>

* Only 2% and 9%, respectively completed college or postgraduate school therefore this group was combined with those attending at least some college or technical school.
rates of incorrectly answering the disease-specific question were 52% and 27%, respectively. Additionally, those who did not consent to ECD and CDCHR also had unacceptably high rates of incorrect disease-specific answers. Subjectively, we noticed that patients often confused the acronyms or could not remember what an acronym stood for, but did understand the concept behind it. In other words, candidates are able to understand the concept that kidneys from older donors have short graft survival but fail to remember what ECD stands for. Similarly, they understood the risk of disease transmission with the use of CDCHR donors, but failed to remember what CDCHR stands for. Our findings of a patient's tendency to confuse the ECD and CDCHR acronyms was previously noted. Gordon et al. found that patients confuse risk posed by OPTN-defined increased risk donors and other non-standard risk donors [26]. Perhaps the newly OPTN-mandated changes in the label of these types of kidneys – CDCHR becoming ‘Public Health Service Increased Risk Donor’ [23] and the ECD dichotomy changing to the ‘Kidney Donor Risk Index’ – will permit reproduction, poor quality measures of most studies indicating high risk of bias in the results, non-randomization in many, topic matter limiting blinding, and lack of reproducible reliable tools to measured outcomes. Furthermore, the authors noted a lack of available and validated instruments to gauge outcomes of education-based interventions. The most improvement was seen with the use of video-assistance teaching prior to discharge in patients who had already had surgery, and monthly pharmaceutical counseling to ensure compliance.

Lastly, a major challenge to the education of kidney transplant candidates is low literacy levels. Chisholm et al. [31] noted that kidney transplant patients’ numerical literacy is low-to-marginal based on the modified Test of Functional Health Literacy in Adults. Escobeno and Weismuller [32] found that 41% of 44 patients attending transplant clinic visits had scores indicating a high likelihood of limited health literacy using the Newest Vital Sign assessment. Dageforde et al. [33] noted that the odds of poor literacy based on the Short Literacy Survey was higher for those receiving deceased-donor kidneys (OR 1.9) compared to recipients of live-donor kidneys. Gordon et al. [34] found that even among a sample of highly educated and literate patients, 81% were unfamiliar with at least 1 kidney transplant-related term. Health literacy is important in the process of evaluation and receipt of a renal transplant. It has been shown that health literacy is lower among blacks, the elderly, and the poor. This in turn is associated with decreased access to transplant evaluation due to perceived diminished ability to manage the complexities of immunosuppression [35].

It has been recommended that patient comprehension can be improved through several strategies, including preparing informed consent and educational materials at a fifth-to-eighth grade reading level and health literacy universal precautions, on-site educational group visits, internet educational resources and videos, and tailoring educational message delivery to individual patient educational level [26]. Two recommended approaches that transplant practitioners may use include the “teach back” method, which entails providers asking patients to recount in their own words the key constructs of information that was just disclosed. Additionally, practitioners may use the Ask Me 3 program that entails encouraging patients to ask practitioners 3 questions [29]. A systematic review [30] evaluating the effectiveness of different educational interventions of kidney transplant recipients found limited evidence of educational interventions used to improve comprehension, and thereby, compliance and outcomes. For the most part this was attributed to insufficient description of the interventions to permit reproduction, poor quality measures of most studies indicating high risk of bias in the results, non-randomization in many, topic matter limiting blinding, and lack of reproducible reliable tools to measured outcomes. Furthermore, the authors noted a lack of available and validated instruments to gauge outcomes of education-based interventions. The most improvement was seen with the use of video-assistance teaching prior to discharge in patients who had already had surgery, and monthly pharmaceutical counseling to ensure compliance.

<table>
<thead>
<tr>
<th>Parameters (reference group)</th>
<th>Low score</th>
<th>adjusted Odds Ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, continuous per year</td>
<td>1.03</td>
<td>(1.01–1.06)</td>
</tr>
<tr>
<td>Education (some college or technical school)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than High School</td>
<td>4.23</td>
<td>(1.23–9.80)</td>
</tr>
<tr>
<td>High School or GED</td>
<td>2.85</td>
<td>(1.43–5.70)</td>
</tr>
<tr>
<td>Race (other)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>2.43</td>
<td>(0.85–6.97)</td>
</tr>
<tr>
<td>Black</td>
<td>1.27</td>
<td>(0.47–3.42)</td>
</tr>
<tr>
<td>Bronx residence (other)</td>
<td>2.18</td>
<td>(0.98–4.85)</td>
</tr>
<tr>
<td>End-stage renal disease (diabetes)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>1.69</td>
<td>(0.84–3.42)</td>
</tr>
<tr>
<td>Other</td>
<td>0.81</td>
<td>(0.36–1.85)</td>
</tr>
</tbody>
</table>

Table 2. Multivariable logistic model for low knowledge score.
Our study has several limitations. It may not be generalizable to other communities because the individuals in our study reflect the referral population of a single center. We did not examine occupation or income. However, others have found that educational level and insurance significantly correlate with occupation and income (precluding their use in final models due to colinearity) [5]. Nevertheless, we did assess a surrogate for income – poverty level by candidate domicile ZIP code. Given that the questionnaire was administered by transplant personnel, social desirability bias may have existed, leading to answering of questions in a manner that will be viewed favorably by those administering the questionnaire. Furthermore, the questionnaire employed in this analysis was not validated; however, we intend on performing validation in the future. This is important since CMS requires that the informing transplant personnel administering the questionnaire [28]. Lastly, the transplant personnel administering the questionnaire were not specifically trained in conducting surveys. The racial and educational level distribution of our cohort is a particular strength as it provides us with sufficient power to examine racial and educational differences in ability to learn about transplantation.

Conclusions

We found that kidney candidate educational level is an independent risk factor for low comprehension of key concepts in kidney transplantation. Additionally, candidates in our center demonstrated suboptimal knowledge of the meaning of ECD and CDCHR, even those who consented to receiving such organs. These findings emphasize the need for improved and tailored education to increase the comprehension of key concepts about kidney transplantation.

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