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# Education Before Kidney Transplantation: What Do Patients Need to Know?

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## **Education before kidney transplant: What do patients need to know?**

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### **Abstract:**

**Context:** Poor knowledge about immunosuppressive medications (IS) remains a major problem for patients in the post-transplant setting. Therefore, more effective educational strategies in the pre-transplant setting are being considered as a possible method to improve knowledge and readiness for the challenges of post-transplant care. However, the most effective/relevant content of a pre-transplant educational program is yet to be determined.

**Objective:** To identify pre-transplant education topics from the post-transplant patient perspective.

**Design:** A focus group meeting was conducted among seven high-functioning, stable adult kidney transplant recipients recruited from the Saskatchewan Transplant Program. Demographic information including age, gender, occupation, background/ethnicity and time since transplant were recorded. A moderator, assistant moderator and research assistant facilitated the 90-minute focus group meeting using a pre-determined semi-structured interview guide. The session was audio-recorded and transcribed verbatim. Nvivo software was used to code the data and identify emerging themes exploring views of participants relating to the educational information required for pre-transplant patients.

**Results:** Patients were satisfied with the education they had received. Ideas were classified into the following major themes: patient satisfaction, transplant waitlist, surgery, medications, post-transplant complications, lifestyle and monitoring, knowledge acquisition, illusion of control, and life changes post-transplant. Knowledge gaps were identified in all areas of the transplant process and were not exclusive to IS medications.

**Conclusion:** Misconceptions regarding transplantation were identified by a group of high functioning, stable adult recipients who were satisfied with their clinical care. Future educational strategies should aim to address the entire transplant process, and not be limited to medications.

**Keywords:** Kidney Transplant Recipient, Body Regions, Education, focus group, qualitative research, patient knowledge

## **Introduction**

Kidney transplantation is the gold standard treatment for end-stage renal disease (ESRD). To ensure optimal outcomes after kidney transplant, patients must commit to several new lifestyle changes, and indefinite therapy with immunosuppressive medications. In addition to understanding timing, administration, and ongoing titration of transplant medications, recipients must adhere to lifestyle changes that include hygiene practices and infection prevention. They must attend routine clinic appointments and frequent laboratory visits to monitor transplant kidney function. They also may experience body image changes, mood and energy level swings, and drug side effects.<sup>1,2</sup> Therefore, adequate knowledge about immunosuppressive medications, graft surveillance and the benefits of specific lifestyle behavior are crucial for transplant success.<sup>3</sup> In order for patients to make informed medical decisions, a clear understanding of these expectations should occur prior to the transplant surgery.

Education and preparation for the post-transplant experience generally begins when the patient is assessed for transplant. In our center, both verbal and written information are provided to patients by the transplant nephrologist, surgeon and nurse co-ordinator. Despite these interventions, many patients have a poor understanding of post-transplant expectations, and some recipients are surprised that they must take lifelong immunosuppression. Our anecdotal experiences are consistent with research indicating that knowledge about transplant medications is a major problem following transplant surgery.<sup>3-5</sup> Other studies in transplant recipients have reported a mismatch between expected and actual quality of life outcomes.<sup>6,7</sup>

We undertook a quality improvement initiative at our center to address this educational gap. We report the findings from the first phase of the needs assessment: a focus group meeting with transplant recipients to identify information they wish they had known prior to transplant surgery.

## **Methods**

The protocol for the study was approved by the Regional Ethics Board (Protocol BEH-14-475). Qualitative methodology using a phenomenology approach<sup>8</sup> was chosen to capture the perspectives of transplant recipients from their frame of reference regarding the kidney transplant process. A focus group design was used facilitate group interaction, which is useful for exploring patient experiences and examining thought processes.<sup>9</sup>

## **Procedure**

Seven intellectually high functioning stable adult kidney transplant recipients cared for by the Saskatchewan Transplant Program (STP) in Saskatoon were recruited for the study. Potential subjects were identified by the program staff, and purposive sampling was used to ensure the group would provide rich dialogue. A research assistant contacted the individuals to confirm participation and the meeting was held at the STP in February of 2015. Participants were provided with refreshments and a \$75 honorarium was offered for participation.

Subjects signed informed consent, and provided demographic information including age, gender, occupation, background/ethnicity and time since transplant prior to the group meeting. The meeting was approximately 90 minutes and ended after all questions were answered. A moderator (HM), an assistant moderator (NR) and research assistant (CL) were present to lead the discussion and audiotape the session. Field notes were taken by the research assistant to aid in interpretation of the audio recording. While the moderator and research assistant had no

previous relationship with the subjects, the assistant moderator was a well-known healthcare provider who could provide empathy and relate to transplant experiences.

A semi-structured interview guide, developed by Korus and colleagues to assess the educational needs of adolescent transplant recipients<sup>10</sup> was used to guide the discussion. In present study, the questions were modified slightly for relevance in the adult population, and adapted as needed throughout the meeting to explore emerging themes (Table 1).

### **Data analysis**

The audio-recordings were transcribed verbatim by the research assistant (CL). The data was analyzed using NVivo qualitative data analysis software (QSR International Pty Ltd. Version 10, 2012) independently by two authors (HM, NR) who had received formalized training. The transcripts were reviewed several times and statements were coded and grouped to identify emerging concepts and themes. Study results were verified independently by an additional researcher with expertise in qualitative data analysis and education (JW). The manuscript was reviewed by the focus group participants prior to publication to verify context.

### **Results**

Eleven participants were purposively identified by the transplant staff and contacted to gauge interest in the study. Due to weather constraints/illness, only six participants were able to attend the meeting on the scheduled date. To ensure we reached our goal sample size of seven participants, data was captured with a participant unable attend the session via one-on-one interview. As shown in Table 2, the average age was 54.9 years and time since transplant was 8.1 years. The ideas generated by the discussion could be classified into the following major themes: patient satisfaction, transplant waitlist, transplant surgery, medications, post-transplant complications, lifestyle and monitoring, knowledge acquisition, illusion of control, and life changes post-transplant.

#### **Satisfaction with transplantation and follow-up**

Overall the group was very positive about the transplant experience. Almost all described it as a “life changing experience”, or a “second chance.” A participant stated, “It changed my life; it was like getting a second chance totally. I was down and out real bad, and all of a sudden I am back functioning and everything is great. It is a strict lifestyle but other than that it is really good.” One patient (participant #4) in hindsight wondered whether she might have chosen to remain on dialysis after fully realizing the commitment of taking medications. “I might have turned down the transplant if I realized. I am not a pill taker,” she explained.

As a whole, the group felt satisfied with the clinical care and education they received. Participant #3: “I think that the follow-up is excellent. I kind of feel like I have a personal team of physicians on call (which I don’t) but I mean if I have a problem it gets fixed. I like that everybody is accessible if you phone in or anything.” Participant #6: “I felt pretty much informed.”

#### **Knowledge Acquisition**

Educational strategies currently used were perceived as helpful, such as the written information and the pill calendar. The pill calendar is a personalized schedule provided by our program pharmacist, depicting when the transplant recipient should take each medication.

Participant #2: “I think the discharge book is important, because it allows you to go back and refer to things like over-the-counter medications.”

While the group supported the production of supplemental videos, they unanimously believed that written materials should continue to be provided during transplant assessment. While online technology is important, they warned that transplant candidates should be cautious when researching information and interpreting online data. They stressed the importance of frequent reminders and a support person (such as a spouse, caregiver or friend) to help remember information. Participant #2: “You get a lot of information after your transplant and having someone else with you to hear some of that stuff is probably key, because you don’t necessarily hear or remember because you are recovering from surgery.

When asked what words of advice they would pass on to a transplant candidate, they strongly agreed that “there are no stupid questions” and recipients should be told to “ask questions!” both before and after the surgery.

### **Transplant surgery**

Participants felt well informed about the transplant surgery. As participant #5 noted, “Mostly talking to the surgeon made me feel at ease. He told me a few things like the time it was going to be and what they were going to do exactly while I was under. It made me feel at ease when I was getting ready to be rolled in. It was just the procedure basically, he didn’t go into any more depth on anything else. Afterwards how many tubes were coming out of you - that was a surprise. One participant was surprised at the amount of urine produced after the transplant, and another noted that family members were surprised and worried at the length of surgery.

Misconceptions were identified regarding the placement of the transplant kidney. Some recipients were surprised that their kidneys were not removed. Participant #7: “There is a lack of awareness among people as to whether their old kidneys are in or not, and where the new kidney is - even with family physicians and so on. I will tell them my kidney is down here in my groin/in my pelvis, and they are like ‘what?’ so it is rather surprising. Another overarching theme among recipients receiving deceased donor kidneys was a sense of chaos and the feeling of being unprepared when they received the call for the transplant. Participant #2: “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’.” Participant #7: “I remember that we were told to have something available in case the call came, but we forgot. It was just like somebody giving birth - it happens all of a sudden, and you rush to the hospital.” Participants agreed that a checklist would be helpful, so that future recipients would know what to pack.

### **Transplant Waitlist**

A sense of confusion was apparent regarding some of the workup testing that is routinely required. Also, anxiety about remaining on the waitlist was described. Participant #2: “I forgot about all those pretests that you have to do before your transplant every year. I don’t know if I actually knew that there was going to be that much of regimen every year that you had to go through it just to stay on the list. It was a big ordeal to get on it and just to stay on it; you do sort of feel, in your head, like they are just trying to find some reason to get you off.” The participants suggested that patients on the transplant waitlist need to be informed of the plan. They also felt that candidates should be reminded to keep healthy and not to lose hope.

## **Medications**

While the group collectively felt they received adequate education about taking transplant medications, they felt overwhelmed once they were discharged home. Overall, medication use was the most frequently discussed topic during the session. Participant #5 explained: "I thought I was well-informed. But when you get home it hits you." Participant #6: "You go through a real traumatic experience and then they put the meds in you, and it is like your brain doesn't work. The one thing I found hard was the meds. Everything is on your mind and they repeat the information 17 times to drill it in to you, but it works."

Some of the participants were surprised to learn about side effects, and continual medications adjustments. Participant #4: "You have to take pills and it is not optional. It never occurred to me that there would be side effects and I don't think I ever heard about any." Participant #3: "I was surprised by side effects and how hard it was to get it just right, like the balancing afterwards. First I was on tacrolimus and then it changes. I had no idea that there was going to be this constant ongoing journey." Participant #2: "I was so high on Prednisone, I cleaned the house in about 3 seconds and I didn't really know that why I was being an energizer bunny was because of all that Prednisone." Others did not recall being told about drug interactions.

The group agreed that patients should be educated on why, how and when to take the transplant medications. Practical information was viewed to be particularly important for transplant recipients early on. Some suggestions included medication management strategies (such as the option of pill packing); education about which medications are the most critical; what to do if a pill is missed, or how to manage and store medications during travel. The participants also stressed the importance of education repetition. When asked about how much repetition should be provided, one participant (#7) responded, "I think as much as you can, I don't think that you can overload people too much."

## **Lifestyle and monitoring**

Participants expressed varied experiences with respect to clinic appointments and bloodwork expectations. Some felt well informed regarding the transplant follow-up, yet others were surprised about the frequency of clinic visits and laboratory monitoring. As noted by participant #2, "You will do blood work every month for the rest of your life and I don't think you are told that ahead of time. Not that it would matter. Maybe for some people it does matter, I guess, I don't know." Participant #5: "I was at home and you guys phoned me and said be here in two days, and after that it was

another four days. It caught me off guard. It was no big deal, but I didn't know." While another participant (#1) stated, "No they told me about all the visits and monitoring."

The participants also acknowledged challenges associated with post-transplant dietary changes. Participant #2: "When you go from worrying about how high your potassium is and how your phosphorus is, to where it is really low and you are going to have to come in and have a transfusion, it is a big switch." Participant #6: "(Before transplant) restrictions are so strong sucking on ice cubes and stuff, and all of a sudden you are chugging water."

## **Post-transplant complications**

While some patients recalled learning about rejection prior to transplant, others did not. All agreed, however, that it was an important aspect of pre-transplant education. Several patients were surprised and overwhelmed to learn about BK virus after the transplant. Participant #2: "You are just absolutely freaked because there you are and you got this kidney, and they tell you

'oh - by the way you could or could not be a BK carrier or maybe the kidney was'." Skin cancer was another complication that was discussed by the group. For instance, participant #3 commented, "I was told about skin cancer, but had no idea how bad it could be, and how much the risk was increased." **Illusion of Control**

Another interesting topic of discussion was the blind faith that a solution would always be available for every medical issue that could arise. Participant #3: "I absolutely assumed that that was the case. I needed to take pills but there is always a pill. There is always going to be a fix. I don't know what the fix is and I don't need to know what the fix is- somebody will tell me what it is- but it will be there." This statement can be described as the illusion of having control over uncontrollable circumstances. Similarly, although the patients were taught about the risk of skin cancer prior to transplant, there was a sense of personal detachment regarding this aspect of education. For instance, participant #2 stated, "I heard about it, but I didn't think that it was going to hit me."

### **Life Changes Post Transplant**

A major recurring theme throughout the session was the idea that life is inevitably different after transplantation. Participant #2: "Getting a transplant means that you are sort of switching one thing for a different thing; there is going to be things that you are going to have to do for the rest of your life and the drugs are part of it. With that comes the potential for a different set of problems, and a different set of side effects." Participant #3: "Life is different after transplant, but we all had a different life." Notably, some of the comments indicated that these life changes were unexpected. Participant #5: "I remember going home and thinking I had a new lease on life and pretty much back to normal; but you are not. Things have changed, but you do have a new lease on life and just a new set of things to deal with."

### **Discussion**

We undertook a focus group discussion with seven kidney transplant recipients in the Saskatchewan Transplant Program. Overall patients were satisfied with the education they received prior to receiving their transplant. Previous studies are conflicting about the level of patient satisfaction among transplant patients, ranging from extremely positive to unsatisfactory.<sup>11-14</sup> Many variables influence satisfaction, including patient-, location-, time- or education-specific factors. The positive responses noted in this group can be considered a testament to the strategies in place at the Saskatchewan Transplant Program, and to the pre-transplant coordinators, nephrologists, surgeons and social worker who provide education.

Overall, the participants in this study were a motivated, engaged group of transplant recipients, with interest in improving the transplant process. We purposefully selected individuals with the ability to see perspective, which may have resulted in a group that was more homogenous in attitude/intellect/social skills, rather than clinical situation or personal health story. Certain themes such as the idea of transplant as "a new lease on life", and statements such as "I can't imagine why nobody would chose a transplant" emerged, that support the group's homogeneity in this regard. This sample was undertaken to enable us to collect widely applicable, high-level information. We can presume that if this ideal cohort has concerns, a more representative sample would have at least as many issues or confusion.

Even though the participants believed they were well educated about the transplant process, several pre-transplant misconceptions were identified. Confusion was expressed regarding the purpose of pre-transplant testing, medication side effects, frequency of monitoring

and clinic appointments, postoperative complications, and even the placement of the transplanted kidney. From this study it seems apparent that transplant education should address multiple aspects of the transplant process. Urstad and colleagues, reported similar findings from an interview-based study. In addition to medication, kidney transplant recipients considered information related to graft rejection, rejection and lifestyle as extremely valuable.<sup>3</sup>

Several emotions that were described by participants provide additional context and contribute to our understanding of the needs of transplant recipients. A sense of chaos was described when patients could not remember what to pack for transplant, but patients felt confident when they were given a plan. Providing clear instructions and providing a list was suggested as a solution. When the participants returned home, many acknowledged that they felt overwhelmed by the medications, and the fear of doing something wrong. As in other reports, the value of information repetition and having a support person to assist with retention was suggested.<sup>2, 5</sup> Confusion regarding the waitlist testing and worry about remaining listed was also expressed. A recent systematic review and thematic synthesis on patient attitudes on the kidney transplant waitlist describes similar frustrations, and identified the burden of tests as one of the six major themes in this population.<sup>16</sup> Perhaps more effort should be undertaken to explain the importance of various tests and to dispel myths about placement allocation and eligibility.

Illusion of control occurs when individuals overestimate their ability to control uncontrollable outcomes.<sup>17</sup> This cognitive type of bias was expressed within the group, as they discussed the blind faith that there would be a fix for every medical issue that could potentially come up. Even though transplant recipients were well informed about certain aspects of their care, it was also challenging for them to transfer the information to their personal situation. Patients reported being informed about the risks of skin cancer, but still believed that it would not happen to them. The challenge of transferring knowledge from one setting to another has been well described by others.<sup>13, 18</sup> Incorporating other patient experiences into pre-transplant education is a potential way to share reliable information, while providing proper context. Supporting this, a qualitative study in stem cell recipients found that patients wanted detailed, practical and genuine information from other patients regarding their own experiences.<sup>19</sup>

The limitations of this study deserve discussion. Our quest to obtain a stable group of transplant recipients that could provide rich data resulted in a cohort with an average time since transplant of 8.1 years, which can be considered both a weakness and strength. On one hand, participants may have had difficulties remembering how they felt at the time of transplant. Alternatively, thoughts and emotions remembered many years after the event should be considered important and highly relevant, particularly since our goal was to collect high-level information. Recruiting individuals was challenging. To obtain a minimum of seven participants as per standard focus group methodology,<sup>9</sup> we interviewed one patient two days after the meeting, as he was unable to attend due to illness. Although this should be considered a limitation, it is noteworthy that this recipient's responses were consistent with the other participants, even though his comments were not biased by the group discussion.

The sample size was seven participants, and purposeful selection was used for recruitment, which limits the generalizability of the results. We recognize that the opinions generated are not necessarily representative of the entire transplant population, particularly of patients who may have poor health literacy, cognitive dysfunction or language barriers, etc. A mixed-methods study is ongoing at our center to investigate health literacy, transplant

knowledge, beliefs as well as education satisfaction, in all transplant candidates to provide additional context. Nevertheless, the high-level themes identified from this focus group meeting have provided a starting point for our quality improvement project.

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**Table 1: Focus group Discussion Guide**

Questions	Probes
<p><b>Introductory Question:</b> 1) How long ago was your transplant and how has it changed your life?</p>	
<p><b>Exploratory Questions:</b> 2) What information do you discharge?</p>	<ul style="list-style-type: none"> <li>• <i>About the operation?</i></li> <li>• <i>About the surgery?</i></li> <li>• <i>About the medicines that you will take?</i></li> <li>• <i>About the time you will be in hospital?</i></li> <li>• <i>About the follow-up that you will require?</i></li> <li>• <i>About the complications of transplant?</i></li> </ul>
<p>3) What information do you recipients to know <i>before</i> kidney</p>	<ul style="list-style-type: none"> <li>• <i>While in surgery?</i></li> <li>• <i>When you are back on the unit?</i></li> <li>• <i>About your medications?</i></li> <li>• <i>What information do you need about complications/what can go wrong?</i></li> <li>• <i>About the time you will spend in the hospital?</i></li> </ul>
<p>4) What information do you <i>time of</i> surgery and while in the</p>	<ul style="list-style-type: none"> <li>• <i>About your medications?</i></li> <li>• <i>About the follow-up you will need?</i></li> <li>• <i>About complications?</i></li> <li>• <i>About how to assess your own health?</i></li> <li>• <i>About your diet?</i></li> <li>• <i>About going back to work and other normal activities?</i></li> </ul>
<p>5) What information do you come back for follow-up?</p>	<ul style="list-style-type: none"> <li>• <i>Does this change the longer you are from transplant?</i></li> <li>• <i>Do you need reminders of the information you received at discharge?</i></li> <li>• <i>If so, how often?</i></li> </ul>
<p>6) In summary, if you had to tell another transplant recipient how to prepare for</p>	
<p>7) Thinking back to what you in the information you were given-but would have liked to have been told before.</p>	<ul style="list-style-type: none"> <li>• <i>Did you get the right information at the right time?</i></li> <li>• <i>Was anything a surprise to you after transplant?</i></li> <li>• <i>Did you experience anything that you were not told about?</i></li> <li>• <i>Did you find the information overwhelming?</i></li> </ul>
<p>8) During the teaching, before given booklets with most of the discussed with you. Are there other preferred to receive this</p>	<ul style="list-style-type: none"> <li>• <i>Would you have preferred it to be on a computer?</i></li> <li>• <i>Can you suggest how information should be displayed on a computer program?</i></li> <li>• <i>Would you like the computer to ask you questions to check your understanding of the information?</i></li> <li>• <i>Where would you like to be able to access this information from?</i></li> <li>• <i>What about a PowerPoint presentation?</i></li> </ul>

<b>Exit Question:</b> 9) Is there anything else that you would like to tell us	
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Adapted from: Korus M, Stinson JN, Pool R, Williams A, Kagan S. [Exploring the information needs of adolescents and their parents throughout the kidney transplant continuum](#). *Prog Transplant*. 2011 Mar;21(1):53-60.

**Table 2: Patient Demographics**

Participant	Age	Gender	Occupation	Background/Ethnicity	Time since transplant
Participant 1	29	F	Commercial catering	Aboriginal	7 years
Participant 2	54	F	Retired (mortgage broker)	Caucasian	3.5 years
Participant 3	63	M	Judge	Caucasian	4.5 years
Participant 4	60	F	Administrative assistant	Caucasian	6 years
Participant 5	53	M	Painter	Caucasian	5 years
Participant 6	60	M	Retired (city worker)	Caucasian	9.5 years (kidney/pancreas)
Participant 7	65	M	University Professor	Caucasian	21 years