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# Perspectives on Quality of Care in Kidney Transplantation: A Semistructured Interview Study

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**Background.** There is currently no agreement as to what constitutes quality transplant care, and there is a lack of consistency in the approach to assessing transplantation quality. We aimed to ascertain the views of patients, clinicians, and program administrators about quality care for kidney transplant patients. **Methods.** Semistructured qualitative interviews were conducted with 20 patients, 17 physicians, and 11 program administrators. Transcripts were analyzed using inductive thematic analysis. **Results.** We identified 8 themes: access to treatment (standardized transplant referral, lengthy transplant evaluation process, lengthy living donor evaluation); accessibility of services (alternative access options, flexible appointment availability, appropriate amount of follow-up, barriers for accessing care); program resources (comprehensive multidisciplinary care, knowledgeable staff, peer support groups, educational resources, patient navigators/ advocates); communication of information (taking time to answer questions, clear communication about treatment, communication tailored to patients, health promotion and illness prevention); attitude of care providers (positive and supportive attitude, patient centered care); health outcomes (freedom from dialysis, Long-term health, short-term health, fear of infections); patient satisfaction (returning to normal life, patient satisfaction with care); and safety (reducing infection risk, quick response to complications, patient health status on the waitlist). **Conclusions.** There is a need to move beyond basic clinical outcomes and focus on increasing ease of access, the patient-provider relationship, and outcomes that are most important to the patients.

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The global prevalence of chronic kidney disease is estimated to be between 11% and 13% of the population,<sup>1</sup> and once this disease progresses to end-stage kidney disease, transplantation is the preferred treatment since it improves quality of life, prolongs survival and is less costly compared with dialysis.<sup>2-4</sup> Significant improvements have been made in survival after kidney transplantation; however, the process is far from optimal, and improvements are still needed to improve the patient experience and quality of life outcomes. In addition, we currently do not know the best approach for determining whether a transplant program is delivering

high-quality, safe care.<sup>5-8</sup> A recent systematic review found no agreement as to what constitutes quality transplant care, and there is a lack of consistency in the approach to assessing transplantation quality.<sup>9</sup> As such, we conducted semistructured interviews with key stakeholders (patients, clinicians, and program administrators) to ascertain their perspectives of quality transplant care.

## MATERIALS AND METHODS

### Design

We used the Consolidated Criteria for Reporting Qualitative Health Research to guide the writing of this article.<sup>10</sup>

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G.K. contributed to the research idea, study design, drafting the interview questions, and article drafting and revision. K.B. contributed to the study design, drafting the interview questions, data acquisition, data analysis and interpretation, and article drafting and revision. E.E. contributed to data analysis and interpretation, and revision of the article. J.G. contributed to the research idea and revision of the article.

Semistructured qualitative interviews were conducted with key informants on quality of care for kidney transplantation using an interview guide (SDC, <http://links.lww.com/TXD/A123> **Materials and Methods 1**). The guide was developed from a literature review and was pilot tested with 2 clinicians before the study. This study received research ethics board approval (OHSN-REB protocol ID 20150796-01H), and consent was obtained from all participants. K.B., a research associate with no previous relationship with the participants, conducted the interviews between July and December 2016. Interviews were conducted in person in a private room or on the phone in a private office. All interviews were audio-recorded with participant consent, and notes were made during the interviews.

### Recruitment

Eligible participants were men and women aged 18 years or older who fit into 1 or more of the categories of key informants: (1) patients who have had (or waiting to have) a kidney transplant; (2) clinicians who work with kidney transplant patients (physicians, nurses); and (3) program administrators (senior staff working at hospitals or organ donation/transplant organizations). Patients were identified through convenience sampling by a transplant nurse at The Ottawa Hospital Renal Transplant Clinic. Interested patients provided written consent to be contacted by the research coordinator, who contacted them by phone or email to consent them into the study. Although our intent was to include some patients waiting for a transplant, our final sample included only posttransplant patients. Clinicians and program administrators were recruited through a targeted email across Canada, requesting that interested participants contact the research coordinator. Participants were offered a US \$30 gift card to a coffee shop or a bookstore at the end of the interview in recognition of their time for participating.

### Data Analysis and Synthesis

Interviews were transcribed verbatim by a qualified professional and checked for accuracy by KB and EE. Interviews were imported into NVivo version 11 (QSR international) to facilitate qualitative data analysis. Before coding, KB read each transcript and selected the key sections of text (utterances) that reflected the context of the interviews and captured the meaningful concepts. Utterances were used to ensure consistent sections of the text were coded by both analysts.<sup>11</sup> Two team members (K.B. and E.E.) independently coded the transcripts using inductive thematic analysis,<sup>12</sup> whereby the data were used to guide the development of the coding scheme rather than trying to fit the data into a preexisting framework. The coding started with the analysts familiarizing themselves with the data by reading through the entire data set at least once. Next, the analysts read the first 4 transcripts line by line and coded all utterances, after which the analysts met to determine a coding scheme (comprised of codes, definitions of the codes, and examples of quotations) by consensus, which was then used to analyze the remaining the transcripts. A separate coding scheme was developed for the patient transcripts, and the clinician and program administrator transcripts. After every 3 or 4 transcripts were coded, the analysts met to review their coding and seek consensus. Coder reliability was assessed using the function on NVivo; if the interrater agreement was less than 75%, the rationale behind the coding

selection was discussed until a consensus was reached. Codes were modified and new codes were added as needed. A log was kept to ensure that each code remained consistent and to establish a decision trail that could be reviewed if necessary. The data were coded for as many potential concepts as possible, and utterances were coded into as many different concepts that they fit into. The coded data were then grouped into similar themes and subthemes by KB, which was reviewed by E.E., and feedback was incorporated into results. In addition, we collected potential quality metrics that discussed within the context of each theme. The subthemes and metrics were categorized into the 6 domains of healthcare quality: access, equitable, patient-centered, efficiency, safety, and effectiveness.<sup>13,14</sup>

## RESULTS

### Sample Characteristics

Twenty patients, 17 physicians, and 11 program administrators participated in the study. One of the program administrators was also a clinician, and 9 of the clinicians also had major administrative roles within their organizations. All patients were kidney transplant recipients (50% had received living donor kidneys) and were a median of 5 years posttransplant (range, 6 months to 20 years). For those patients who received a deceased donor transplant, the median waiting time to their transplant (as reported by the patient) was 1.5 years (range, 10 days to 3 years). The physicians had been working in nephrology or transplantation for a median of 16 years (range, 5-40 years). The program administrators had a median of 8.5 years of experience (range, 0.5-26 years). For simplicity, physicians and program administrators will be referred to as health professionals (HPs). Health professionals were from the following provinces: Alberta (n = 7), British Columbia (n = 2), Manitoba (n = 1), Newfoundland (n = 1), Nova Scotia (n = 3), Ontario (n = 11), Quebec (n = 1), and Saskatchewan (n = 2), and types of centers: general hospitals (n = 2), teaching hospitals (n = 21), and organ and tissue donation agencies (n = 5). Interviews were on average 27 minutes (range, 13-44 minutes), 2 interviews were conducted face-to-face, and the rest were conducted on the phone.

### Themes

We identified 8 major themes: (1) access to treatment, (2) accessibility of services, (3) program resources, (4) communication of information, (5) attitude of care providers, (6) health outcomes, (7) patient satisfaction, and (8) safety (Appendix). Potential quality metrics that were discussed within the themes are summarized in Table 1. The healthcare quality domains identified within each subtheme are shown in Figure 1. Additional quotations in support of the subthemes are provided in **Table S1**, <http://links.lww.com/TXD/A123>. Five additional subthemes were identified (see SDC, <http://links.lww.com/TXD/A123> **Materials and Methods 2**) but were not included in the summary of the results because they do not relate to measureable attributes for *individual* transplant programs given that they are inherent issues within the field of transplantation and could not be addressed at the program level.

**TABLE 1.**

**Proposed metrics by theme**

	<b>Access</b>	<b>Effectiveness</b>	<b>Efficiency</b>	<b>Equitable</b>	<b>Patient-Centered</b>
Access to treatment	<ul style="list-style-type: none"> <li>Are patients referred for transplant evaluation in a timely manner?</li> <li>-Time from referral to final disposition, and to various stages of the workup</li> <li>-Necessary testing available at centers?</li> <li>-Time from registration to testing, from testing to clinical visit, from clinic visit to approval, approval to donation</li> <li>-Wait time for consultation with specialist, and evaluation tests</li> </ul>	<ul style="list-style-type: none"> <li>-Donor survival</li> <li>-Donor short or long-term comorbidities</li> </ul>	<ul style="list-style-type: none"> <li>-Transplant eligibility evaluation completed in a timely manner?</li> <li>-Are fast-track spots available for diagnostic imaging?</li> <li>-Lost preemptive transplant opportunities</li> <li>-Cost of donor evaluation</li> <li>-Donors who starts the process, and completes it?</li> <li>-Rates of lost donors</li> </ul>	<ul style="list-style-type: none"> <li>-Are all potentially eligible patients referred for transplant evaluation?</li> </ul>	<ul style="list-style-type: none"> <li>-Out of pocket expenses for donor</li> </ul>
Accessibility of services	<ul style="list-style-type: none"> <li>-Are satellite clinics available in more remote areas?</li> <li>-Do the clinics offer flexibility with booking appointments? (Days, times, last minute)</li> <li>-Can patients be seen by family doctors rather than their specialist?</li> </ul>	<ul style="list-style-type: none"> <li>-Is follow-up provided in accordance with patient needs? (appropriate amount)</li> <li>-frequency of follow up?</li> </ul>	<ul style="list-style-type: none"> <li>-Are older, sicker, or highly sensitized patients eligible for transplants?</li> <li>-Does access differ across race, cultures, language?</li> </ul>	<ul style="list-style-type: none"> <li>-Can technology be used to communicate with patients who live far from the clinic?</li> <li>-Are care providers available to answer questions on the phone?</li> <li>-Are missed appointments tracked and rebooked?</li> <li>-Do patients feel they have enough time with the doctor at each visit?</li> </ul>	<ul style="list-style-type: none"> <li>-Patient-Centered</li> </ul>
Program resources	<ul style="list-style-type: none"> <li>-Can a patient see multiple healthcare providers in one visit to the clinic?</li> <li>-Is peer counseling available?</li> <li>-Are preemptive transplants promoted?</li> </ul>	<ul style="list-style-type: none"> <li>-Access to: Pharmacists, physiotherapy, dietitian, social worker, psychologist, etc.</li> <li>-Appropriate ratio of staff to patients?</li> <li>-Are information sessions available?</li> </ul>	<ul style="list-style-type: none"> <li>-Are programs meeting proper target hours of care per day?</li> <li>-Patients understand the information provided to them?</li> </ul>	<ul style="list-style-type: none"> <li>-Are peer support groups, patient navigators/ advocates available?</li> <li>-Are patients happy with the quality or quantity of information?</li> <li>-Support to help patients ask for living donors?</li> </ul>	<ul style="list-style-type: none"> <li>-Are staff adequately trained for working in transplant?</li> </ul>
Communication of information	<ul style="list-style-type: none"> <li>-Is there a protocol for explaining the process to patients?</li> </ul>	<ul style="list-style-type: none"> <li>-Do patients feel that they had all of their questions answered?</li> <li>-Do patients understand the steps in the process? The risks and benefits?</li> <li>-Are expectations of the treatment outlined?</li> <li>-Do patients feel the information is communicated clearly?</li> <li>-Do patients understand the information they receive?</li> </ul>	<ul style="list-style-type: none"> <li>-Do patients feel they had all of their questions answered?</li> <li>-Do patients understand the risks and benefits?</li> <li>-Are expectations of the treatment outlined?</li> <li>-Do patients feel the information is communicated clearly?</li> <li>-Do patients understand the information they receive?</li> </ul>	<ul style="list-style-type: none"> <li>-Do staff regularly remind patients how to avoid complications?</li> </ul>	<ul style="list-style-type: none"> <li>-Safety</li> </ul>

*(Continued on next page)*

**TABLE 1. (Continued)**

	<b>Access</b>	<b>Effectiveness</b>	<b>Efficiency</b>	<b>Equitable</b>	<b>Patient-Centered</b>
Attitude of care providers	-Can patients speak to the doctor 1-on-1?		<b>Patient-centered</b> -Do patients feel that they are treated with dignity? -Do patients feel that the staff are supportive and friendly? -Are patients satisfied with care? -Do patients feel supported and engaged in their care? -Are doctors treating the whole person?		
Health outcomes		<b>Effectiveness</b> -Graft survival, patient survival, graft rejection -Early hospital readmission; 1 year Hospital readmission; DVT, pulmonary embolisms, cardiovascular disease, bone problems, cancer, diabetes, diarrhea -In-hospital morbidity, length of stay, delayed graft function; Medication errors; Acute rejection; Surgical Complications; Infection rates		<b>Safety</b> -Incidence of hospital acquired infections? -Rate of wound infection? -Rate of posttransplant viruses or infections?	
Patient satisfaction		<b>Effectiveness</b> -Symptom burden -Have patients regained energy	<b>Patient-centered</b> -Quality of life -How intrusive is posttransplant care? -Able to resume previous activities? Work, travelling, school, social activities, exercise, etc. -Patient experience and satisfaction with: thoroughness of care; provider level of expertise; organization of clinics; education, communication -Complaints		
Safety		<b>Access</b> -Is there a separate blood lab for transplant patients? -Are patients notified immediately if there is a problem with their blood work?	<b>Effectiveness</b> -Health status of patients on the waitlist	<b>Safety</b> -Do patients have a private room? -Do staff follow the protocols for interacting with transplant patients? -Are rooms cleaned frequently? -If complications are identified, how quickly is the problem fixed? -Waitlist mortality -Withdrawals from the waitlist and reasons	

		Access	Effectiveness	Efficiency	Equitable	Patient-Centered	Safety
Access to Treatment	Standardized transplant referral	✓			✓		
	Lengthy transplant evaluation process	✓		✓			
	Lengthy living donor evaluation	✓	✓	✓		✓	
Accessibility of Services	Alternative access options	✓				✓	
	Flexible appointment availability	✓				✓	
	Appropriate Amount of Follow-up	✓		✓		✓	
	Barriers for accessing care				✓		
Program Resources	Comprehensive multidisciplinary care	✓	✓				
	Knowledgeable staff		✓	✓			✓
	Peer support groups	✓				✓	
	Educational resources		✓	✓		✓	
	Patient navigators/advocates	✓				✓	
Communications of Information	Taking time to answer questions					✓	
	Clear communication about treatment		✓			✓	
	Communication tailored to patients				✓	✓	
	Health promotion and illness prevention						✓
Attitude of Care Providers	Positive and supportive attitude					✓	
	Patient centered care	✓				✓	
Health Outcomes	Freedom from dialysis		✓			✓	
	Long term health		✓				
	Short term health		✓				
	Fear of infections						✓
Patient Satisfaction	Returning to normal life		✓			✓	
	Patient satisfaction with care					✓	
Safety	Reducing infection risk	✓					✓
	Quick response to complications	✓					✓
	Patient health status on the wait list		✓				✓

FIGURE 1. Healthcare quality domain within each subtheme.

## Access to Treatment

*Standardized transplant referral:* HPs remarked that there was no standardization as to when patients should be referred for transplant evaluation, which may influence the time it takes for a patient to receive a transplant, or result in lost opportunities for preemptive transplants. Disparities exist between dialysis centers, and possibly between provinces, with regards to when physicians discuss the option of transplant with patients. *Lengthy transplant evaluation process:* Patients were frustrated with the length of time for the transplant eligibility evaluation process. Although they recognize that external factors contribute to the wait times, they still found the process “scary.” Health professionals found the transplant evaluation process to be time-consuming and “onerous” at some centers; whereas others felt that their programs had efficient systems to facilitate the work up (ie, fast-track spots in diagnostic imaging). *Lengthy living donor evaluation:* Patients and HPs expressed frustration with the prolonged process for evaluating potential living donors. Donors often incur unnecessary costs during this process, and it is a “burden for the donor and sometimes they don’t continue on to donate as a result.”

## Accessibility of Services

*Alternative access options:* Accessing care in-person at transplant centers was not always feasible, and it was important for patients to have alternative access options, such as Telehealth communication. Patients who live outside of major urban centers value having blood work done at local facilities rather than traveling to transplant centers. Health professionals also felt that satellite clinics were better able to accommodate patients who lived far away. Patients and HPs both expressed value in the ability to call the clinic and speak directly to a care provider when questions arose. *Flexible appointment availability:* Flexibility in clinic schedules helped patients maintain a sense of autonomy, while HPs felt that offering clinic appointments 7 days a week could help improve access for patients, while maximizing resource use. The ability to make appointments at the last minute eased feelings of worry for patients, and HPs recognized the benefit of seeing patients in real time, rather waiting extended periods of time to book appointments or reschedule missed appointments. *Appropriate amount of follow-up:* Patients appreciated the extensive posttransplant follow-up that they received, and having adequate time with the clinicians at these appointments. However, some patients questioned whether such thorough follow up with the nephrologist was always necessary, particularly if they are not experiencing any problems. Health professionals felt that the best care model has yet to be determined (eg, visit frequency, type of provider), although it is assumed that more follow-up translates into better outcomes. *Barriers for accessing care:* Barriers to accessing transplantation identified by HPs include the center’s eligibility criteria/level of risk tolerance (eg, comorbidities, highly sensitized patients, age), as well as patient socioeconomic status, culture, and health literacy. For patients, it was important to be able to communicate with providers in their own language, and they were concerned that new arrivals to Canada, or those unable to speak English or French would be overwhelmed by the process.

## Program Resources

*Comprehensive multidisciplinary care:* Having multidisciplinary care available within the transplant program gave patients a sense of well-coordinated, excellent care. However, some patients spoke of the need for additional resources for the emotional/psychosocial side of care. Health professionals also praised the multidisciplinary care approach; a program that treats the whole patient, and not just the kidney by having direct access within the clinic to various allied health professionals (eg, dietitians, social workers, and psychologists). *Knowledgeable staff:* Both patients and HPs recognized the importance of having nurses and physicians that are formally trained in and experienced in working with transplant patients. One HP remarked that housing their patients outside the transplant unit led to a drop in the quality of care. Having an adequate number of staff to serve the volume of patients was also noted by HPs. *Peer support groups:* It was important for patients to be able to speak with other transplant patients, to gain insight and address concerns which cannot be addressed by clinicians. Health professionals thought that peer support groups allowed patients to connect with people in similar situations, and provided someone else for patients to “reach out to”. *Educational resources:* HPs spoke to the value of providing extensive education to the patients and their families, before and after the transplant, using both in-person education sessions and reading material. While patients appreciated the reading materials they were provided, 1 patient expressed that a potential downside is that there is no guarantee that the patients would read the information, or whether they understood what was read. Patients offered the highest praise for the group information sessions where the different disciplines spoke, and patients were given the opportunity to ask questions. *Patient navigators/advocates:* An area identified as lacking was the availability of patient navigators or advocates. Health professionals felt that having someone help patients navigate the healthcare system would facilitate getting patients on the waiting list. One patient explained how they had to advocate for their own care, and worried that other patients might experience difficulties in doing so. In addition, patient advocates could help patients approach and engage potential living donors.

## Communication of Information

*Taking time to answer questions:* The staff’s willingness and ability to answer all of their questions was important to patients. Having “no questions unanswered” made patients more comfortable with the process, and left lasting positive impressions. *Clear communication about treatment:* Patients felt well informed going into the transplant; their treatment options, the plan of treatment, and the aftercare were all well explained, and they appreciated that there were no surprises. In contrast, HPs felt that there needs to be better communication of the risks and benefits of the different treatment options, as many patients do not fully understand the process of a kidney transplantation. Health professionals reflected on the need to reduce unrealistic expectations about transplant; setting clear, realistic outcomes for this treatment could help patients cope posttransplant. *Communication tailored to patients:* HPs need to be aware that there is sometimes a disconnect between what is said and what the patient understands. The information and communication style needs

to be tailored to specific cultures, languages, and education levels to ensure that patients and their families grasp the information properly. *Health promotion and illness prevention:* Patients noted that the clinic staff is vigilant about reminding patients to wear sunscreen, drink enough fluid, and to avoid people who are unwell, among other good behaviors needed to help prevent complications and promote a healthy lifestyle posttransplant.

### Attitude of Care Providers

*Positive and supportive attitude:* The patients felt that the staff “really care” about them, and valued the staff’s positive and supportive care. Patients mentioned numerous positive traits of the providers, including: caring, willingness to listen, nice, helpful, attentive, supportive, compassionate, friendly, positive, good bedside manner, sympathetic, encouraging, patience, concern, accessible, and understanding. *Patient-centered care:* For the patients, high quality care encompassed being treated as a whole person; good bedside manner; a more personal approach to care; and receiving 1-on-1 care from the doctor. For HPs, it is important that patients maintain a sense of autonomy, and are engaged in their healthcare decisions over the course of their treatment.

### Health Outcomes

*Freedom from dialysis:* For patients, the most important outcome was receiving a well-matched kidney; one that works, lasts a long time, and ultimately keeps them from returning to dialysis. Patients want longevity out of the graft, with some patients hoping for the graft to last 25 years. Health professionals recognized that the most important outcome from the patient’s perspective was freedom from dialysis. However, given the high rates of success, they admitted that it is important to look beyond graft and patient survival for other worthy measures of quality. *Long-term health:* In addition to patient and graft survival, HPs also considered other outcomes, such as readmission rates, cardiovascular disease, malignancies, and infections, to be important. In contrast, it was noted that patients are so focused on their transplant, that they are not concerned about cardiovascular disease, even though it is the leading cause of death for these patients. *Short-term health:* HPs thought that short-term metrics which provide more immediate feedback (eg, surgical complications, length of stay, etc.) can help programs ensure that their processes are improving. Although other short-term outcomes, such as acute rejection, may also reflect components of the patient evaluation process or the aggressiveness of the center in case selection. *Fear of infection:* For many patients, their biggest safety concern was the risk of infections, either hospital acquired infections or posttransplant viruses. Health professionals were primarily concerned with infection transmission from the organ to the recipient, but were also concerned with posttransplant viral infections.

### Patient Satisfaction

*Returning to normal life:* For patients, one of the best measures for the success of the transplant is how closely your life “mirrors what you consider to be ideal.” Patients discussed having more energy, and participating in activities such as traveling, working, and exercising. Patients spoke of getting back to a “new normal”; the expectation was not necessarily that they would have an equal quality of life as before, but

that their quality of life would be as close to normal as possible. Health professionals also listed improved quality of life, and “returning to normal” (eg, travelling, going back to work, exercising, having a family, and a liberalized diet and fluid intake) in their definition of a successful transplant. *Patient satisfaction with care:* Although most HPs reported that their institutions were not measuring patient satisfaction, they believed it should be measured. Health professionals were also interested in the patient’s overall experience of their care: whether patients felt prepared, whether they received sufficient education, and whether their expectations were met.

### Safety

A few HPs suggested that there may not be a need for transplant specific safety metrics because established hospital safety metrics may be sufficient. In addition, many HPs mentioned short- and long-term outcomes as potential measures of safety. Nonetheless, 3 safety subthemes emerged from the data. (1) *Reducing infection risk:* Patients appreciated the hospital’s efforts to keep them safe by separating them from other patients through the use of private rooms after surgery and a separate area within the blood lab for their regular follow up tests. Patients were also impressed with the cleanliness of the hospital and thought it was important that the hospital took sanitation and sterilization of the rooms very seriously. Some patients reported needing to intercede when staff did not follow proper protocols for interacting with transplant patients. (2) *Quick response to complications:* Patients appreciated being kept informed about changes to their health, and were impressed when providers were able to quickly identify and respond to complications, such as changes in blood work. (3) *Patient health status on the waitlist:* Some HPs suggested that changes to a patient’s health while on the waitlist could provide valuable information about the quality of care patients are receiving from the program. However, high waitlist mortality rates may indicate that sicker people are being given the opportunity of receiving a transplant, and therefore adjusting for the patient health status is important.

## DISCUSSION

Quality of care is a multifaceted concept. Although transplantation is the best treatment option for patients with kidney failure, the quality of care received by patients may differ depending on their institution. Our study revealed detailed insights into quality of care in transplant programs from the perspectives of patients, clinicians, and program administrators, and numerous themes were identified from which quality indicators can be developed.

Our results suggest that there are still notable barriers for accessing care in a timely manner, particularly in the early stages of the care continuum. Although the scarcity of organs is the main barrier to receiving a transplant, this work highlighted discrepancies with regards to referral and evaluation times, suggesting the need to establish benchmarks for these processes. Furthermore, our study indicates that the convenience of care is a key element of accessibility. Patients desire care that is as minimally disruptive to their lives as possible with ready access to care providers by telecommunications and/or local clinics for routine follow-up. Creating quality standards for transplant programs with regard to how patients access care providers would allow for the use of structure and process

metrics to evaluate whether programs are providing care that is minimally intrusive to their patients.

The interpersonal interactions between care providers and patients emerged as essential to quality transplant care. Prime examples of these important interactions include clear communication of care plans, communicating at an appropriate level for their patients, and having sufficient time to answer questions. Whether patients are given information that is tailored to meet their needs and delivered at appropriate times in the care continuum could be monitored through a combination of process metrics (eg, patients are provided with written and verbal discharge instructions) and patient-reported experience measures (PREMs) (eg, do the patient's feel that information was communicated clearly). Indeed, patient-centered and access were the 2 quality domains that were identified the most frequently within the subthemes.

We found that the availability of a wide range of resources was crucial for a quality transplant program. Comprehensive multidisciplinary care that was structured to provide easy access to allied health professionals was highly valued. Other important resources for quality transplant care included peer support groups, patient navigators, experienced care providers, and sufficient educational materials. Structure indicators (eg, the availability of dieticians or education sessions) and process indicators (eg, the percentage of patients who were given the option of speaking with a pharmacist at every follow-up visit) could be developed to help ensure that programs are meeting benchmarks for care.

Our interviews identified other components of high-quality care that would best be measured using patient-reported outcome measures (PROMs) or PREMs, such as the supportive environment provided by the staff. However, there are many challenges associated with measuring PROMs and PREMs, including the need for properly translated and validated tools, the feasibility of the instrument, staff training in collecting the data, and the financial burden of data collection and analysis.<sup>15</sup> Standardized PROMs and PREMs have yet to be established for kidney transplantation, however, a consensus meeting on instruments for renal registries recommends the following PROMs: the SF-12 and the EQ-5D-5L as generic instruments, and the Kidney Disease Quality of Life Instrument (KDQOL)-36 for disease-specific outcomes.<sup>15-18</sup> Furthermore, a systematic review found strong evidence supporting the KDQOL-36 for predialysis patients; moderate and strong evidence for the KDQOL-36 and KDQOL-short form for dialysis patients; and strong evidence for the End Stage Renal Disease-Symptom Checklist Transplantation Module in transplant recipients.<sup>19</sup>

In our results, patient experience was a key attribute of quality, which differs substantially from published quality indicators for chronic kidney disease<sup>20</sup> and dialysis facilities.<sup>21,22</sup> The quality indicators used in chronic kidney disease have focused on screening and diagnostic measures, treatment targets, and process metrics.<sup>20</sup> Meanwhile, the measures of quality for dialysis facilities focus mainly on clinical performance measures (clinical outcomes, treatment targets, and process metrics) and the facility's reporting of these measures.<sup>21,22</sup> Reporting PROMs and PREMs alongside patient survival and laboratory values would provide the best assessment of overall quality of care of a transplant program, and is the driving force behind Nissenon's patient-focused "quality pyramid" for kidney failure.<sup>23</sup> The foundation

of the pyramid captures biochemical data (eg, hemoglobin), followed by intermediate clinical outcomes (eg, fluid management), measures of effectiveness (mortality, hospitalization, and patient experience), and at the top is health related quality of life.<sup>23</sup> The quality indicators currently used for dialysis facilities<sup>21,22</sup> and chronic kidney disease<sup>20</sup> align well with the bottom 2 layers of the pyramid, meanwhile, a number of the themes identified in this study represent the top 2 tiers of this quality paradigm. Incorporating metrics from all levels of the quality pyramid will likely represent the best way to monitor real-time program performance.

The strengths of this study are its exploration of quality of care for kidney transplant patients across a broad range of perspectives, including patients, physicians, and program administrators. The physicians and program administrators were recruited from across Canada and encompassed diverse roles from various institutions. Interviewer training included orientation to the study and practice interviews. The interviews were coded by 2 individuals, and all discrepancies were resolved by a consensus discussion between the 2 analysts.

Study limitations relate to the sample. Most of the patients were recruited from 1 center, which may have introduced an element of bias, nonetheless, we feel that a substantial number of topics/ issues were identified and discussed. In addition, all of the patients were transplant recipients (none of the patients was on the waiting list at the time of the study); however, this ensured that the patients had experienced all the different aspects of care from referral to the posttransplant follow-up. The sample did not include any transplant surgeons, which may have contributed to the limited discussion about the quality of the transplant surgery. Finally, we only included Canadian participants, which may reduce the generalizability, however, we feel that most of the elements identified represent important components of quality of care, regardless of the type healthcare system.

In conclusion, quality transplant care is multidimensional and encompasses the structure of the program, clinical care processes, the patient experience, and outcomes that are important to patients. Patients are looking for holistic care that improves the quality of their lives, care that minimizes the burden on their life, and caregivers who treat more than just their disease. The findings of this study suggest that there is a need to move beyond basic clinical information, and focus on increasing ease of access, the patient-provider relationship, and outcomes that are most important to the patients.

## NEXT STEPS

Our goal is to establish a core set of quality metrics for kidney transplantation. These findings, along with the results from our systematic review,<sup>9</sup> will be incorporating into an online modified Delphi study that aims to identify the metrics that are most important to patients and healthcare providers. After the Delphi survey, we will host a to ensure that the metrics identified as important meet the additional criteria for a good measure outlined by Janakiraman and Eker<sup>24</sup>: (i) easy to define and observe; (ii) amenable to change; and (iii) obtainable from existing or easily collected data.

## ACKNOWLEDGMENTS

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**APPENDIX.****Illustrative quotations****Quotations****Access to Treatment**

## Standardized transplant referral:

"I find it I guess my best word is bizarre or perhaps shocking or stunning that at this point we are not automatically providing dialysis patients very early on in fact even before they're on dialysis with information about the opportunity for transplant. I think we could preempt dialysis and we certainly could take a lot of action that would move a patient more quickly to transplant whether it's through living donors or, or deceased donors." (Ad #43)

"I think there are issues around referring physicians and either their knowledge about transplant or willingness to put patients forward for transplant and that's an immediate barrier that really the patient themselves has little control over. And is strictly the luck of the draw as to how they ended up with a particular physician in a particular dialysis unit or dialysis setting. So there's a lack of uniformity there." (Dr #48)

## Lengthy transplant evaluation process:

"Of course, there's always frustrations with the tests but they don't control that, right so they have to, how do I word that, they're at the mercy of all the various departments who conduct all the various tests . . . . So the process can be very lengthy at times." (Pt #9)

"It can't be, the same can't be said for all centers. I know people in different areas who I know one friend of mine waited almost 2 years for her testing to be completed recently which is scary." (Pt #9)

"I think it's, it's just onerous. It's, it's like, you know, there's so many tests that need to be done. The healthcare system for evaluation isn't very patient-centric to be honest. So all these hoops you have to go through to make sure you're eligible to receive a transplant and ultimately be listed." (Dr #40)

"As much as possible we try and coordinate those so that they're not here for many, many days to do that. So we try and book multiple things so it might be a 2-day work-up process. We've actually created what we call a fast track clinic so that we have been designated spots in imaging etc. to help facilitate some of that." (Ad #29)

## Lengthy living donor evaluation:

"And I think it was 18 months from the time we first said "Yes I'll take the transplant." And I had a, I had a brother who was willing to give me a kidney and it still took us 18 months to go, you know, all those different tests and for him and for me and all those things" (Pt #14)

"The people who have potential living donors I think it's usually an issue of the, for us anyway, the work-up period and the fact that they've got to go through so many assessments and they're not easy to coordinate. . . . So if you start a process too early you, you are reassessing people over time. That can be a burden for the donor and sometimes they don't continue on to donate as a result." (Dr #25)

"We also have a lot of barriers for our potential living donors. They're willing, they're healthy, they look like they're going to be a good living donor and we just can't get their testing in a timely fashion"(Dr #32)

"We're also not looking at the total out-of-pocket expenses for the donor because only certain things are covered so we're not really understanding what it costs donors to do this work-up." (Ad #35)

**Accessibility of Services**

## Alternative access options:

"The only thing that I, I did not like it's like because I live in I kind of live in a remote area, so it was about like 2 hours away. But now they have a unit in [small town] . . . I did go to [small town] a bit but if there's any major problems then they sent me to [major city]"(Pt #10)

"Hmm like I said like as far for me I guess the most difficult part is having I'm in [small town] so having my transplant team be so far away is now they do accommodate to me through Telehealth and stuff like that" (Pt #1)

"And any time I've had a problem I've always called the nurses at the transplant unit and they were able to help me." (Pt #10)

"One of the things that we have done is although the southern [province] transplant program is housed in [major city], we actually have a satellite unit, a satellite clinic rather, in [small city] which is about 2 ½ hours away. And so in that satellite clinic I use renal nurses in a predialysis clinic to do sort of like the 5,000 mile tune-ups for transplant patients. And then the major tune-ups for transplant patients are done in [major city]." (Ad #34)

"And I would say perhaps maybe more use of Telemedicine services. Something along those lines so families that are a bit more remote don't have to travel and make the distance to us." (Ad #36)

## Flexible appointment availability:

"To know that some of us are out there trying to hold down jobs even if it is part-time. So scheduling of appointments having that flexibility to choose the day and time that you're able to be seen; knowing that other things matter to you in terms of your general health." (Pt #8)

"Yes like when I it's not even my appointment but I have something worry I call and I want to see them right away. Yeah and they still talk to me" (Pt #20)

" . . . there's key resources Monday to Friday and maybe not as much on the weekend. And so that's something that we've been talking about really looking at a 7-day a week resource structure so that, you know, the key needs of the patient can be met at all times 7 days a week." (Ad #29)

"I think there's lots of important aspects; one is timeliness of care so to be able to see the patients in real time when they are requiring care. So in our program we've set up a daily drop-in transplant clinic to accommodate that."(Dr #33)

"When patient miss any appointment I think like reschedule that appointment will take at least maybe like 3-4 months before anyone can re-see that patient one more time." (Dr #28)

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**APPENDIX. (Continued)**

## Appropriate amount of follow-up:

"A lot of times when I'm there I'm thinking, you know, I don't really need to be here. I feel like I'm wasting the doctor's time." (Pt #15)

"Like to be followed really close and then eventually when things getting better the appointments are more further apart. But in the first few months you're you know what's going on and where you're at and all that stuff" (Pt #6)

"The PRI was nice because they, you didn't feel that you had 10 minutes with the doctor or 20 minutes with the doctor. If you needed 5-10 you were out, if you needed more because you had more questions it would take that time." (Pt #6)

"I don't think we've actually been able to come up with the right amount of posttransplant follow-up that's required. It's hard to really know what the gold standard is." (Ad #27)

"I think different programs have different strategies for how those patients are followed up clinically. Sometimes they sort of remain linked to the transplant program forever versus being decanted back to their primary nephrologist in the community versus a hybrid model. . . . I think as transplant physicians we like to believe that care by ourselves gives you the best outcomes but maybe more frequent care by a less expert physician is better than less frequent care by a transplant physician just because they live a 10-hour drive away." (Dr #32)

## Barriers for accessing care:

"There's some people who don't understand English well. I've, I've seen them in, in the clinic and they're trying to process what, what the doctors are saying. They do have a translator and all that jazz but for some of the people that don't have English as a first language it can be a bit of a trick." (Pt #3)

"Maybe someone wants to move to [major city] to get a transplant. . . . Where patients who can afford to relocate to another center are gonna have access to healthcare that patients who live in [major city] don't. . . . We like to think of ourselves as an equitable system just because you don't get a bill, but we don't have an equitable system because your income, your education absolutely affects your access to care and your potential to change or to and to actually impact your own access to care." (Dr. #32)

"The other element of this is living donation which certainly would facilitate transplantation especially in a preemptive period. But again there are a number of sort of cultural, social, potentially financial and other sort of barriers that seem to—and educational or knowledge base that seem to reduce the likelihood of pursuing those things." (Dr #24)

"The biggest issues would be patients who are complex who are not necessarily obviously the best candidates for transplant many comorbidities. Some centers might feel they're too high risk and I think the biggest barrier then is can they be, get appropriate access to second opinions at other centers that are maybe used to doing more complex or higher risk patients." (Dr #32)

## Program Resources

## Comprehensive multidisciplinary care:

"I mean they, they weren't like robots but they were pretty rigid in their structure about seeing a nurse, seeing a social worker, seeing a dietitian and seeing the doctor all in one visit and all within 15-20 minutes of your appointment. So I found that part of it excellent." (Pt #7)

"There actually isn't a physio program for, for healing which is odd . . . . And really lack of psychosocial support afterward." (Pt #9)

"But for me personally being able, you know, being told maybe you should speak with a dietitian it would be, you know, it would have been that much nicer for me to have that dietitian available to me then and there. You know what I mean?" (Pt #8)

"And I found that very helpful. The dietitians being, being on the same floor.." (Pt 2)

"We focus on the patient to provider care. So when the patient comes into our center they see the physician. They see the pharmacist. They may see the dietitian. They may see a social worker. They may see a psychologist or psychiatrist. We have everybody in the same clinic area and some of the care providers share the same space." (Ad #34)

"I mean sometimes, you know, I struggle with your care team and who does it include and what the focus is. . . . So yes, the access to psychology, you know, social workers, dietitians, pharmacists, the other allied healthcare professionals." (Dr #26)

## Knowledgeable staff:

"Obviously you want the staff to be knowledgeable and experienced in the area because it's kind of a different world from other sickness." (Pt #6)

"I think it is very, it's very important for transplant, posttransplant care to become a specialty. So a specialty for nursing and a specialty obviously it is already for physicians in terms of nephrology." (Ad #41)

"We're fortunate in our center that we have a dedicated transplant unit, staffed by expert personnel who do this as their full-time job taking care of transplant patients. And so that has a huge impact on our, our outcomes and we certainly notice when we have to house our patients somewhere other than in our transplant unit that there's a drop off in quality." (Dr #44)

## Peer support groups:

"The fact that we were able to contact someone that had same disease got the treatment and ask them questions that's more specific to their case. That was another thing that I really liked." (Pt #6)

"And I think the other thing would be, you know, we had a peer support group when I first was going through the dialysis and, you know, going into transplant it was a really, I thought a really good tool. Not that you don't trust your doctors but sometimes it's nice to be able to speak to other patients." (Pt #8)

"And to set up peer networks so that there is some, somebody to reach out to other than directly to the care team if they run into issues posttransplant." (Dr #33)

## Educational resources:

"I did like the pre transplant information sessions right at the outset. That was very good where possible patients, transplant patients and their families were given a rundown of everything that would be happening that was very good." (Pt #2)

"Oh they give you a lot of information. They, it's verbal information they talk to you, you know, they tell you what to do and what not to do. They give you papers of foods, diet, what you're supposed to eat and what you're not supposed to eat" (Pt #5)

"Yeah so for instance if you don't have time to provide one-to-one face-to-face education to a patient then therefore, you know, you have to put them all together in one room. And you have one person doing a teaching session for perhaps 40 people. So to me I think the quality of one-to-one is, is significant it would be different." (Ad #50)

"And then to really have a good package, you know, education package that either they themselves can read in advance that kind of works, takes them through different steps even questionnaires where it would enable them when they first come in for that initial assessment they have some key questions that they can have addressed right away. So that they have a really good understanding before even coming for a work-up." (Ad #29)

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**APPENDIX. (Continued)**

## Patient navigators/advocates:

- "Some people advocated to having a provincial ombudsperson where any patient having difficulty who's not able to successfully navigate solutions within the healthcare system could at least call someone for advice." (Dr #40)
- "I think it's unfamiliarity with how the system works. You know not knowing how to navigate the system. I think patients, you know, patients who do know how to, how to navigate the system get on, get on the list on average more efficiently than patients who, who do not. ... And so, you know, patient navigators become really important in that situation." (Dr #42)
- "I think I fell through the cracks at some point in one of the different parts of the process. And I had to kind of be my own advocate to say "Hey I recall having heard something about having to need a catheter implanted, when can you do that?" ..... So that caused me a little bit of anxiety at a certain point." (Pt #11)
- "I think some jurisdictions I know out West there are people who are put in place to advocate for a potential recipient to obtain a live donor. I think I mean our society people find it difficult to ask family members or relatives or friends to act as a live donor for them. So in that context a lot can be done." (Dr #47)
- "So there's an organ shortage and it's actually very difficult for many people with kidney failure to conceive of the option of the living donation. And to make the request to family members and friends we call it the 'big ask' on how to do that." (Dr #40)

## Communication of Information

## Taking time to answer questions:

- "On the contrary, you know, for every question I had I had a doctor or healthcare professional able and willing to give me an answer that satisfied my need for information. You know, that made a difference to me. I mean that was really important to me." (Pt #11)
- "And then the availability through staff I found was great. If you asked questions like you always get the answers you need. Patients just need to know that they can ask questions any time they, they want." (Pt #9)
- "Like I said we were very well informed both preoperative, during, and postoperative. We never had any questions unanswered." (Pt #7)

## Clear communication about treatment:

- "It was just like there was no surprises when like especially around the transplant. Everything was well explained and I knew exactly what was going to happen before the transplant and after the transplant" (Pt #15)
- "The one thing I really loved with here in [major city] we have a lady, she's I guess the lead transplant facilitator and she set up a meeting with a whole bunch of us. There was about 15 of us in a room where she went over the procedure and that. We had a little, little binder of all the different things and all the different medicines and things we would have and that was like the best meeting ever. It just enlightened me and gave me a whole bunch of information to feel more confident about going through with the transplant." (Pt #3)
- "Like I don't think we have got it right yet. That anybody would choose not to have a preemptive transplant if they could means that we don't do a very good job of explaining to them the real risks of dialysis." (Dr #23)
- "And I, you know, I think a lot of things some patients think that the transplant's gonna solve all their problems but it doesn't, you know, grow their feet back on when they've had amputations and that sorts of things." (Dr #21)
- "I think one of our major initiatives here is to try to reduce unrealistic expectations in the patient population because transplantation is a treatment for renal disease it's not a cure." (Dr #28)

## Communication tailored to patients:

- "So quality of information for patients so our biggest problem—let me just and we actually don't speak in a language that any of the patients understand. So our biggest problem is we think we're telling them things simply and we're not" (Dr #23)
- "And it's not tailored to specific cultures. And it's not tailored to specific education. And I think that, you know, we do a one size fits all and, you know, I don't think it always works. So I think that's one of our biggest failings" (Dr #23)
- "I have found this again I go back to my own personal experience in when family members need care or have to make decisions, they, they need a lot of information and they need it simplified." (Ad #43)

## Health promotion and illness prevention:

- "And I'm struck by the fact that when I had my renal transplant follow-up appointments, you know, when I speak with a nurse well I mean every visit it might be a different nurse, but I would say 7-8 times out of 10 I'll be asked by the nurse you know "Are you remembering to put on sun block every time you go outside?" because as an immunocompromised person I'm more susceptible to skin cancer. And, ... I think argues in favor of the fact that there is a high degree of vigilance paid to patients like me." (Pt #11)
- "But they really, they really ram it into you to be careful of what you do like and who you hang around with. Don't hang around with any people that's got a cold or anything, you know." (Pt #4)
- "But and the nurses were very specific. Make sure like watch for the mosquitoes, cover up your, you know, use lots of lotion and don't go like in the direct sun be careful." (Pt #10)

## Attitude of Care Providers

## Positive and supportive attitude:

- "The people that I had dealing with me showed me a lot of support and compassion toward me." (Pt #1)
- "From my experience the staff have been, you know, were always happy, you know, there's, you know, the doctors and the nurses and the people that you meet are, are always very positive and, and helpful. ... You know the people are, are fun and, and friendly and, you know, upbeat and that makes a big difference in my mind because, of course the, you know, if you go into an atmosphere where it's doom and gloom and, you know, everyone's grumpy then you automatically take that." (Pt #16)

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**APPENDIX. (Continued)**

## Patient centered care:

"Bedside manner so just the way that that medical staff treat their patients. I think that's probably the most important thing for me. Because I can have, you know, the best doctors in the world but if they don't know how to talk to me and if I don't feel like I'm being treated like a person then I don't respond to it well I guess." (Pt #17)

"Hmm I don't know I mean I think, you know, anybody having a transplant that's certainly a big part of your life and I think as long as, you know, the, the people that are providing the care in that regard in terms of your kidney see you as a whole person, right." (Pt #8)

"And we let the patient quite active in any kind of life decision and let them know that they are the main team player in the patient care." (Dr #28)

"So, more involved, you know, more involving the patient in, in their care plan and and in their, in self, you know, with regards to their own management. (Dr #42)

## Health Outcomes

## Freedom from dialysis:

"Obviously one that's not rejected but that has some longevity to it. Like it's not something that lasts a year that it's, it is a long-term plan and that it works for that length of time." (Pt #17)

"But to me it's a trade-off, right. It's still better than dialysis. You know I have to put up with getting sicker, more frequently, but I'm not on dialysis which is great." (Pt #18)

"If you can go on with life and not go back on dialysis, you know, whether it's one more year or 20 more years that's success." (Ad #43)

"And what was the most important thing was their, you know, not going back to dialysis. So graft survival was the most important thing. And I think well from my experience they really underestimate all the other complications they are really graft centered." (Dr #22)

"And I think especially in an era where graft survival and rejection rates are low we need to look elsewhere to understand whether in addition to producing these quantitative benefits in terms of graft outcome we are also delivering on the, on the quality metrics that patients are perhaps more interested in." (Dr #44)

## Long-term health:

"Well, you know, they're well our research project was looking at, you know, their perspective on cardiovascular disease. And it was really not a priority for them even though it's what; it's the principal cause of death for these patients. But, you know, the most important thing was the functioning of their graft." (Dr #22)

"And then posttransplant so, you know, immuno suppressants, your monitoring and evaluation of your graft function. Your, you know, your rejection, getting back to the community. Who's following you as far as posttransplant, if it's transplant center specifically or is it, you know, you're out in a community that doesn't have the same level of expertise" (Ad #30)

"Readmission within the first month after transplant is a very important quality metric because it suggests potentially issues that were not resolved appropriately before transplant." (Dr #32)

## Short-term health:

"Delayed graft function is a multifaceted quality metric but there are some elements of it that may be related to quality. We can look at consistency of adherence to a certain immuno suppressant protocol." (Dr #32)

"Length of stay in hospital I think is a bit of a marker of, of how well the, the recipient evaluation process has gone to choose people that that are well enough to undergo the rigors of transplant. As well as that the transplant itself goes well gives you an estimate of how well your surgical processes are and your wound prophylaxis and your general nursing care posttransplant" (Dr #48)

"Posttransplant, you know, success early on, length of stay, readmissions, complications, post op monitoring, you know, are they, you know, rejection rates and some of that will vary depending on how aggressive centers are in terms of transplanting patients." (Dr #21)

## Fear of infections:

"Well yeah I, I heard about the BK virus. I know that's a really, really bad one that you could lose your kidney if that one takes over too much and can compromise the transplant itself. The CMV virus is just simply like a little herpes virus it's not that much but it can, it can certainly take a toll on one's body. [laugh] Yeah it's I wasn't a happy camper when that was in full affect. I was nausea, vomiting, and just everything was just not going as planned." (Pt #3)

"I had I did catch the infection when they first put my stent in but that had more to do with the [major city hospital] at the time than, than anything else. I mean it was the infection I got was directly related to the hospital so." (Pt #12)

"We have to, to be sure that there is no infectious transmission during the transplantation so well that's the idea that I have." (Dr #22)

"You could look at any incidences of donor transmission of any diseases" (Dr #37)

## Patient Satisfaction

## Returning to normal life:

"Because when you're on dialysis before the transplant, of course, you know quality of life is somewhere some percentage less than normal. So, of course, you, you're part of the success of the transplant is that you get a good quality of life back again." (Pt #14)

"I guess just to know that you're back to normal again. You don't I mean I, I, I was back doing everything I did before my kidney started quitting and I had energy to burn." (Pt #12)

"Yeah so after, after transplant and I think my life is more free, yeah. And my, my dream before was like I can travel our country with my family. Yeah but I couldn't. . . . So the first thing is I went back to [country] to visit my brother with my family reunion and then we have couple more and my dream come true, yeah." (Pt #20)

"Once they've been transplanted the most important thing is that they get back to feeling like normal, whatever their normal was. So that means they either can get back to work. They get back to, you know, raising their kids or whatever it was that normal was before they got sick. A steady state or return to steady state." (Ad #35)

"You know freedom from dialysis to be able to have a normal life. To be able to find a job because they, they can't, they easily the rate for people after transplant to be able to find a, you know, job suitable for their education and qualification is higher in, statistically." (Ad #50)

## Patient satisfaction with care:

"I think there's a difference between satisfied with your care and satisfied with your outcome and I think those 2 things get conflated sometimes" (Dr #23)

"Patient satisfaction is not something we measure here objectively in a, in a really comprehensive way. I think that is a gap. And patient satisfaction is obviously an extremely important outcome metric." (Dr #31)

"I would be much more interested in whether we're delivering on our promise of transforming lives and, and I would be very interested in being able to measure patient satisfaction, whether the patients' expectations of transplantation were met or if they're not being met and in what areas they're not being met. (Dr #44)

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**APPENDIX. (Continued)**

- Safety
- Safety (broad theme)
- “So I think a transplant program exists within a larger hospital system. And there’s a number of safety metrics for patients within that hospital through that given hospital’s quality management program that are totally applicable to transplant and we don’t need to rethink those.” (Dr #32)
- “Well I guess death [laugh] is a pretty good indicator of safe versus unsafe. Readmission rates may impact or may have an indication of safety. And I guess you could look at just generally complication rates. And I suppose you could make that list fairly broad but, you know, surgical complications, other complications that, you know, might have been in the first week of transplant, you know, infections, DVTs.” (Dr #31)
- Reducing infection risk:
- “Postsurgery you always are automatically placed in a private room because obviously you’re highly susceptible, you’re immuno compromised and we don’t want to expose you to, you know, other patients who might, you know, inadvertently put you at risk” (Pt #11)
- “After the transplant you’re in the hospital for 5 or 6 days or whatever and they tell you to be careful of germs, germs, germs, germs, germs, germs. One day the nurse came in to take blood or something like that check my whatever sniffing, and sniffing, and sniffing, you know. I said “Aren’t you supposed to wear a mask or something?” like, you know. And she never came back again.” (Pt #4)
- “I think it’s fine the way it is really. I, it’s really great since they switched us from like down in the blood lab there now we go right into a separate room instead of being with the other people because sometimes you do pick up stuff from there.” (Pt #13)
- “I was struck by the fact that it seemed the hospital took sanitation and hygiene very seriously.” (Pt #11)
- Quick response to complications:
- “Well my setting I guess was at [major city] General, right for the kidney transplant and like I said they’re very thorough with anything, any changes in your blood work they’re on top of it and any med changes they notify me right away.” (Pt #1)
- “So I mean even if I go for blood work and they’re going to make an adjustment to my medication within the same day I’ll get a phone call from the hospital with, you know the results. So I was impressed by the fact that, you know, you’re not constantly having to call.” (Pt #8)
- Patient health status on the waitlist:
- “In the waiting period I think that’s a tough one because it’s, you know, death on the waitlist is challenging. And if they come off the waitlist because they’re sick and then die we don’t always know how well we capture that.” (Dr #37)
- “I think monitoring death on the waiting list would probably be useful, although that could be interpreted in different ways. ... It may not be a bad thing to have people die on the waiting list because if you may be putting, you may be having people that are sicker wanting to take the chance of transplant.” (Dr #38)
- “... health status of the patient as they progress through the process. So one good example of that is if they came in not on dialysis with these delays and other things did they require the initiation of dialysis before a final decision was made.” (Dr #24)
- “I guess if patients are under dialysed or if patients are noncompliant during that phase if that’s not being picked up. Then, then that would be as well an issue of safety. If they’re not being coached in the way they should be to maintain their healthy lifestyle or as healthy as possible.” (Dr #47)

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