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The Health-Care Provider's Perspective of Education Before Kidney Transplantation

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Abstract

Context: Adequate patient education is essential for preparing potential recipients for kidney transplantation. Health-care providers play a vital role in education and can identify gaps in patient understanding.

Objective: To identify deficits in patient knowledge from the perspective of a transplant multidisciplinary care team and determine whether their perceptions align with patients who have previously undergone a transplant.

Design: An open call was advertised for health-care providers to attend a focus group discussion regarding the educational needs of pretransplant patients in 1 Canadian center. A predetermined, semistructured set of questions was used to collect the views of transplant caregivers. A moderator, assistant moderator, and research assistant facilitated the discussion, which was transcribed verbatim. Paper surveys were distributed to collect opinions of those unable to attend or uncomfortable to voice their opinion in an open forum. Qualitative analysis software was used to identify any emergent themes. Results were compared to a previous study undertaken in transplant recipients.

Results: Despite pre- and posttransplant education, specific themes emerged including misconceptions about the assessment process and time on the wait list and the surgery, incongruity between patient expectations and outcome, and confusion regarding medications. Health-care provider perceptions were remarkably consistent with transplant recipients.

Conclusion: Health-care providers identified gaps in patient understanding indicating that transplant candidates may not be internalizing what is taught. Innovative educational approaches may be needed to provide more successful patient education. Similarities between health-care provider and patient perceptions suggest that care providers are a valuable source of information.

Keywords kidney transplant, patient education, staff perspectives, education, qualitative analysis, focus group

Introduction

End-stage renal disease (ESRD) has been estimated to affect nearly 5000 million people worldwide.¹ Kidney transplantation is considered the gold standard therapy for ESRD as it is associated with decreased morbidity, mortality, and improved quality of life compared to the dialysis.²⁻⁴ Transplantation, however, comes with its own set of challenges.

The first hurdle for potential recipients is to complete the assessment process, which determines suitability to be placed on the kidney transplant wait list. This process can be confusing and a significant source of anxiety for patients.⁵ Once the potential recipient is cleared for transplant, waiting for a kidney can be tedious. Since the median Canadian wait time for a deceased donor kidney transplant is 4 years,⁶ the health status of the patient can decline during this time, and the patient may require reassessment.

Once successfully transplanted, patients are required to take immunosuppressive medications. These medications can have significant adverse effects that affect quality of life^{7,8} and contribute to medication nonadherence.⁹ Beyond the complex learning issues associated with transplant medications,¹⁰ kidney transplant recipients are faced with adapting to lifestyle changes. They must pay close attention to their health and learn to recognize symptoms that may indicate changes in the function of their kidney. To ensure optimal management, patients must also be willing to maintain a follow-up care plan with their transplant team involving regularly scheduled appointments and laboratory blood work.

Health-care providers play an important role in preparing patients and their families for the process of transplantation.¹¹ The transplant team is an essential source of support and information to patients and those involved in their care, both before and after the surgery.^{11,12} Comprehensive transplant education must address the entire transplant process, from the assessment process to the ongoing follow-up necessary after transplant.¹³ Individuals contemplating kidney transplantation must also understand the surgical risks, posttransplant lifestyle changes, and the necessity of lifelong medication adherence. Unfortunately, patient expectations of the transplant process do not always correlate with reality,^{14,15} and knowledge after transplant remains suboptimal in this population.¹⁶⁻¹⁸

The goal of this program evaluation was to identify gaps in patient comprehension from the perspective of the health-care provider. This topic has been examined from the perspective of the transplant recipient,¹⁹⁻²¹ however, the perceptions of care providers have largely been unexplored. A secondary objective was to compare the views of care providers with the patient perspective at our center²¹ and to identify whether their perceptions align. Taken together, these results will help guide a quality improvement project to improve transplant education at our center.

Methods

The protocol for the program evaluation was reviewed by the Behavioral Research Ethics Board at the University of Saskatchewan and met requirements for exemption status per Article 2.5 of the Tri-Council Policy Statement.²² A phenomenology approach was used; the purpose of the research was to describe and explore the topic from the participants' perspectives. A focus group-style discussion was used to generate the perspectives of health-care providers involved in the care of transplant recipients using their experiences.

Procedure

A semistructured interview guide assessing the educational needs of adolescent transplant recipients²³ was modified for relevance in gathering the perspectives of health-care providers at this Canadian center. The questions were adapted as needed throughout the meeting to fully explore emerging themes (Table 1). Our group used this questionnaire previously to determine patients' perspectives on pretransplant education.²¹

Criterion sampling was used to select the sample, which included health-care providers involved in the transplant process with the Saskatchewan Transplant Program. The Saskatchewan Transplant Program is the primary care service for patients who are at all stages of transplantation, encompassing both inpatient and outpatient care from nephrologists, surgeons, pharmacists, nurses, dieticians, and social workers, in 1 Canadian province. The Saskatchewan Transplant Program is based at 2 clinical sites in Saskatchewan, St Paul's Hospital in Saskatoon and the Kidney Health Centre in Regina. We aimed to capture the perspectives of all health disciplines working with transplant patients, hence, no other restrictions were placed on the participants, such as occupation or work location, and we invited participants from both inpatient and outpatient caregivers. The session was held at the Saskatoon location of the Saskatchewan Transplant Program, and the session was teleconferenced to include the participants located at satellite clinic in Regina. Since the transplant surgeries are performed at the Saskatoon location only, we anticipated participation from both inpatient and outpatient caregivers from Saskatoon (including physicians, nurses, social worker, and pharmacists) and outpatient caregivers of the Regina satellite (primarily nurses). To enhance attendance, the session was held during a scheduled transplant grand rounds seminar conducted on June 16, 2015, and attendees were informed in advance that the topic would be a focus group discussion. Posters were used to advertise the session and all care providers on the group e-mail list for transplant grand rounds were sent the notification.

The discussion was led by a moderator (male, P.T.) and assistant moderator (female, H.M.) who had been previously trained in leading focus group meetings. The moderator (a summer research student) and assistant moderator (PharmD/pharmacist) were both well known to most participants in the discussion. The moderator was also a kidney transplant recipient, who was able to provide a unique perspective to further facilitate discussion. A research assistant (female, C. L.) was also present to audio record the session and take field notes to aid in interpretation of the responses. Questions were asked in an open manner, and participants were invited to share their thoughts. The grand rounds discussion continued until data saturation was reached, and staff members had acknowledged that they did not have any other thoughts to add. The session lasted approximately 60 minutes.

Since not all care providers were comfortable sharing their opinions in an open forum, a paper copy of the questions was distributed, so that participants share their thoughts honestly and discretely if preferred. It also allowed us to collect the opinions of care providers who could not attend the session. In order to maintain anonymity among coworkers, only the work location was collected in terms of demographic information.

Data Analysis

Audio recordings and field notes taken during the focus group discussion were transcribed verbatim. After the transcribed and handwritten results were reviewed by all authors, the information was input into NVivo qualitative analysis software by P.T. (version 10, 2012; QSR International Pty Ltd). The data

were coded and categorized to identify emerging themes. The results were reviewed independently (H.M.).

Results

The focus group was attended by approximately 30 health-care providers who work with transplant patients. Eight respondents actively participated in the discussion, and a further 15 paper responses were collected. Participants were a mix of practitioners who provide outpatient care from the Saskatchewan Transplant Program, as well as practitioners involved in the care of inpatient transplant recipients at St. Paul's Hospital. The participants included nephrologists, surgeons, nurses, and pharmacists who work both in the inpatient and outpatient setting from Saskatoon, as well as nurses who work in the satellite clinic in Regina.

Several themes emerged from this discussion. These included perceptions of misconceptions about the assessment process and time on the wait list, misconceptions about the surgery, incongruity between patient expectations and outcome, and confusion regarding medications.

Misconceptions During Assessment and Waiting for a Transplant

Many ideas were generated from the discussion regarding the pretransplant period. Participants noted that the length of time it takes to be assessed for transplant and then wait for an organ was a source of concern and misunderstanding for patients. Patients do not always realize that the assessment process requires extensive testing. Depending on their comorbidities, multiple medical appointments are required for some patients to determine fitness for surgery. Once listed, patients often do not recognize that their health is not static. As such, some testing and perhaps even specialist appointments will need to be repeated on at least a yearly basis. Given the often extensive wait times to receive a deceased donor kidney, some potential recipients will end up repeating the same tests year after year until a kidney becomes available. As stated by respondent 3: "we try our best" [with the time and resources that we have available] "but they get confused." It seems that the complexity of the process leads to confusion in all areas of the process, and sometimes even basic concepts such as keeping contact information current with the transplant program are missed.

Participants noted that patients often don't realize that the assessment may determine they are unsuitable for transplant. As explained by respondent 8: "We want the kidney transplant to actually enhance their life instead of making it worse. We have cases where people want to outweigh that risk and have a kidney transplant anyway."

Misconceptions About the Surgery

Concerns about transplant surgery itself were noted. Respondents perceived considerable confusion regarding the operation, its duration, and the length of hospitalization after transplant. Ten participants indicated that the operation is not as simple as patients may believe. Respondent 9 simply stated: "it's [a] major surgery," noting that the operation and its associated risks are sometimes lost on patients.

The group noted that patients may not remember instructions given immediately before the surgery, since recipients are excited, nervous, and understandably focused on the surgical procedure. Teaching provided in hospital after surgery may not be retained. Patients may feel unwell during surgical recovery. Emotions such as worry for their live donor or gratitude to the family of a deceased donor may

also impact information retention. Respondent 16 stated: “I don’t think they retain much at the time of surgery. The event itself is enough [information].”

Incongruity Between Patient Expectations and Outcome

Health-care professionals indicated that despite education, patients do not seem to comprehend that transplantation will not cure other preexisting diseases and comorbidities. The most common response in the transcripts was “transplantation is not a cure but a treatment” (13 respondents). Respondent 13 stated: “it is not a miracle fix. It will likely make them feel better and give them a better quality of life but not every transplant works and you still have important things to do to keep yourself healthy.”

Six respondents commented that quality-of-life improvements do not always match patients’ expectations. Patients are surprised at the frequency of clinic visits (12 respondents) and may not understand the importance of regular blood tests (14 respondents). It was also noted that patient expectations vary considerably after transplant.

Participants indicated that the goal of the transplant team is to provide support and education, but it is essential that patients are involved in their own care. Six respondents commented transplantation requires a significant long-term commitment from the patient. For instance, respondent 16 stated: “[Transplantation is a] long-term commitment ... Patients need to take personal responsibility for their role in the process.”

Confusion Regarding Medications

Medications were a common topic for discussion for participants in the focus group. More than 40 separate references were identified in the transcripts regarding the “need for lifelong immunosuppression” (12 respondents) and “the complications of nonadherence” (7 respondents). The exact quote “medications for life” was noted from 4 respondents. Respondent 20 stated, “Still a commitment and compliance is huge!” Despite education, health-care professionals believed that medication regimens are still confusing for patients once they are discharged from the hospital. Respondent 5 stated that one of the possible sources of confusion could be the hospital medication distribution system. During the hospital stay, the ward nurses administer the medications to the new transplant recipients resulting in patients “not being familiar with their medications” on discharge.

Ten respondents indicated that patients are often surprised to experience side effects from immunosuppressive medications and that patients are not always confident on how to manage them. Further, 6 respondents noted that patients are often unaware of the long-term side effects associated with immunosuppressants, such as the increased risk of cancers (9 respondents). Lifestyle changes recommended after transplant were also cited as a source of misunderstanding for patients. For example, the requirement of proper hygiene and infection control and the importance of monitoring for signs and symptoms of infection sometimes appear lost on patients.

Discussion

We undertook a qualitative analysis to identify gaps in patient comprehension from the perspective of the health-care provider. The participants in this study consisted of frontline health-care workers immersed in the field of transplantation, many with several years of experience.

Two ideas that arose from the discussion were “patients do not always realize that transplant is not a cure, but a treatment” and that “patient quality of life does not always improve as expected after transplant.” It seems reasonable to suggest that these themes are fundamentally related. If a potential transplant recipient has false expectations prior to receiving a kidney, this could lead to a discrepancy in quality of life perception after transplant. Emphasizing the actual outcomes of transplant in education may narrow the expectation gap that patients experience.

Consistent with the present project, other researchers have noted a mismatch between expectation and outcome after transplant. Cleemput and colleagues compared perceptions of quality of life and health-care status in a cohort of health-care professionals (n = 123) and newly transplanted renal recipients (n = 107).²⁴ Their findings indicated patients had higher expectations about their quality of life than the physicians and nurses involved in their care. Health-care professional perceptions were closer to the actual health state after transplant, indicating that physicians and nurses are a reliable source of information.

We recently held a focus group to identify in hindsight what transplant recipients wished they would have known.²¹ Several themes were strikingly consistent among transplant recipients and the care providers in this project. Similar to this project, patients identified opportunities to improve education in all phases of the transplant process, including the wait list period, the surgical procedure, and life after transplant. Notably health-care professionals were unaware of the results from the patient focus group at the time of this project.

Health-care professionals noted a sense of frustration from their patients while waiting for their kidney transplant. They were clearly aware and concerned that despite their best efforts using currently available processes and tools, not all individuals understand why the assessment process and time on the wait list are so lengthy. They perceived that candidates do not fully comprehend the purpose of the tests and why they are necessary to ensure patient safety and optimal outcomes. Transplant recipients from the previous focus group confirmed this confusion. One patient stated: “I didn’t know that [the assessment series of testing] was going to be that much of a regimen every year that you had to go through just to stay on the list ... you do sort of feel, in your head, like they are trying to find some reason to get you off [the wait list].”²¹

Parallels between provider and patient were also noted regarding the surgery. Both parties agreed that education at this juncture is not likely to be retained. As stated by one health-care professional (respondent 1): “I think right before surgery, it is a very short time, and we should not give too much information because the patient is so excited to go in.” Patients echoed this sentiment, saying “When they phone you, they rattle off the stuff you should do, or bring, or pack, and you are like ‘I am not even hearing this.’”²¹ Both groups also commented on the large responsibility placed on patients immediately after the surgery and the importance of self-efficacy. One health-care professional from the present study remarked that “it is like you are getting into marriage and you are excited but now you are married so there are responsibilities.” Similarly, respondents from the patient focus group compared responsibilities of having a new transplant to having a new marriage or a baby.

Medication was also a major topic of discussion in both the health-care provider and patient focus groups. Both cohorts commented on the necessity, side effects, importance of medication adherence, and the risks of nonadherence. Health-care providers relayed concerns that the medication regimen is overwhelming,²¹ a theme that was confirmed by the patient focus group. As illustrated by 1 transplant

recipient “when you get home, it hits you” and “you have to take the pills, it is not optional.”²¹ Both health-care providers and transplant recipients reiterated the importance of educating candidates about the necessity for lifelong medication adherence and that the side effects associated with the medications can be a surprise for patients. Respondent 20 from the present project noted that patients are told “not to stop [immunosuppressive medications] on their own if experiencing side effects but call us first,” expressing concerns about patient modifying their own regimes. Patients relayed the concern, “It never occurred to me that there would be side effects and I don’t think I ever heard about any,”²¹ indicating a possible disconnect between information provided and patient retention.

Participants in the transplant recipient focus group generally perceived that they were well educated by the transplant team, yet identified gaps and misunderstandings.²¹ Health-care providers, on the other hand, expressed frustration that despite providing education prior to transplantation, patients are still unable to retain all of this information. Taken together, we conclude that comprehensive education is provided at this center, but nevertheless a significant gap exists between educating and understanding. Many studies have shown that retention of information and transferral of knowledge from 1 setting to another can be challenging.^{14,15,18,25} Perhaps more efforts need to be undertaken to provide repetitive education in a manner that is appropriate for the literacy and language skill of the patient group.

Several strategies emerged from this evaluation, which may assist in providing more meaningful education at our center. Health-care providers and patients from the previous study indicated that the time immediately surrounding the surgery is not appropriate for educating patients. The assessment process should provide basic information about medications and their role in transplant success. The pretransplant education tools need to be constructed to allow the generalities of topics such as medications to be retained before transplant to provide a framework for patient-specific teaching after transplant.

The idea of implementing a self-medication administration system on the transplant unit was another strategy that was generated from this group. A self-medication administration system could provide an opportunity for patients to learn how to take their medications independently while in the hospital, which could in turn potentially minimize the confusion when they arrive home. The concept of medication self-administration has shown promise in improving patients understanding of medications, however, it is not known whether this intervention improves medication adherence.^{26,27}

More efforts should be undertaken to explain the reason and necessity for the testing and specialist referrals that occur during the assessment process. This could potentially enhance patient comprehension regarding the length of time required to complete the assessment. Finally, patient education must be tailored to imprint a more realistic version of expectations for life after transplant.

It is important to acknowledge the limitations of this study. The Saskatchewan Transplant Program is a center that provides service to transplant candidates and recipients in 1 province in Canada, so these results may not be generalizable to other programs. We decided to use a focus group-type discussion for this qualitative analysis, which was held during a regularly scheduled transplant rounds. Typically, focus groups consist of 7 to 12 participants to allow for participation from all members.²⁸ In an attempt to hear from all eligible participants, we did not limit the number of participants in this study. The alternative of hosting smaller focus group sessions of 7 to 12 participants on multiple occasions was explored. This option was not feasible, however, due to conflicting schedules of the health-care providers involved.

Focus group methodology involves creating a relaxed and natural environment to maximize group dialogue and to help identify group norms.²⁸ It could be argued that the use of a microphone during the session limited the ability to create a relaxing atmosphere. Transplant grand rounds in this setting, however, are used as a forum for debate and discussion among these health-care professionals; hence, the natural environment for interaction was replicated.

Finally, the inclusion of paper questionnaires in the data analysis may be considered a limitation, since the research assistant was not able to observe the accompanying emotion and context. We opted to use the paper questionnaire in addition to the rounds discussion to minimize the potential for bias that could occur if some individuals were uncomfortable sharing their opinions with the rest of the team. Nevertheless, this approach has not traditionally been used in the focus group methodology.

Conclusion

Health-care professionals identified gaps in patient knowledge throughout all stages of the transplant process. The themes derived from this study are remarkably consistent with a previous qualitative study in transplant recipients, indicating that health-care provider perceptions are an accurate source of information. Taken together, health-care provider perspectives and patient perspectives suggest potential areas of improvement in the educational process at our center.

Declaration of Conflicting Interests

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Table 1. Questionnaire and Discussion Guide for Staff

Transplant Program Needs Assessment for Patient information: Questions for staff: Rounds June 16, 2015	
1	What information do you think is important for patients to know before discharge?
2	What information do you think is important for transplant recipients to know <i>before</i> kidney transplant surgery?
3	What information do you think is important to know <i>at the time of surgery</i> and while in the hospital after the operation?
4	What information do you think is important to know when patients come back for follow-up?
5	In summary, if you had to tell a transplant recipient how to prepare for this process, what would be the key things important for them to know?
6	Identify any potential gaps in the information patients receive prior to transplant?
7	Are there other ways we could present information (in addition to the routine written information) that you think would benefit patients?
8	Is there anything else that you would like to tell us about that you think is important?
9	What department are you from?