Comparison of Patient and Provider Goals, Expectations, and Experiences Following Kidney Transplantation

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Highlights

- Patients reported higher QOL than providers assessment of their typical patient
- Patients anticipated longer graft life and remaining life as compared to providers
- Providers had higher expectations of patients’ future affect and well-being
Abstract Objective: This study examined whether kidney transplant recipients’ post-transplant goals and expectations align with those perceived by their healthcare providers. Methods: Post-transplant goals and expectations across four domains were assessed via a descriptive survey of healthcare providers (N=72) and kidney transplant recipients (N=476) at the University of Michigan from March 23 - October 1, 2015. Demographic and transplant-related data were collected via a retrospective review of medical records, and survey responses were compared using Chi-square tests, Wilcoxon two-sample tests, and logistic regression. Results: Patients expressed higher quality of life (mean Neuro-QOL T-score 60.2 vs. 52.7), were less likely to report that they were currently experiencing complications (11% vs. 24%), and anticipated their transplants to last longer (median 25 vs. 15 years) and to live longer (median 80 vs. 71 years) than providers expected for their typical patient. However, provider perceptions of patients’ future ability to feel well, perform daily activities and work were significantly higher than those expressed by patients (all p<0.05). Conclusion: Kidney transplant patient and provider expectations differ in significant ways. Practice Implications: Identified areas of discordance may provide opportunities for patients and providers to better evaluate treatment option tradeoffs in post-transplant clinical interactions.

Key Words: outpatient care; patient education; quality of care/care delivery; quality of life (QOL); kidney transplant recipient

1. Introduction

There are over 193,000 patients in the United States with a functioning kidney transplant, and approximately 17,600 patients receive a kidney transplant in the United States annually.¹ In addition to transplant recipients requiring coordinated care, the healthcare system is increasingly focused on patient-centeredness,² which incorporates patients’ goals and expectations pertaining
to medical and non-medical aspects of life. Identifying such goals allows patients and providers to better evaluate treatment option trade-offs.

Prior investigations examining quality of life (QOL) scores find that transplant recipients are more optimistic than their providers. However, these studies are limited in their ability to assess differences in goals and expectations as they are mostly longitudinal (with a focus on comparing views pre- and post-transplant\(^3-5\)) or cross-sectional (with a focus on the recipient’s current, rather than future, status\(^6\)). In studies that did include goals, patients were frequently within a year of transplant\(^3,7-9\) and may not reflect the perspectives of longer-term recipients.

Comparative studies of end stage renal disease patients and providers have generally limited the provider population to nurses and/or physicians\(^6,7,9-11\) whereas care may be provided and influenced by a range of professionals. The focus has also been on QOL scores\(^6,7,11\), return to work\(^9\), and adherence\(^10\). There have not been comparisons of other aspects of the recipient experience – including health outcomes, costs, medication use, and relationships. Thus, a better understanding of how transplant recipients’ goals and expectations compare to providers’ perceptions is needed.

The primary aim of this study was to compare the self-reported post-transplant goals, expectations, and experiences of kidney transplant recipients to healthcare providers’ perceptions of recipients’ goals, expectations, and experiences. Specifically, we sought to compare goals and expectations in three novel areas – relationships with healthcare providers, general and transplant related health-outcomes, and elements of clinical care including medication use and cost concerns – as well as quality of life. The objective was to assess the null hypothesis that there are no differences between recipient and provider reported goals, expectations, and experiences. Identified areas of discordance may provide opportunities for discussion and improvement in
understanding by both providers and recipients in post-transplant clinical interactions. The scope of the questions asked, inclusion of both recipients and providers, and focus on expectations fill an important gap in the literature.

2. Methods

2.1 Design

Study approval was received by the University of Michigan (UM) Institutional Review Board (HUM00079279) and all research activities being reported are consistent with the Principles of the Declaration of Istanbul as outlined in the 'Declaration of Istanbul on Organ Trafficking and Transplant Tourism'.

This study utilized a survey to assess whether the goals, expectations, and experiences of kidney transplant recipients aligned with those of their healthcare providers. **The survey was developed and administered through a three phased approach consisting of** I) focus groups; II) cognitive interviews; and III) survey deployment. **Each phase included two populations: kidney transplant recipients and their healthcare providers. Survey development began with two, one-hour focus groups, i.e., one for patients and one for providers. Each group included five study participants to determine broad topics regarding the goals, expectations, and patient experiences that were important to each group with regard to post-transplant course. These ideas were used as a basis for developing draft survey questions. The draft survey was discussed with three patient participants and five provider participants (who participated in the Phase I focus groups) in separate one-hour cognitive interviews to determine whether the survey questions were worded in a manner that promoted consistency of meaning.**
Prospective patient focus group and cognitive interview participants who met the eligibility criteria (as described in the Population section) were nominated by participating healthcare providers and were recruited via telephone. Care was taken to recruit participants representing a range of patient demographics including age, gender, and time since transplant. Prospective provider focus group and cognitive interview participants included a diverse subset of kidney transplant program staff members with substantial patient interaction.

Finalized questionnaires were deployed to patients and providers from March 23 to October 1, 2015. Patients completed a paper version of the survey during their post-transplant follow up clinic appointment and were asked to respond to the questions based on their perspective (e.g., “How important is your healthcare relationship with your UM nephrologist?”). Given that many of the items had not been previously studied we were not able to perform traditional power calculations, however, we targeted 500 patient responses to ensure that we had a representative sample of the population and that the sample size was large enough to enable us to detect important differences between patients and providers.

Providers completed either a paper (20 respondents) or electronic version (52 respondents) of the survey and were asked to respond to questions in terms of the typical kidney transplant recipient that the provider sees in the course of his/her work that would have met the patient survey eligibility criteria rather than in terms of a specific patient. All providers at the institution were invited to participate in the survey as outlined in the following section. Research staff were not present while patients or providers completed the survey.
Survey questions consisted of items from validated instruments (SF-36 version 2\textsuperscript{12} and Neuro-QOL Item Bank: v1.0-Positive Affect and Well-Being\textsuperscript{13}) as well as additional investigator-developed questions in four broad categories: 1) healthcare provider-patient relationships; 2) general and transplant-related health; 3) elements of clinical care; and 4) affect and well-being. The healthcare provider-patient relationship questions rated the importance of individuals that aid in a patient’s healthcare decisions. General and transplant-related health questions assessed common kidney transplant-related complications and comorbidities, anticipated life expectancy and kidney graft survival, and included the SF-36 version 2 question related to general health.\textsuperscript{12} Elements of clinical care addressed aspects of managing post-transplant health, including medications, transplant monitoring requirements, and dietary restrictions. Finally, affect and well-being was assessed with a modified six item subset from the Neuro-QOL Item Bank, v1.0-Positive Affect and Well-Being survey.\textsuperscript{13} Although the Neuro-QOL items were designed to assess QOL for individuals with neurologic disorders, they have also been administered to the United States general adult population and are valid measures for this study.\textsuperscript{13} The patient and provider surveys are included in Appendix A–B.

Questions pertaining to importance and agreement were assessed using a five point Likert-type scale. Importance measure response categories included not at all important, a little important, important, very important, or extremely important, while agreement question response categories were strongly disagree, disagree, neither agree nor disagree, agree, and strongly agree. For this preliminary analysis, these scales were collapsed into “high importance” (i.e., extremely important/very important/important) versus “low importance” (i.e., a little important/not at all important) and “positive expectation” (i.e.,
agree/strongly agree) versus “no expectation” (i.e., neither agree nor disagree/disagree/strongly disagree), respectively due to low frequency of endorsement at the extremes of the rating scales for some items. Consistent with the Neuro-QOL format, Neuro-QOL questions had response categories of never, rarely, sometimes, often, and always. Additionally, responses to the Neuro-QOL questions were scored using the T-score metric. SF-36 responses were categorized as “positive” (i.e., good/very good/excellent) and “negative” (i.e., fair/poor). For the distribution of responses using the full response categories as well as missing data for each question, see Appendix Table C.1.

Demographic and transplant-related data were abstracted via retrospective chart review for all eligible patients regardless of study enrollment (through an IRB informed consent waiver) for comparative baseline population statistical purposes. Provider data pertaining to age, gender, the number of years as a transplant healthcare provider, and type of provider were self-reported through the provider survey.

2.2 Population

The study consisted of two participant groups at UM: kidney transplant recipients and healthcare providers. The UM Kidney Transplant Program is organized into pre- and post-transplant teams. Kidney transplant candidates are seen pre-transplant in a single half-day session during which they participate in a nurse-led group teaching session, and are seen individually by a transplant nephrologist, transplant surgeon, transplant social worker, and –if necessary- by a financial counselor. During this evaluation, patients are given opportunities and encouraged to ask questions and explore any concerns they may have. There are also early and as-needed phone follow-up with a pre-transplant nurse
coordinator and once or twice yearly in-person follow-up in the pre-transplant clinic. All patients are informed that it is necessary to take medications and undergo laboratory monitoring for the duration of their kidney transplant’s function. Expected post-transplant graft function and survival, medication side effects and follow-up protocols are detailed and this information is re-iterated at each subsequent pre-transplant clinic visit and as necessary during post-transplant clinic visits.

Unless there are complications requiring surgical assessment or intervention, post-transplant care is provided by transplant nephrologists or mid-level providers on a schedule that offers graduated transition to referring physician practices. However, recipients are seen by their transplant-center provider at least once yearly for the duration of kidney transplant function. Additionally, post-transplant nursing and social work efforts focus on helping patients adapt to and succeed in meeting the demands of post-transplant care.

The pre- and post-transplant nursing and medical assistant teams are distinct and do not see transplant patients outside of their prescribed domains. Transplant surgeons, nephrologists, social workers, financial counselors, dieticians, pharmacists and support personnel may see both pre- and post-transplant patients, but there is not carryover between the two patient service domains, i.e. the caregivers that see the patients pre-transplant are unlikely to see the same patients after transplant. Both pre- and post-transplant teams were surveyed for this study.

We use “healthcare provider” to refer to any kidney transplant program staff member with substantial patient interaction; eligible participants included surgeons, nephrologists, dieticians, physician assistants, nurse practitioners, nurse coordinators, registered nurses, doctors of pharmacy, pharmacists, pharmacy technicians, financial coordinators, social workers, and
ancillary healthcare workers. Prospective provider participants were identified through employee
directories and recruited via email and in person at conferences and meetings.

 Eligible recipient participants received a primary kidney-only transplant at UM at age
18 years or older, were at least one month post-transplant, had not had any other
transplants, and had a functioning graft at the time of study participation. Patients who
met eligibility criteria and appeared for a post-transplant follow up clinic appointment
during the March 23 to October 1, 2015 enrollment period were recruited in-person by
trained research staff to participate in the survey.

 All study participants had the ability to read and understand English and provided informed
consent.

2.3 Data Analysis

 Demographic and clinical characteristics of the patient study population and the broader UM
kidney transplant population that met eligibility for the study were explored using means,
standard deviations, frequencies, and percentages. To test for selection and responder bias, we,
respectively, compared the demographics of patient participants to UM kidney transplant patients
who met the eligibility criteria for our survey but were not approached to participate (e.g., no
clinic appointment during enrollment period) and to patients who were approached for
participation but declined. Comparisons were performed using t-tests and chi-square tests for
continuous and categorical variables, respectively.

 Differences between patient and provider expectations were assessed by descriptively
comparing percentage of endorsement and statistically using logistic regression models. If all
responses for a given respondent type fell into a single category, differences were tested using a
chi-square test. Continuous measures of expected patient and transplant lifetime, as well as
Neuro-QOL T-scores, were analyzed using means and standard deviations; responses by patients and providers were compared using Wilcoxon two-sample tests. Analysis of free response questions is not included in this paper.

3. Results

3.1 Demographics

Of the 755 kidney transplant recipients approached for participation, 500 were enrolled in the study (66%), 230 declined participation (30%), and 25 were screening errors (3%, Figure 1a). Of the 500 patients enrolled, 24 (5%) were subsequently determined to be ineligible and excluded from further analyses. No demographic differences between eligible enrolled patients (n=476) and patients that were approached for consent but declined to participate (n=230) were identified (all p>0.1).

Patient participants were statistically significantly older and transplanted more recently compared to the general UM kidney transplant population that met the eligibility criteria for our study (mean age 48.7 vs. 46.3, respectively, p=0.001; median years post-transplant 5 vs. 8 (IQR 2-9 vs. 4-14, p<0.001, Table 1), however, the age difference was not considered clinically relevant. There was also a higher proportion of males (64% vs. 59%, p=0.04) and living unrelated donor transplant recipients (29% vs. 23%, p=0.01) in the patient study participant group, although there was no difference between the proportions who received a deceased donor transplant (p=0.1). Ethnic and racial distributions were similar, with non-Hispanic (97%), white (77%), and male (64%) demographic groups predominant among patient participants.

Among providers, 83% (82/99) agreed to participate, 72 of whom met all eligibility criteria and completed the survey (Figure 1b). The distribution of provider types was similar for providers that did not participate (due to refusal or ineligibility, n=27) and those who enrolled
(n=72, p=0.06 based on Fisher’s exact test, excluding two non-participating providers due to missing provider type information). Characteristics of the participating providers are shown in Table 2.

### 3.2 Healthcare Relationships

The overall distribution of responses regarding who the transplant recipient relied on most to help with healthcare decisions was significantly different between patients and providers (p<0.001). Both patients and providers most often indicated that the UM nephrologist was the person they (or their typical patient) relied on most to help with healthcare decisions (65% patients; 70% providers). However, a spouse, family member, or other helper was endorsed as the person relied on most by 24% of patients but only 10% of providers, while 10% of providers indicated the UM nurses were relied on most compared to less than 5% of patients.

Ratings of the importance of patients’ healthcare relationships with their UM nephrologist, other UM doctor, and non-UM doctor did not differ significantly between patients and providers. However, compared to providers’ ratings for their patients, patients had significantly lower odds of rating the relationships with their non-UM nephrologists, UM nurses, and UM social workers as important (69% vs. 87%, odds ratio [OR]=0.32, p=0.003; 90% vs. 99%, OR=0.13, p=0.04; 60% vs. 87%, OR=0.22, p<0.001, respectively, Figure 2a).

### 3.3 General and Transplant-Related Health

Patients were more likely than providers to rate their current overall health as positive (i.e., good, very good, or excellent) (81% vs. 68%, OR=1.98, p=0.02; Figure 2b). Odds of agreement regarding common post-transplant complications and comorbidities were significantly different (p<0.05), with patients expressing more optimistic responses for each condition except hypertension (p=0.08) and bone disease (p=0.4). Patients had higher odds of reporting
medication adherence; 97% stated that they take all of their prescribed medication more than half of the time compared to only 84% of providers expecting this behavior of a typical patient (OR=29.53, p<0.001). Compared to providers thinking of their typical patient, patients were significantly less likely to report that they were currently experiencing complications (11% (patients) vs. 24% (providers), OR=0.39, p=0.004).

Patients expected to live longer (median age of 80 vs. 71 years, p<0.001) and expected that their transplants would last longer (median of 25 vs. 15 years, p<0.001) than providers did for their typical patient (Figure 3a).

3.4 Elements of Clinical Care

Patients placed greater importance on taking the lowest dosage of medications (90% rated highly important compared to 74% of providers, OR=3.16, p<0.001, Figure 2a) and having few dietary restrictions (highly important: 79% (patients) vs. 65% (providers), OR=2.08, p=0.009). However, compared to patient responses, providers rated taking the lowest cost medications (highly important: 74% (patients) vs 87% (providers), OR=0.44, p=0.03) and keeping laboratory and other testing costs as low as possible (highly important: 81% (patients) vs. 91% (providers), OR=0.40, p=0.04) with higher importance.

3.5 Affect and Well-Being

The average patient Neuro-QOL Positive Affect and Well-Being T-score was 7.5 points higher than that reported by providers assessing their typical patient (60.2 [SD=6.9] vs. 52.7 [SD=3.8], p<0.001), and one standard deviation higher than the United States general population norm (mean=50, SD=10, Figure 3b).

In contrast, patients had lower odds (compared to providers thinking of their typical patient) of reporting that they will feel well (88% vs. 97%, OR=0.21, p=0.03) and would be well enough to work in the future (76% vs. 96%, OR=0.14,
p=0.001). Notably, 100% of providers expected their typical patient to be well enough to perform normal daily activities in the future, compared to 87% of patients (chi-square p=0.001).

4. Discussion and Conclusion

4.1 Discussion

Consistent with other literature,\textsuperscript{11} our patients were more optimistic than healthcare providers about their post-transplant health, particularly regarding life expectancy and expected longevity of their transplanted kidney. Since the average provider response of 15 years of graft function aligns much more closely with published literature – 11.9 year half-life after deceased donor and 15.9 year half-life after living donor transplant, each conditional on one year survival\textsuperscript{15} – the marked difference in expectation could have a major effect on patient satisfaction and underscores the importance of discussions regarding life expectancy and transplant longevity. Furthermore, a recent study showed that kidney transplant patients prioritize graft survival longevity as the most important post-transplant outcome when compared to other results, such as cardiovascular disease, excessive weight gain, and dying with a functioning graft.\textsuperscript{16} Additionally, the average patient response of 25 years could be due to survey design; respondents may have chosen the middle of the provided response scale. However, this is unlikely given the wide distribution of responses (see Figure 3a) that spanned the range of options provided.

Patients were also more optimistic about managing comorbidities and avoiding complications. Other studies have suggested that kidney transplant recipients’ generally positive perception of their medical status, in spite of comorbidities, represented an attempt to recover control over their health\textsuperscript{17} and that patients may tolerate even serious adverse events to avoid graft loss.\textsuperscript{18,19} Alternatively, patients who feel well and are experiencing fewer than average
health-related complications are more likely to participate in studies such as this, potentially biasing the results.\textsuperscript{20}

Patient-reported QOL was significantly higher than both provider perceptions of a typical patient and the United States general population self-reported QOL. This could be due to the marked improvement in QOL after receiving a kidney transplant, which can secondarily increase patient happiness and emotional well-being.\textsuperscript{8,21} Furthermore, the pre-transplant psychosocial evaluation may inherently favor individuals with higher pre-transplant QOL as it seeks patients who are motivated, have demonstrated adherence with health regimens, and live in an environment capable of supporting compliance with a complex post-transplant regimen.

By contrast, providers were more optimistic about the future ability of a typical patient to feel well, perform normal daily activities, and work if he/she chooses to do so, although the majority of patients also agreed with these statements. One potential explanation for this difference is that the set of patients a provider cares for may include a lower proportion of patients with impaired health compared to the surveyed kidney transplant recipients. Additional study of paired patient-provider responses could help determine whether these expectations truly differ. Differences may also result from dissimilar perceptions of “normal daily activities” (e.g., eating, bathing, walking) or illness (e.g., comorbidities versus medication side effects\textsuperscript{10}). Finally, within the full spectrum of patients they see, providers may view kidney transplant recipients as relatively healthy while patients may view themselves as more fragile.\textsuperscript{17}

Adherence to medication regimens and related costs were additional major areas of discordance. The results suggest that providers place more importance on lower medication and laboratory cost, which is consistent with findings from another study.\textsuperscript{7} This may reflect that co-pays are relatively insensitive to changes in dosage and routine laboratory monitoring. In contrast
to the high percentage of medication adherence reported by our patient participants, other studies have found lower levels of patient-reported compliance with medication regimens.\textsuperscript{22,23} It is thus possible that patients were reluctant to report nonadherence.

The results of this study should be interpreted in light of its limitations. The study was conducted at a single center with a relatively homogeneous population of patients; additional study is needed to determine whether these results are generalizable to a broader patient population: The University of Michigan Transplant Center is a large program, located in a small city, so most of its patients travel long distances (one to eight or more hours by car) for transplant care. In addition, many transplant recipients live in rural communities and are challenged by having to navigate through unfamiliar urban settings, city traffic and the large hospital campus. Both the setting and the experience of transplant care can be unsettling. Much of the efforts of the nurses and social workers focus on collaborating with patients to assist them in navigating the “mechanics” of post-transplant care. However, it must be acknowledged that, even with support, success and survival require tremendous effort and commitment on the part of recipients who exhibit a range of understanding, coping styles, capabilities, energy and commitment.

Additionally, despite being provided the eligibility criteria for the study, the providers’ view of a typical patient may not have aligned precisely with this study sample, resulting in them rating a more or less healthy population than the one that was surveyed. In addition, asking providers to rate a “typical” patient may have resulted in less variation in provider responses compared to patient responses. We intend to conduct a follow-up paired comparison of healthcare provider perceptions of each of their individual patient’s goals, expectations, and experiences (rather than to an aggregate typical patient).
Furthermore, given the small sample sizes within each provider type, we were limited in our ability to distinguish potential differences in expectations among the various types of providers that interact with transplant patients. However, our preliminary analysis revealed few differences in responses by provider type. Given that patients have substantial interaction with many types of healthcare providers as part of their coordinated care, the inclusion of a variety of provider types is a strength of our study that was lacking in previous literature.\textsuperscript{6,7,9–11} Finally, while prior studies typically focused on patient expectations within one year of transplant,\textsuperscript{3,7–9,11} we included a broader range of patients in our study. This is a potential limitation since patient goals, expectations, and experiences may change over time, leading to greater heterogeneity in the responses from our study when compared to prior investigations. Future data analysis to investigate potential associations between patient expectations and time since transplant are underway.

4.2 Conclusion

This study assessed the degree of concurrence in patient and provider perceptions of kidney recipient post-transplant goals, expectations and experiences across several areas and found significant differences. Patients expressed higher quality of life (mean Neuro-QOL T-score 60.2 vs. 52.7), were less likely to report that they were currently experiencing complications (11% vs. 24%), and anticipated their transplants to last longer (median 25 vs. 15 years) and to live longer (median 80 vs. 71 years) than providers expected for their typical patient. However, provider perceptions of patients’ future ability to feel well, perform daily activities and work were significantly higher than those expressed by patients (all p<0.05).

4.3 Practice Implications
Patients may alter their adherence to medical treatment if they perceive themselves to be healthier than they are or experience psychological distress if their health outcomes do not meet their expectations. Thus, it is important for healthcare providers to be aware of patient goals, expectations, and experiences regarding post-transplant care, and to tailor care or engage in discussions relative to such elements. Additionally, it is important that patients have an accurate understanding of post-transplant outcomes they can expect so that they can make informed decisions about their health management and plan appropriately. This study provides hypothesis generating data to guide future work in aligning patient and provider goals and expectations that could lead to improvements in post-transplant care.

We confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

**Author Contributions:**

KLM, HS, PHC, SJG, MSD, RMM, and ABL designed the study and oversaw execution of the study protocol. SJG conducted pilot testing including focus groups and cognitive interviews. Data were collected by KLM, HS, SMC, and EG. Statistical analyses were performed by ARS. The manuscript was developed and written by KLM, ARS, ELT, PHC, SJG, MSD, RMM, and ABL. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions
pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved. KLM and ABL take responsibility for ensuring that this study has been reported honestly, accurately, and transparently; that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained.

**Declarations of interest:** none

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**References**


UM kidney transplant recipients with clinic appointments scheduled between 3/23/2015 and 10/1/2015 who met initial eligibility screening n=1126

Not approached/Canceled appointment/Missed appointment n=371

Approached for survey n=755

Not surveyed (Total=255)
  - Screen error (n=25)
  - Declined to participate (n=230)

Completed survey n=500

Found ineligible post-survey (Total=24)
  - Under 18 at transplant (n=4)
  - Not transplanted at UM (n=20)

Survey analyzed n=476

UM kidney transplant providers who met initial eligibility screening and were approached for survey n=99

Declined to participate n=17

Completed survey n=82

Found ineligible post-survey (Total=10)
  - No direct patient interaction (n=8)
  - Unable to determine eligibility (n=2)

Survey analyzed n=72

a) Patient STROBE diagram

b) Provider STROBE diagram

Figure 1: STROBE diagram
a) Healthcare relationships and management of health

Percentages of importance endorsement were out of the total number of responses to each question, which ranged from 67 to 71 for providers and 456 to 469 for patients, with the exception of questions regarding healthcare relationships with providers other than a University of Michigan nephrologist, which ranged from 343 to 404. Non-response to these questions was likely due to the questions not applying to patients if they did not have relationships with these provider types.

<table>
<thead>
<tr>
<th>% Provider Endorsed</th>
<th>% Patient Endorsed</th>
<th>p-value</th>
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<tr>
<td>95%</td>
<td>99%</td>
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<tr>
<td>84%</td>
<td>78%</td>
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<td>87%</td>
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</table>

Greater provider endorsement Greater patient endorsement

b) Health outcomes, current health, and medication adherence

Percentages of endorsement were out of the total number of responses to each question, which ranged from 66 to 70 for providers and 451 to 470 for patients, with the exception of questions regarding bone disease and diabetes, which were only answered by 277 and 276 patients, respectively.

![Figure 2: Rating importance of healthcare relationships and management of health](image-url)
a) Life and graft expectancy
Boxplots showing the distribution of age expected to live and years transplanted kidney expected to function by response type with p-values from t-tests

b) Neuro-QOL Positive Affect and Well-being responses
Boxplots showing the distribution of raw scores and T-scores for the Neuro-QOL Positive Affect and Well-being scale by response type with p-values from t-tests; t-scores are referenced to the US general population (mean=50, SD=10)

Figure 3: Box plot distributions by responder type
Table 1: Survey Participant and Population Demographics for Kidney Transplant Recipients

<table>
<thead>
<tr>
<th></th>
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<th>Eligible UM Kidney Transplant Patient Population* (n=1539)</th>
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<td>Age at Transplant</td>
<td>48.7 (13.4)</td>
<td>46.3 (13.7)</td>
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<td>White</td>
<td>77% (362)</td>
<td>76% (1141)</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>18% (85)</td>
<td>18% (267)</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>2% (11)</td>
<td>2% (32)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>3% (13)</td>
<td>4% (56)</td>
<td></td>
</tr>
<tr>
<td>Ethnicityβ</td>
<td></td>
<td></td>
<td>0.63</td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>97% (437)</td>
<td>96% (1158)</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>3% (15)</td>
<td>4% (46)</td>
<td></td>
</tr>
<tr>
<td>Donor Type¥</td>
<td></td>
<td></td>
<td>0.01</td>
</tr>
<tr>
<td>Living Related</td>
<td>29% (139)</td>
<td>32% (488)</td>
<td></td>
</tr>
<tr>
<td>Living Unrelated</td>
<td>29% (140)</td>
<td>23% (348)</td>
<td></td>
</tr>
<tr>
<td>Deceased</td>
<td>41% (197)</td>
<td>46% (703)</td>
<td></td>
</tr>
<tr>
<td>Years Post-transplant</td>
<td>5 (Median)</td>
<td>8 (Median)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>&lt;36 months post-transplant</td>
<td>32% (154)</td>
<td>20% (305)</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

*Excludes patient study participants
*Eligibility criteria: Single kidney transplant recipients at least 18 years old at transplant, transplanted on or before 10/1/2015 at UM alive without graft loss as of 10/1/15, and with no other transplants
δp-value from Chi-square, or t-test
βMissing 5% for study participants and 22% for eligible UM population; All other variables missing <5%
¥p=0.1 for living donor vs. deceased donor
Table 2: Provider Demographics

<table>
<thead>
<tr>
<th>Gender</th>
<th>N or Median</th>
<th>Percent or Interquartile Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>21</td>
<td>31.8%</td>
</tr>
<tr>
<td>Female</td>
<td>45</td>
<td>68.2%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age</th>
<th>N or Median</th>
<th>Percent or Interquartile Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>20-29</td>
<td>10</td>
<td>15.6%</td>
</tr>
<tr>
<td>30-39</td>
<td>16</td>
<td>25.0%</td>
</tr>
<tr>
<td>40-49</td>
<td>17</td>
<td>26.6%</td>
</tr>
<tr>
<td>50-59</td>
<td>18</td>
<td>28.1%</td>
</tr>
<tr>
<td>60-69</td>
<td>3</td>
<td>4.7%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Provider Role</th>
<th>N or Median</th>
<th>Percent or Interquartile Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nephrologist</td>
<td>8</td>
<td>11.1%</td>
</tr>
<tr>
<td>Surgeon</td>
<td>8</td>
<td>11.1%</td>
</tr>
<tr>
<td>Midlevel Provider</td>
<td>10</td>
<td>13.9%</td>
</tr>
<tr>
<td>Nurse</td>
<td>17</td>
<td>23.6%</td>
</tr>
<tr>
<td>Financial Counselor</td>
<td>9</td>
<td>12.5%</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>8</td>
<td>11.1%</td>
</tr>
<tr>
<td>Social Worker</td>
<td>6</td>
<td>8.3%</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>8.3%</td>
</tr>
<tr>
<td>Years worked as transplant healthcare provider</td>
<td>7</td>
<td>3-14</td>
</tr>
</tbody>
</table>

*Missing for n=6 providers
*Missing for n=8 providers
*Missing for n=14 providers