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Journal Clinical Transplantation, 31(5)

ISSN 0902-0063

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Publication Date

2017-05-01

DOI

10.1111/ctr.12944

Peer reviewed

Received Date : 08-Aug-2016 Revised Date : 21-Feb-2017 Accepted Date : 23-Feb-2017 Article type : Original Article

Cultural Competency of a Mobile, Customized Patient Education Tool for Improving Potential Kidney

Transplant Recipients' Knowledge and Decision-Making

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Running title: Kidney Transplant Education Application

Key words: kidney transplant, patient education, living donor, KPDI, EPTS, outcomes research

Abbreviations: African American (AA), Kidney donor profile index (KPDI), Donor Service Area (DSA), Expected post-transplant survival (EPTS), living donor kidney transplant (LDKT), My Transplant Coach (MTC), deceased donor kidney transplant (DDKT), public health service (PHS), United Network for Organ Sharing (UNOS),

This article has been accepted for publication and undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/ctr.12944

Authors: Axelrod DA, Kynard-Amerson CS, Wojciechowski D, Jacobs M, Lentine KL, Schnitzler MA, Peipert JD, Waterman AD.

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Abstract:

Patients considering renal transplantation face an increasingly complex array of choices as a result of the revised kidney transplant allocation system. Decision aids have been shown to improve patient decision making through the provision of detailed, relevant, individualized clinical data. A mobile iOS based application (app) including animated patient education and individualized risk adjusted outcomes following kidney transplants with varying donor characteristics and DSA waiting times was piloted in 2 large US transplant programs with a diverse group of renal transplant candidates (N=81). The majority (86%) of patients felt that the app improved their knowledge and was culturally appropriate for their race/ethnicity (67%-85%). Patients scored significantly higher on transplant knowledge testing (9.1/20 to 13.8/20 p<0.001) after viewing the app, including patients with low health literacy (8.0 to 13.0 p<0.001). Overall knowledge of and interest in living and deceased donor kidney transplantation increased. This pilot project confirmed the benefit and cultural acceptability of this educational tool, and further refinement will explore how to better communicate the risks and benefits of non-standard donors.

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Introduction

The growing complexity of United States kidney allocation policy leaves patients with end stage renal disease (ESRD) with a daunting array of choices when considering transplantation. At the time of initial evaluation, patients are provided with generic education about the risks and benefits

of kidney transplantation. Patients who decide to pursue kidney transplantation then need to consider the relative benefits of living donor kidney transplant (LDKT), deceased donor kidney transplant (DDKT) with a low to moderate kidney donor profile index (KDPI), DDKT from a high KPDI (> 85) donor, or a DDKT from a US Public Health Service (PHS) Increased Infectious Risk donor. Patient education generally includes national "expected patient outcomes" without adjustment for individual patient characteristics, nor the wide variation in regional DDKT waitlist time---both of which can influence patients' survival before and after transplant.

As a result of this complexity, potential candidates for transplant report that they do not fully understand their options, leading some to pursue strategies that are not expected to optimize survival.[1] Inadequate education may particularly impact patients with lower socioeconomic status or members of racial/ethnic minorities, contributing to lower rates of referral and transplant listing[2-6]. In addition, patients may choose to reject high KDPI and PHS increased risk organs that are expected to provide benefit out of fear or incomplete understanding of the relative risk of death on dialysis. Nationally, consent rates for non-standard kidney transplants demonstrate that only half of patients who are expected to benefit from non-standard DDKT actually consent to receive these organs [7] contributing to organ discard and reducing access to transplant. [8 9]

The use of decision aids to assist patients in making complex medical decisions has been demonstrated to improve patient empowerment, reduce anxiety, and enhance patient satisfaction [10 11]. Currently, education programs aimed at increasing interest in transplant do not include individualized, patient and donor-service area (DSA) specific estimates of transplant benefit with each donor type to assist patients in making informed decisions at the time of listing. [12-15] My Transplant Coach (MTC) is a mobile application (app) that provides a self-contained, patient-centered educational program to fully inform patients with ESRD about the impact of these choices on survival. This report describes the content of MTC, its acceptability and culturally competency in a racially and educationally diverse population, and the impact of MTC on patient knowledge, informed-decision-making, and interest in kidney transplant in a pilot study.

Methods

Content Development: MTC was developed by a multidisciplinary team including education professionals, nephrologists, physicians, transplant surgeons, statisticians and patient representatives. Initial content was developed by the education professionals and validated by the medical nephrology team. Next, the content was reviewed in three focus groups (n=20 participants)

at the University of California, Los Angeles (UCLA) who evaluated data presentation, script content, and overall structure. The data presentation and content were reviewed with the focus groups to assess usability for patients with differing numeracy and literacy skills. Following refinement, an iOS app was developed that includes animated presentation with professional voice-over performances. Currently, the application is only provided in English.

Description of the Application: MTC asks patients to enter essential demographic and clinic information and their anticipated transplant center, from which the program generates estimates of survival time for patients with similar characteristics who remain on dialysis, join the DDKT waiting list (including survival associated with willingness to accept non-standard organs), or receive a LDKT. Patients also receive information on expected post-transplant survival with various levels of KDPI DDKTs and PHS high risk organs. As these results require explanation, the MTC program includes a series of short video presentations that describe the patient's treatment options, followed by presentation of survival projections in graphical format. The patients are also taught about PHS high risk donors, the potential for living donor exchange, and the risks of remaining on long term dialysis. Information about next steps in pursuing a transplant evaluation, local transplant programs, and the ability to email the results of the analysis are also included in the tool.

Statistical Model Development for Risk Assessment: Analyses in the MTC app were designed to provide projected outcomes for patients considering all renal replacement options using a complex multistage Markov model. In Stage 1, data from the United States Renal Data Service (USRDS) were used to estimate survival following waitlist time for patients on the basis of easily identified factors (age, race, diabetes, and time on dialysis). Cox proportional hazard modeling was utilized to develop risk-adjusted mortality rates for patients on dialysis. These mortality rates were used to estimate pre-transplant mortality in the Markov model that was censored at the time of transplant.

Information on user's preferred transplant center was collected to assign patients to a specific DSA. Users were asked to provide their blood type (if known) or were assumed to have blood group O if not known. Median time to DDKT by blood group and DSA was estimated using data from the Standard Analytic Research File from the United Network for Organ Sharing (UNOS). For the purposes of the initial application development, patients accepting US PHS increased-risk organs or high-KPDI organs were assumed to have 50% shorter wait times, as this is generally consistent with clinical experience. Subsequent versions of the app are currently being designed to include estimates of transplant waiting times and rates for a wider range of KDPI levels.

Post-transplant survival was estimated using coefficients derived from the current Expected Post-Transplant Survival (EPTS) model utilized in the UNOS allocation system. These estimates were then adjusted for donor type (LDKT vs. DDKT) and in the case of DDKT, survival estimates also considered the US PHS risk or KDPI level of the deceased donor kidney the patient was willing to accept. Survival with US PHS increased-risk kidneys was assumed to be the similar to the non US-PHS high risk kidneys with average KDPI scores based on national data.[16]

Data presentation: MTC includes 3 analyses for patients. First, patients are provided with 5-year survival estimates for individuals with comparable risk who either remain on dialysis, are waitlisted for a DDKT, or immediately receive a LDKT (**Figure 1A**). Second, the application presents estimates of survival and transplant rates for patients the waiting list over years 1-5 incorporating the expected mortality rate of dialysis and DSA specific waiting times based on UNOS data(**Figure 1B**). Finally, users were provided with a single chart that displays expected 5-year survival comparing dialysis, post-transplant survival with a DDKT of varying quality (KPDI 0-20, 21-50, 51-84, 85+), and living donor (**Figure 1C**). Users were offered the opportunity to email the results to themselves and/or their physician.

Evaluation design: The MTC application was piloted in two large US transplant programs on the East and West coasts of the U.S.: Ronald Regan UCLA Medical Center and Massachusetts General Hospital. Patients were recruited at the prior to their initial transplant evaluation and were offered the opportunity to use the application with the assistance of a research assistant. The app pilot and pre/post testing was completed prior to standard educational sessions at the transplant program or in the patient's home prior to initial visit. All patients were provided a gift card (\$25) for participating in the study. Prior to using the MTC app, participants completed an initial survey (presurvey) to determine demographic data including age, race, ethnicity, whether they were on dialysis, socioeconomic status, educational achievement, health literacy [17], and previous access to transplant education. Access to and comfort with technology, including mobile phones and iPads, was assessed by asking whether participants had access to a mobile phone with internet access or an iPad (yes/no), and whether they were comfortable browsing the internet or downloading apps on these two technologies (comfortable/not comfortable). Participants also responded to questions regarding knowledge of transplant options and ability to make an informed decision about ESRD treatment options.

Shortly after using the MTC program, participants were surveyed again (post-survey) about their ability to make an informed decision about ESRD treatment options and their knowledge of transplantation. They also rated the acceptability and cultural competence of the MTC. Acceptability

was rated with multiple questions on the participants' experience while using the app (e.g., "My Transplant Coach helped me to understand the available treatment options," "I could trust the information provided by My Transplant Coach"). Cultural competency was assessed by examining differences in patient reported acceptability across racial groups and levels of access to and comfort with technology, as well as with two specific questions: "My Transplant Coach is suitable for people of my race and ethnic group," and "The graphs were suitable for people with an educational background similar to mine". On both the pre- and post-surveys, knowledge of transplant was rated by summing the number of correct answers to 20 true/false and multiple choice questions about basic facts, benefits, and risks of transplant to create a scale ranging from 0-20. Participants were also asked for general and specific feedback regarding the app.

Statistical methods: Patient demographics and ratings of the app were summarized using univariate statistics. Differences reported on the post survey in rated acceptability and cultural competence from the app by race and comfort using technology were tested with chi-square tests. Change in knowledge levels from the pre- and post-surveys were tested using paired *t*-tests, and were made for the total sample, as well as stratified by race/ethnicity, education level, health literacy level, and comfort using technology. Increases in ability to make an informed decision about ESRD treatments (e.g., dialysis, deceased or living donor transplant, KDPI or PHS increased risk deceased donor transplant) from the pre- to post- survey were rated as the % reporting they would "Completely Agree" that they have all the facts they need to make an informed decision about each option, and were tested with McNemar's tests for the total sample and stratified by race/ethnicity and comfort using technology. Finally, the additional, qualitative comments left on the post-survey were revised and clustered based on thematic analysis.

Informed consent: Participants provided written informed consent to participate in the trial prior to beginning the use of the app. The project was reviewed and approved by the Institutional Review Boards at the Ronald Regan UCLA Medical Center and Massachusetts General Hospital.

Results

Participant Characteristics. The MTC application was piloted with 81 patients at the two participating transplant centers between February 2015 and May 2016. The average age of the patients surveyed was 52 years and 49% of the patients were female (**Table 1**). Patients came from a broad spectrum of racial and ethnic backgrounds including African Americans (AA) (26%), Hispanics (15%), Asians (25%) and whites (27%). Participants were of modestly higher education than the

average population of ESRD patients: 20% of patients had a high school education or less, 55% attended or completed college, and 23% had more than a college degree. More than 50% of the patients had private insurance, and 60% of patients were currently on dialysis. In general, the pilot population was moderately health literate. When asked about assistance with reading hospital materials, 40% of patient reported needing only a little of the time. While most participants had access to a mobile phone with internet (84%), less than half (48%) had access to an iPad. Sixty percent of participants were comfortable browsing the internet and downloading apps on a mobile phone, and approximately half were comfortable browsing the internet and downloading apps on an iPad. (**Table 1**).

Acceptability. The overall impression of the app was very positive, with 86% of users strongly agreeing/agreeing that the MTC app helped them to understand their available treatment options, 83% reported they could trust the information provided by the app, and 85% said they would recommend the app to others (**Table 2**). Regarding the graphs specifically, 86% reported that they could understand what the graphs meant, 81% said the graphs contained information relevant to them, and only 17% reported that the graphs were upsetting to them. Finally, 78% and 74%, respectively, said that after using the MTC app, they felt more comfortable speaking to doctors and family/friends about transplant.

Cultural Competence. In general, patients reported that they believe that the content of the app was appropriate for patients of their race/ethnicity (67%-85%) (**Table 2**). There were no statistically significant differences in ratings of acceptability by race/ethnicity, indicating that the app is culturally competent with regards to race and ethnicity. When queried about their response to the app, 64%-100% of respondents felt that the data display was useful for patients of similar educational achievement.

When stratified by levels of access to and comfort with technology, some differences in ratings of the MTC app's acceptability were observed. Belief that the app was appropriate for them was higher in patients who were comfortable downloading an app on a mobile phone (84% vs. 60%, p=0.02), browsing the web on an iPad (88% vs. 61%, p=0.001;), and downloading an app on an iPad (90% vs. 61%, p=0.002). Compared to those who were not comfortable browsing the internet on a mobile phone, those who were comfortable more frequently reported being comfortable speaking to their doctor (p=0.04) and family/friends (p=0.02) about transplant after using the MTC app. Regarding comfort browsing the internet on an iPad, those who reported being comfortable with this activity more frequently reported the MTC app being acceptable. Technology savvy users were more likely to agree that the graphs added to the information presented in the video (90% vs. 78%,

p=0.03), they understood what the graphs meant (93% vs. 83%, p=0.04), they would watch MTC app again (88% vs. 72%, p=0.02). These patients are also comfortable talking about transplant with a doctor (90% vs. 72%, p=0.01) or family/friends (85% vs. 69%, p=0.04) after using the MTC app.

Transplant Knowledge and Informed Decision-Making. Use of the MTC app dramatically increased transplant knowledge in the pilot sample. Median scores on the 20-point test, increased by 52% (9.1 to 13.8 p<0.001) (**Table 3**). Following the MTC app exposure, the percent of patients able to correctly report that living kidneys last longer than deceased donors increased from 27% to 69% (p<0.001) and that the kidney donor profile index predicts graft survival improved from 27% to 80% (p<0.001). (**Supplemental Table S1**). Patients also demonstrated a better understanding of the risks of PHS high risk kidneys, the improvement in quality of life after transplant, the mechanics of the waiting list, and the purpose of the KPDI score.

Knowledge scores increased among members of all racial and ethnic groups: whites (8.9 to 14.9 p<.001), AAs (9.7 to 11.8 p=0.01), Hispanics (8.4 to 13.1 p<0.001), and Asians (9.6 to 14.8 p<0.001). The app also appeared to be effective in patients with low educational achievement (6.9 to 11.9 p<.001) and low health literacy (8.0 vs. 13.0 p<0.001). Finally, the MTC increased knowledge among patients significantly regardless of whether they reported having access to, or being comfortable with, technology including mobile phones and iPads.

The MTC application also significantly impacted patients' ability to make informed decisions about deceased and living donor kidney transplantation.(**Supplemental Tables S2-S4**). There was a no significant change in patients understanding of the risks and benefits of dialysis. Prior to viewing the app, only 27% of patients felt that they had all the information needed to make the decision about pursuing DDKT, compared to 52% after viewing the app (p<.001). The proportion of patients who reported sufficient knowledge to make an informed decision about DDKT increased among members of most racial and ethnic groups, levels of educational achievement, and health literacy levels. Among patients who reporting access to or comfort with technology (mobiles phones and iPads), increases in informed decision-making around DDKT were statistically significant, but not for patients reporting no access or comfort with technology. After viewing the app, there was no significant increase in the proportion patients who would "try to get a public health service increased risk kidney" or "try to get a public health service high KDPI organ" (P>0.05) for both; however, patients were not surveyed about their willingness to accept these organs if offered.

Notably, MTC significantly increased patients' understanding and interest in LDKT, with 72% of patients reporting that they felt fully informed about LDKT after viewing the app, compared with only 40% on the pre-survey (p<.001). Among AA patients participating in the pilot, 76% of patients

reported feeling fully informed compared with 48% pre-MTC (p=0.09) about LDKT. Among whites, the number of patients who felt fully informed about LDKT increased from 18% to 68% after viewing MTC (p<0.001). There was a significant benefit for patients across health literacy levels, including those who were least literate (20% to 52%, p=0.02). Both patients who reported having access to and comfort with technology, as well as those reporting no access or comfort, had significant increases in informed decision-making about LDKT.

Discussion

The MTC app resulted in statistically and clinically significant increases in patient knowledge of transplantation, acceptance of LDKT and DDKT options, and comfort in discussing transplantation with physicians and family. This pilot project demonstrated that the app is culturally acceptable to patients from diverse racial and ethnic backgrounds. Furthermore, integration of general patient education and patient specific outcomes proved useful for patients with limited educational achievement and medical literacy. The program successfully increased interest in pursuing DDKT and LDKT in general. We did not see a significant impact in interest US PHS increased risk or KPDI donors based on the questions included in assessment tool used in the pilot.

The use of decision aids that couple the technological capacity of individualized risk predictions with patient-focused tools to ascertain patient preferences and guide complex medical decision making has expanded dramatically[18-20]. In a review of 86 randomized studies involving 20,209 participants, researchers from the Cochrane collaborative demonstrated that use of decision aids increased medical knowledge by approximately 14% (95% confidence interval[CI] 11.4 to 16.2) [21]. Following the use of decision aids, patients were more likely to have accurate risk perceptions (RR 1.74, 95%CI [1.46 – 2.08]). Risk assessment improved to a greater extent when data was presented with numerical probabilities (RR 1.93, 95% CI [1.58 -2.37]) compared with words (RR 1.27, [1.09-1.48)]). Decision aids also resulted in lower decisional conflict related to perceived limitation in knowledge and poor understanding of personal values and increased the active participation in the decision making. Review of the MTC pilot suggests similar results, with demonstrable improvement in medical knowledge and patient's beliefs that they sufficient knowledge to determine the benefit of LDKT and DDKT.

The need for effective educational interventions in patients with ESRD is crucial as patients must choose between dramatically different renal replacement therapy options, especially given the ongoing and profound disparities in access to transplantation [22-25]. Patients with reduced access to specialty care and health information (e.g. low socioeconomic status and/or racial-ethnic minority status) are more likely to start dialysis without transplant education, less likely to be referred for

transplant evaluation, and less likely to have access to living donor transplant procedures)[4 26]. The current system of pre-referral education regarding transplant is flawed, as 30% of patients begin dialysis without prior knowledge of transplantation [27 28]. Within the pre/post education pilot, MTC demonstrated significant capacity to increase knowledge of, and favorability toward, both deceased and living donor transplant among a diverse set of patients. The patients demonstrated more than a 50% improvement in knowledge scores regarding transplant risks and benefit overall. African Americans did not attain the same median score on the post-test as member of other races and ethnicity, but did improve significantly over baseline values.

While education programs focus specifically on improving access to transplant for ESRD patients of diverse races and facing myriad barriers have been successful, these interventions may be time and staff-intensive, and difficult to implement in all clinical settings. [12 14 15 29] A clear benefit of the MTC app is that it is likely very easy for clinicians to use in self- and clinician-assisted transplant education with patients in the nephrology offices, dialysis units, or transplant centers. This differs from other currently available tools (e.g. iChooseKidney) which provide survival estimates to inform patient choice but do not provide context for patients and family members. The application was viewed as useful by members of all racial and ethnic groups. However, African Americans rated the app lower than other ethnic groups regardless of comfort with technology. Consequently, further refinement of the presentation methods and communication is underway to improve it utility for all patients including patients with limited numeracy or other barriers.

While the MTC app did increase knowledge and motivation in patients to pursue transplant in general, the pilot data failed to demonstrate a beneficial impact of MTC on acceptance of higher risk organs. This may reflect either the construction of the survey question, which asked if the recipient would "try to get a PHS high risk donor" or the need to improve the MTC presentation itself. The MTC's failure to encourage acceptance of increased risk deceased donor kidneys mirrors that of another mobile app-based decision-aid, the Inform Me app, which also seeks to increase ESRD patients' knowledge of the risks and benefits of increased risk deceased donor kidney options [30]. Using a randomized controlled trial design, a recently published evaluation of "Inform Me" found that while it was associated with a 44% higher increased risk kidney knowledge score than a control group, but was actually associated with a trend toward lower willingness to accept increased risk kidneys. When patients learn about increased risk kidneys along with standard criteria deceased donor and living donor kidneys as possible transplant options, without presenting the corresponding risk of death on dialysis, patients rationally question why they would accept increased risk kidneys.

The MTC app provides this context, and the impact on consent rates for high risk donors will be evaluated in a future trial. Subsequent versions of the app are being developed to improve the presentation of data non-standard DDKT (high KDPI, PHS high risk) to encourage patients to consent for transplantation with these organs, and success will be determined through better designed assessment tools.

The pilot study demonstrated the need for some technical improvements in the MTC application which are currently being addressed. The application was perceived as too long by some patients. This has been addressed through content and presentation revision. This pilot study was not designed to assess the impact of MTC on patient's actual acceptance of organs of a variety of qualities (e.g. high-KDPI organs, PHS increased-risk donor organs). Rather, we focused on knowledge acquisition and cultural acceptance. The data presented in the initial pilot included estimates of the benefits of accepting a high-KPDI or PHS donor kidney and further revision of both presentation and evaluation methods are needed to accurately assess the impact of the MTC app on this decision. A major concern regarding the reported reduction in effectiveness for patients who were less comfortable with, or who had less access to, technology required to use the app, including mobile phones and iPads. This could be addressed by providing devices within the healthcare environment (e.g. dialysis center, transplant center) or training proctors (e.g. dialysis technicians) who could assist the user. Future refinement of the MTC will seek to improve the user experience so that it is easy to navigate even for individuals who do not have a high level of proficiency with such technologies. Finally, the models used to predict outcomes are imperfect and will be improved using updated data from the national transplant registry [27]. In the newer versions of the program, DSA and blood group specific assessments of waiting time will be assessed for KDPI quartiles and PHS high risk status.

In conclusion, MTC offers patients with ESRD a comprehensive, culturally acceptable, patient-centered decision aid that improves knowledge of transplant options and empowers patients. After further refinement, a randomized control trial will be launched to evaluate the impact of this tool on access to transplant services including waitlist rates, transplant rates, and early post-transplant outcomes.

Tables and Figures

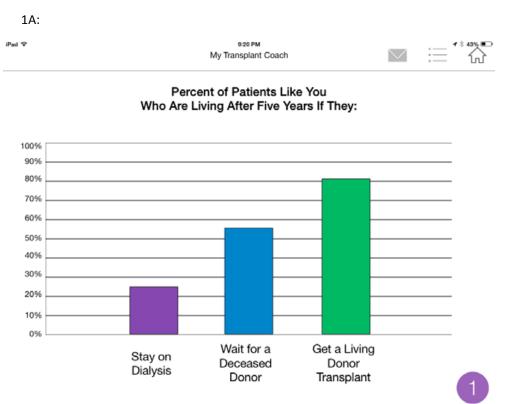
Race (%, n)	
Black	26% (21)
Hispanic	15% (12)
Asian	25% (20)
White	27% (22)
Other	7% (6)
Female (%, n)	49% (40)
Age (mean, SD, range)	52 (14, 21-75)
Education (%, n)	
High School or Less	20% (16)
Some College	22% (18)
College Degree	33% (27)
More than College Degree	23% (19)
Currently on Dialysis (%, n)	60% (49)
Employment (%, n)	
Employed Full or Part Time	42% (34)
Not Employed	58% (47)
Has Private Insurance (%, n)	51% (41)
Health Literacy	
How often needs help reading hospital materials: (%, n: A little/some of the time)	40% (32)
How confident filling out forms: (%, n: Extremely/quite a bit)	67% (54)
Comfortable asking your doctor a question about transplant (%, n: completely agree) Access to and Comfort with Technology	73% (59)
Has access to cell phone with internet	84% (68)
Has access to ten phone with internet	48% (39)
Comfortable browsing the internet on a mobile phone	60% (49)
Comfortable downloading a mobile phone app	60% (49)
Comfortable browsing the web on an iPad	51% (41)
Comfortable downloading an app on an iPad	48% (39)

Strongly agree/agree with the	All	Black	Hispanic	Asian	White	Other	р-
following statements	(%, n)	(%, n)	(%, n)	(%, n)	(%, n)	(%, n)	value
My Transplant Coach is fun to	73%	67%	83%	75%	64%	100%	0.24
watch.	(59)	(14)	(10)	(15)	(14)	(6)	
My Transplant Coach helped me to	86%	76%	92%	85%	91%	100%	0.40
understand the available	(70)	(16)	(11)	(17)	(20)	(6)	
treatment options.							
The graphs presented in My	83%	76%	92%	80%	82%	100%	0.45
Transplant Coach were helpful for patients like me.	(67)	(16)	(11)	(16)	(18)	(6)	
I could trust the information	83%	81%	83%	80%	82%	100%	0.81
provided by My Transplant Coach.	(67)	(17)	(10)	(16)	(18)	(6)	
The graphs were upsetting for me	17%	19%	17%	20%	14%	17%	0.96
to see.	(14)	(4)	(2)	(4)	(3)	(1)	
The graphs were suitable for	73%	67%	83%	75%	64%	100%	0.26
people with an educational background similar to mine.	(59)	(14)	(10)	(15)	(14)	(6)	
The graphs added to the	83%	67%	83%	85%	91%	100%	0.35
information presented in the	(67)	(14)	(10)	(17)	(20)	(6)	0.55
animated video.	(07)	(14)	(10)	(17)	(20)	(0)	
The graphs contained information	81%	71%	83%	85%	82%	100%	0.69
that was relevant to patients like	(66)	(15)	(10)	(17)	(18)	(6)	
me.							
I understood what the graphs	86%	81%	92%	85%	86%	100%	0.61
meant for patients like me.	(70)	(17)	(11)	(17)	(19)	(6)	
I would feel comfortable	85%	81%	92%	90%	77%	100%	0.32
recommending My Transplant	(69)	(17)	(11)	(18)	(17)	(6)	
Coach to others.							
My Transplant Coach	83%	76%	83%	90%	82%	83%	0.84
acknowledged both the pros and	(67)	(16)	(10)	(18)	(18)	(5)	
cons of transplant.							
I would watch My Transplant	79%	81%	83%	75%	73%	100%	0.49
Coach again if I forget something.	(64)	(17)	(10)	(15)	(16)	(6)	
After using My Transplant Coach, I	78%	67%	92%	85%	68%	100%	0.09
feel more comfortable speaking to	(63)	(14)	(11)	(17)	(15)	(6)	
my doctor about transplant.							
After using My Transplant Coach, I	74%	67%	83%	80%	64%	100%	0.20
feel more comfortable speaking to	(60)	(14)	(10)	(16)	(14)	(6)	
friends, family, and loved ones							
about transplant.		ļ					
My Transplant Coach is suitable for	77%	67%	75%	85%	77%	83%	0.79
people of my race and ethnic	(62)	(14)	(9)	(17)	(17)	(5)	
group.							

	Pre	p-value	
	(mean score)	(mean score)	
All	9.1	13.8	<0.001
Race			
Black	9.7	11.8	0.01
Hispanic	8.4	13.1	< 0.001
Asian	9.6	14.8	< 0.001
White	8.9	14.9	< 0.001
Other	7.8	15.3	0.002
Education			
High School or Less	6.9	11.9	< 0.001
Some College	10.2	13.6	< 0.001
College Degree	8.6	14.7	< 0.001
More than College Degree	11.1	15.3	< 0.001
Health Literacy			
Requires no help reading hospital materials	10.0	15.1	< 0.001
Requires help reading hospital materials	8.8	13.4	< 0.001
Confident filling out medical forms	9.6	14.7	< 0.001
Not confident filling out medical forms	8.0	13.0	< 0.001
Access to Technology			
Has access to a mobile phone with internet	9.5	14.2	<0.001
No access to a mobile phone with internet	6.8	12.7	<0.001
Has access to an iPad	9.5	14.2	<0.001
No access to an iPad	8.9	13.9	<0.001
Comfort with Technology			
Comfortable with browsing the internet on a mobile phone	10.2	14.9	<0.001
Not comfortable with browsing the internet on a mobile phone	7.5	12.8	<0.001
Comfortable with downloading an app on a mobile phone	9.8	14.5	<0.001
Not comfortable with downloading an app on a mobile phone	8.3	13.3	<0.001
Comfortable with browsing the internet on an iPad	10.0	14.9	<0.001
Not comfortable with browsing the internet on an iPad	8.2	13.1	<0.001
Comfortable with downloading an app on an iPad	9.9	14.7	<0.001
Not comfortable with downloading an app on an iPad	8.4	13.4	<0.001

	Pre	Post	p-value	
	(mean score)	(mean score)		
All	9.1	13.8	< 0.001	
Race				
Black	9.7	11.8	0.01	
Hispanic	8.4	13.1	< 0.001	
Asian	9.6	14.8	<0.001	
White	8.9	14.9	<0.001	
Other	7.8	15.3	0.002	
Education				
High School or Less	6.9	11.9	< 0.001	
Some College	10.2	13.6	< 0.001	
College Degree	8.6	14.7	<0.001	
More than College Degree	11.1	15.3	< 0.001	
Health Literacy				
Requires no help reading hospital materials	10.0	15.1	<0.001	
Requires help reading hospital materials	8.8	13.4	<0.001	
Confident filling out medical forms	9.6	14.7	< 0.001	
Not confident filling out medical forms	8.0	13.0	< 0.001	
Access to Technology				
Has access to a mobile phone with internet	9.5	14.2	< 0.001	
No access to a mobile phone with internet	6.8	12.7	< 0.001	
Has access to an iPad	9.5	14.2	< 0.001	
No access to an iPad	8.9	13.9	<0.001	
Comfort with Technology				
Comfortable with browsing the internet on a mobile phone	10.2	14.9	<0.001	
Not comfortable with browsing the internet on a mobile phone	7.5	12.8	<0.001	
Comfortable with downloading an app on a mobile phone	9.8	14.5	<0.001	
Not comfortable with downloading an app on a mobile phone	8.3	13.3	<0.001	
Comfortable with browsing the internet on an iPad	10.0	14.9	<0.001	
Not comfortable with browsing the internet on an iPad	8.2	13.1	<0.001	
Comfortable with downloading an app on an iPad	9.9	14.7	<0.001	
Not comfortable with downloading an app on an iPad	8.4	13.4	<0.001	

Figure 1: Graphical display of survival estimates from the My Transplant Coach Application. The screen shots demonstrated the outcome of patients after 5 years if they remain on dialysis, wait for deceased donor transplant, or receive a live donor transplant (1A), waitlist outcomes after four years (1B), and post-transplant survival comparing deceased and living donor transplant with extended time on dialysis (1C).



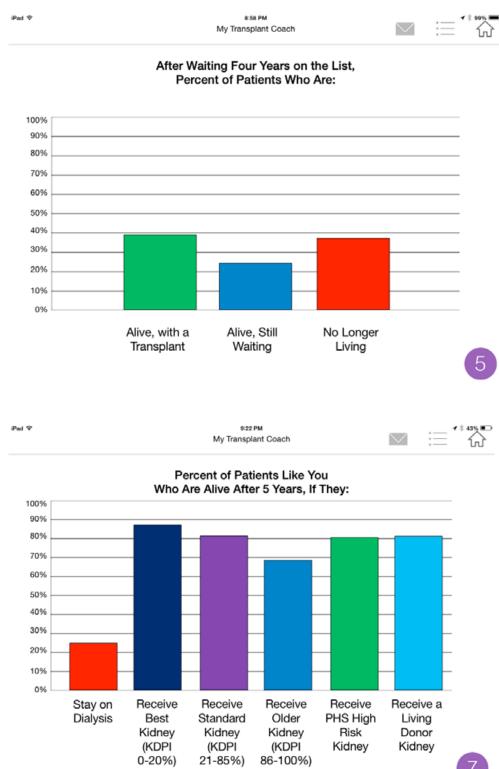
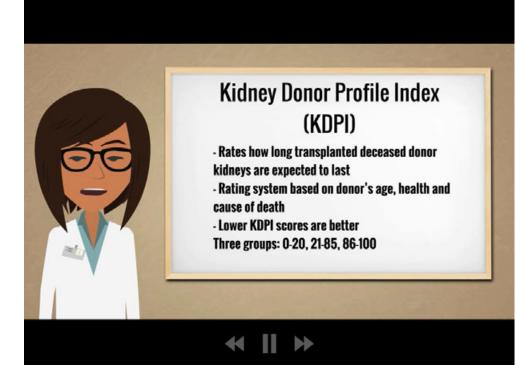


Figure 2: Brief video explaining the new Kidney Allocation System

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1B:

1C:



References

- 1. Ros RL, Kucirka LM, Govindan P, Sarathy H, Montgomery RA, Segev DL. Patient attitudes toward CDC high infectious risk donor kidney transplantation: inferences from focus groups. Clinical transplantation 2011 doi: 10.1111/j.1399-0012.2011.01469.x[published Online First: Epub Date]|.
- Monson RS, Kemerley P, Walczak D, Benedetti E, Oberholzer J, Danielson KK. Disparities in completion rates of the medical prerenal transplant evaluation by race or ethnicity and gender. Transplantation 2015;99(1):236-42 doi: 10.1097/tp.000000000000271[published Online First: Epub Date].
- 3. Weng FL, Joffe MM, Feldman HI, Mange KC. Rates of completion of the medical evaluation for renal transplantation. Am. J. Kidney Dis. 2005;**46**(4):734-45
- 4. Patzer RE, Plantinga LC, Paul S, et al. Variation in Dialysis Facility Referral for Kidney Transplantation Among Patients With End-Stage Renal Disease in Georgia. JAMA 2015;**314**(6):582-94 doi: 10.1001/jama.2015.8897[published Online First: Epub Date]].
- Patzer RE, Plantinga L, Krisher J, Pastan SO. Dialysis facility and network factors associated with low kidney transplantation rates among United States dialysis facilities. Am. J. Transplant. 2014;14(7):1562-72 doi: 10.1111/ajt.12749[published Online First: Epub Date]].
- 6. Johansen KL, Zhang R, Huang Y, Patzer RE, Kutner NG. Association of race and insurance type with delayed assessment for kidney transplantation among patients initiating dialysis in the United States. Clinical journal of the American Society of Nephrology : CJASN 2012;7(9):1490-7 doi: 10.2215/CJN.13151211[published Online First: Epub Date]].
- Grams ME, Womer KL, Ugarte RM, Desai NM, Montgomery RA, Segev DL. Listing for expanded criteria donor kidneys in older adults and those with predicted benefit. Am. J. Transplant. 2010;10(4):802-9 doi: AJT3020 [pii]

10.1111/j.1600-6143.2010.03020.x[published Online First: Epub Date]|.

- 8. Snyder JJ, Salkowski N, Wey A, et al. Effects of High-Risk Kidneys on Scientific Registry of Transplant Recipients Program Quality Reports. American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons 2016 doi: 10.1111/ajt.13783[published Online First: Epub Date]].
- 9. Matas AJ, Smith JM, Skeans MA, et al. OPTN/SRTR 2012 Annual Data Report: kidney. American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons 2014;14 Suppl 1:11-44 doi: 10.1111/ajt.12579[published Online First: Epub Date]].
- Stacey D, Legare F, Col NF, et al. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev 2014(1):CD001431 doi: 10.1002/14651858.CD001431.pub4[published Online First: Epub Date]].
- 11. Patzer RE, Basu M, Larsen CP, et al. iChoose Kidney: A Clinical Decision Aid for Kidney Transplantation Versus Dialysis Treatment. Transplantation 2016;**100**(3):630-9 doi: 10.1097/TP.00000000001019[published Online First: Epub Date]].
- Rodrigue JR, Paek MJ, Egbuna O, et al. Making House Calls Increases Living Donor Inquiries and Evaluations for Blacks on the Kidney Transplant Waiting List. Transplantation 2014 doi: 10.1097/tp.00000000000165[published Online First: Epub Date]].
- Rodrigue JR, Cornell DL, Lin JK, Kaplan B, Howard RJ. Increasing live donor kidney transplantation: a randomized controlled trial of a home-based educational intervention. Am. J. Transplant. 2007;7(2):394-401
- Boulware LE, Hill-Briggs F, Kraus ES, et al. Effectiveness of educational and social worker interventions to activate patients' discussion and pursuit of preemptive living donor kidney transplantation: a randomized controlled trial. Am. J. Kidney Dis. 2013;61(3):476-86 doi: 10.1053/j.ajkd.2012.08.039[published Online First: Epub Date]].
- 15. Improving education increases dialysis patients' pursuit of transplant: Explore Transplant RCT findings. American Transplant Congress; 2009 May 30-June 3; Boston, MA. American Journal of Transplantation.
- 16. Chow EK, Massie AB, Muzaale AD, et al. Identifying appropriate recipients for CDC infectious risk donor kidneys. American journal of transplantation : official journal of the American Society of Transplantation and the American Society of Transplant Surgeons 2013;**13**(5):1227-34 doi: 10.1111/ajt.12206[published Online First: Epub Date]].
- Chew LD, Griffin JM, Partin MR, et al. Validation of screening questions for limited health literacy in a large VA outpatient population. J. Gen. Intern. Med. 2008;23(5):561-6 doi: 10.1007/s11606-008-0520-5[published Online First: Epub Date]|.
- 18. Salkeld G, Cunich M, Dowie J, et al. The Role of Personalised Choice in Decision Support: A Randomized Controlled Trial of an Online Decision Aid for Prostate Cancer Screening. PloS one 2016;**11**(4):e0152999 doi: 10.1371/journal.pone.0152999[published Online First: Epub Date]|.
- Knops AM, Goossens A, Ubbink DT, et al. A decision aid regarding treatment options for patients with an asymptomatic abdominal aortic aneurysm: a randomised clinical trial. Eur J Vasc Endovasc Surg 2014;48(3):276-83 doi: 10.1016/j.ejvs.2014.04.016[published Online First: Epub Date]|.
- Knops AM, Legemate DA, Goossens A, Bossuyt PM, Ubbink DT. Decision aids for patients facing a surgical treatment decision: a systematic review and meta-analysis. Annals of surgery 2013;257(5):860-6 doi: 10.1097/SLA.0b013e3182864fd6[published Online First: Epub Date]|.
- Irwin FD, Wu C, Bannister WM, et al. A commercial transplant network's perspective of value in solid organ transplantation: Strategizing for value in transplant care. Transplant Rev (Orlando) 2016;30(2):71-6 doi: 10.1016/j.trre.2015.11.002[published Online First: Epub Date]|.

- 22. Waterman AD, McSorley AM, Peipert JD, et al. Explore Transplant at Home: a randomized control trial of an educational intervention to increase transplant knowledge for Black and White socioeconomically disadvantaged dialysis patients. BMC Nephrol 2015;16:150 doi: 10.1186/s12882-015-0143-0[published Online First: Epub Date]].
- Waterman AD, Peipert JD, Goalby CJ, Dinkel KM, Xiao H, Lentine KL. Assessing Transplant Education Practices in Dialysis Centers: Comparing Educator Reported and Medicare Data. Clin. J. Am. Soc. Nephrol. 2015;10(9):1617-25 doi: 10.2215/CJN.09851014[published Online First: Epub Date]|.
- Waterman AD, Morgievich M, Cohen DJ, et al. Living Donor Kidney Transplantation: Improving Education Outside of Transplant Centers about Live Donor Transplantation--Recommendations from a Consensus Conference. Clin. J. Am. Soc. Nephrol. 2015;10(9):1659-69 doi: 10.2215/CJN.00950115[published Online First: Epub Date]].
- 25. Skelton SL, Waterman AD, Davis LA, Peipert JD, Fish AF. Applying best practices to designing patient education for patients with end-stage renal disease pursuing kidney transplant. Prog Transplant 2015;**25**(1):77-84 doi: 10.7182/pit2015415[published Online First: Epub Date]].
- 26. Newman KL, Fedewa SA, Jacobson MH, et al. Racial/Ethnic Differences in the Association Between Hospitalization and Kidney Transplantation Among Waitlisted End-Stage Renal Disease Patients. Transplantation 2016 doi: 10.1097/tp.000000000001072[published Online First: Epub Date]].
- 27. Balhara KS, Kucirka LM, Jaar BG, Segev DL. Disparities in provision of transplant education by profit status of the dialysis center. Am. J. Transplant. 2012;**12**(11):3104-10 doi: 10.1111/j.1600-6143.2012.04207.x[published Online First: Epub Date]].
- 28. Kucirka LM, Grams ME, Balhara KS, Jaar BG, Segev DL. Disparities in provision of transplant information affect access to kidney transplantation. Am. J. Transplant. 2012;12(2):351-7 doi: 10.1111/j.1600-6143.2011.03865.x[published Online First: Epub Date]].
- 29. Sullivan C, Leon JB, Sayre SS, et al. Impact of Navigators on Completion of Steps in the Kidney Transplant Process: A Randomized, Controlled Trial. Clin. J. Am. Soc. Nephrol. 2012 doi: 10.2215/CJN.11731111[published Online First: Epub Date]].
- 30. Gordon EJ, Sohn MW, Chang CH, et al. Effect of a Mobile Web App on Kidney Transplant Candidates' Knowledge About Increased Risk Donor Kidneys: A Randomized Controlled Trial. Transplantation 2016 doi: 10.1097/TP.000000000001273[published Online First: Epub Date]|.