Partnering with Patients to Enhance Access to Kidney Transplantation and Living Kidney Donation

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Abstract

Kidney transplantation gives many patients with kidney failure a longer and healthier life. Unfortunately, some transplant-eligible patients will never receive one. In this paper, we describe how patients and researchers collaborated on new strategies and programs to enhance access to kidney transplantation and living kidney donation. These efforts led to the creation of the Transplant Ambassador Program (TAP). TAP is a patient-led program that helps connect patients who have kidney failure to individuals who have successfully received a kidney transplant or donated a kidney. We also detail barriers, facilitators and lessons learned from engaging patients in research.

Key Points

- Patients and researchers collaborated to enhance access to kidney transplant. Efforts led to the creation of the Transplant Ambassador Program – a patient-led program that connects patients who have kidney failure with kidney transplant recipients.
- Several facilitators, barriers and lessons learned from engaging patients in research were identified. Some facilitators included biweekly meetings with patients and the research team to sustain engagement and keep an open line of communication.
- Patient partners were involved throughout the study, from study development to manuscript preparation, which enriched the research and ensured that the research is meaningful to patients and healthcare professionals.

Introduction

Patients with kidney failure have two main treatment options: dialysis or a kidney transplant. Compared with patients on dialysis, patients who receive a kidney transplant often live longer and experience an improved quality of life (Ortiz et al. 2014; Tonelli et al. 2011). Patients can receive a kidney from a deceased or living donor. Unfortunately, some transplant-eligible patients will never receive one. There are many barriers to receiving a kidney transplant, including a low number of kidneys available for transplant and a lack of knowledge about living kidney donation and transplantation among many patients and families (Garg 2018). Researchers and patients worked together to develop strategies to enhance access to kidney transplantation and living kidney donation. This paper describes our patient-oriented research (POR) project and the barriers, facilitators and lessons learned.

Development of Strategies to Enhance Access to Kidney Transplant

In 2015, a conference was held by Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD), a POR network that works to transform the care of people affected by kidney disease (https://cansolveckd.ca/). At the conference, patients with kidney disease, researchers, policy makers and healthcare professionals

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P = Patient partner.

ranked improving access to living donor kidney transplantation as a top research priority. Then, in 2016, a workshop led by 19 patients was held in Ontario to understand patient-identified barriers and solutions to improve access to living donor kidney transplantation (living donor kidneys provide superior patient survival compared with deceased donor kidneys) (Axelrod et al. 2010; Getchell et al. 2017). A key solution suggested was to provide support to patients with kidney failure from kidney transplant recipients and living kidney donors. A subsequent collaboration between patients and researchers led to the development of the Transplant Ambassador Program (TAP) (transplantambassadors.ca), a patient-led, volunteer-driven support program for patients with kidney failure. With initial funding from Can-SOLVE CKD, we were able to make TAP a reality. Additional funding was received from the Ontario Strategy for Patient-Oriented Research (SPOR) SUPPORT Unit (OSSU) EMPOWER award to adapt and optimize TAP's online operation in response to the COVID-19 pandemic and to prepare a plan to implement and sustain TAP at CKD programs across Ontario.

TAP

> As a living donor, I see the importance of TAP every time I speak with a patient or a potential donor. When we share our lived experiences, we demystify the process of transplant and vividly show an example of life after the operation. People are eager to speak with someone with first-hand experience. It helps them feel less anxious and more confident in their decision to pursue kidney transplant. (Living kidney donor and transplant ambassador)

FIGURE 1.
Transplant ambassadors

Transplant ambassadors wear bright green vests that indicate whether they are a kidney transplant recipient or a living kidney donor. The back of the vest contains a print invitation to "Ask me about kidney transplantation." The vests make it easy for patients to identify transplant ambassadors.

TAP connects patients who have kidney disease to transplant ambassadors: individuals who have successfully received a kidney transplant or donated a kidney. Transplant ambassadors share their stories, offer practical advice and emotional support, share strategies on how to discuss living kidney donation with family and friends, connect patients with educational resources and help guide and motivate patients through the transplant evaluation process (Figure 1). Compared to healthcare professionals, they can often spend more time discussing transplantation and provide inspiration and hope to patients with kidney failure. TAP was initially developed by a kidney transplant recipient and by an individual whose mother received a living kidney donation from her father.

Enhance Access to Kidney Transplantation and Living Kidney Donation Strategy

Based on feedback from the patient-led workshop and evidence on the benefits of peer-support programs (Marlow et al. 2016; Sullivan et al. 2012), patients and researchers decided to include TAP as a key component in a province-wide, multi-component quality improvement intervention: The Enhance Access to Kidney Transplantation and Living Kidney Donation (EnAKT LKD) strategy. In brief, EnAKT LKD is a cluster-randomized clinical trial being tested in Ontario's 27 CKD programs, which care for ~28,000 patients with kidney failure. The four main intervention components include (1) quality improvement teams; (2) education for staff, patients and living kidney donor candidates; (3) TAP; and (4) CKD program-level performance reports on transplant metrics. The overall objective is to determine if the intervention enables more patients to complete key steps toward receiving a kidney transplant. The intervention (including TAP) began in November 2017. Further details on the EnAKT LKD trial can be found in the published protocol and in Figure 2 (Yohanna et al. 2021). The trial period ended on December 31, 2021.

Transplant Ambassador Program's Progress to Date

Since its inception, TAP has recruited over 100 transplant ambassadors in 13 of Ontario's 27 CKD programs (TAP was offered to all CKD programs starting in January 2022). Ambassadors have had thousands of interactions with patients and families. Although we do not yet know the impact of TAP on increasing access to transplant (results from the EnAKT LKD trial are expected in 2023), patients, healthcare professionals and transplant ambassadors have commented on the positive impact that they perceive TAP has had on patients. To improve interpretation of trial findings and future implementation, we are also conducting a mixed-methods process evaluation, which consists of surveys and interviews with healthcare providers at the CKD programs. Results from the process evaluation will provide further insights into the use of TAP.

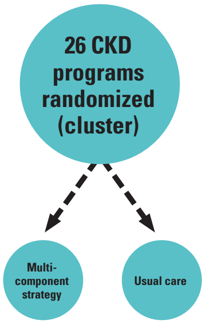
FIGURE 2.
Summary of the EnAKT LKD trial

EnAKT LKD

EnAKT LKD Summary:
A cluster randomized clinical trial designed to determine if a quality improvement intervention provided in Ontario's chronic kidney disease (CKD) programs (vs. usual care) enables more patients with CKD to complete more steps toward receiving a kidney transplant.

The EnAKT LKD trial comprises four main components:

1. Local quality improvement teams and administrative support
2. Education and resources for staff, patients and living kidney donor candidates
3. Program-level performance reports and oversight by program leaders
4. Support from kidney transplant recipients and living kidney donors through TAP



Source: Yohanna et al. 2021.

Patient Partnership

In addition to patients developing and leading TAP, patients helped formulate the EnAKT LKD research questions, select and design the intervention components and deliver intervention components. Briefly, the patient partners (1) are members of the quality improvement teams at each CKD program in the study; (2) helped review, create and select educational materials and connect patients to these resources; (3) review quarterly performance reports on transplant metrics to monitor their CKD program's progress; and (4) collect the data on process measures to include in these performance reports. Two of the patient partners are members of the provincial priority panel to improve access to kidney transplant. Patients continue to co-author all related manuscripts. Once results are available, patients will play a key role in interpreting the results and disseminating the results through patient and family advisory councils and through TAP.

To foster engagement with this work, patients meet regularly. For example, transplant ambassadors who have taken on a leadership role at their CKD program meet monthly, all transplant ambassadors meet twice a year, three transplant ambassadors attend monthly provincial calls with the 13 CKD-program quality improvement teams and one patient representative attends monthly calls with the core research team for the EnAKT LKD trial. Including patients on the core research team has been integral to ensuring that patients recognize themselves as equal members of the project and ensuring that patient input is incorporated into the project.

Researchers have commented that having patients involved in all parts of the research process and leading a key component of the intervention has generated unique insights about improving access to transplant. For example, through conversations between patients and transplant ambassadors, TAP has improved the patient experience by bringing forward patient-identified barriers to transplant. For example, some potential donors had commented that they had to wait a long time before receiving a call from the living kidney donor coordinator; transplant ambassadors brought this issue forward, which resulted in a solution to reduce wait times. Patients have commented that having a strong leadership role on the research team has provided them with a sense of empowerment and responsibility. Patients who have experienced kidney failure are often the most passionate to drive change in the transplant process and, therefore, it makes sense to have a group of motivated people lead TAP. Clinicians on the quality improvement teams have felt that having patients on the team has kept them accountable to improve access to kidney transplants and challenged them to change processes. Patients with kidney failure have commented that transplant ambassadors have been invaluable with helping them through the difficult journey to receiving a transplant, and the educational events hosted and attended by transplant ambassadors have been well received by patients.

Impact of the COVID-19 Pandemic

The COVID-19 pandemic forced all interactions between transplant ambassadors and patients to be virtual (i.e., via telephone or Zoom for Healthcare). There have been challenges with the switch to virtual, including the virtual environment being less engaging for patients and their families. The inability of ambassadors to be present in the clinic has impacted patient referrals to TAP. Patients are often less likely to engage with transplant ambassadors outside the clinic setting. For patients who engage virtually, transplant ambassadors have been given additional training on strategies to build rapport with patients in this new setting. For the broader EnAKT LKD strategy, we had to change all in-person meetings to a virtual format, which reduced opportunities for informal discussions and networking between healthcare professionals and patient partners across CKD programs.

Despite the challenges presented by the pandemic, the patients leading TAP continued to provide support to patients and even made improvements to the existing program. The new virtual environment provided an opportunity to connect ambassadors with patients in different locations. For example, a patient in London, ON, can now connect with an ambassador in Sudbury, ON. The pandemic also generated the idea to gather profile information on all the ambassadors (e.g., age, gender) so patients can connect with ambassadors who may have similar life experiences. During this time, TAP also expanded its recruitment using social media. One of the goals of this expansion was to create a more diverse group of transplant ambassadors and increase TAP's visibility.

Barriers and Facilitators to Patient Engagement

Despite our overall success with engaging patients in this research, there have been some barriers. First, it has been difficult to embed a patient-led program (TAP) into the workflow of the CKD programs. One reason for this difficulty is that during the pandemic, healthcare providers who were champions of TAP were often redeployed to other departments. To help embed TAP into the workflow, we gave presentations to the CKD program staff on TAP and encouraged healthcare professionals on the quality improvement teams to champion TAP to their colleagues. Second, ensuring full cultural, gender and kidney failure/transplant experience diversity across transplant ambassadors and patient partners on the research team has been difficult. To help overcome this barrier, TAP has increased its online presence to expand recruitment efforts and has recruited volunteers to help develop a diversity strategy for TAP, which will include diversity training for all ambassadors. Finally, it has been difficult to ensure that the CKD programs recognize patients as key members of the quality improvement teams. Patients sometimes struggle to describe barriers identified by other patients and donors in a way that can be acted upon by healthcare professionals. This has improved over time as healthcare professionals became more comfortable with having patients make these suggestions.

Despite some barriers, there have been multiple facilitators to engaging patients in this work. First, several of the patients had worked with the researchers on prior projects, establishing trust and a rapport. This trust allowed for an open line of communication between the researchers and patients to discuss any issues that might arise. This trust also allowed patients to develop, lead and run an entire component of the intervention (i.e., TAP). This contrasts with many other POR projects where researchers lead the research and patients support it. An assumption some researchers have is that patients should only be required to put in minimal effort; this may be because of concerns about the burden of disease in patients, misconceptions that POR is simply having a patient tell their story or because many patients are volunteers. While we must be cognisant of all members of the research team's time, TAP is proof that many patients are willing to put in hours of effort with patients having a vested interest in improving the system. Second, including patients in all components of the intervention has increased the quality and relevance of the intervention. Specifically, having patients lead an entire component of an intervention has allowed patients to be involved with identifying barriers and solutions and then actively break down those barriers. Third, having patients lead a component of the intervention has allowed for additional barriers and solutions to transplant be identified through ambassador conversations with patients. Finally, biweekly meetings with the core research team, including patients, has been key to sustaining patient engagement throughout this multi-year trial.

Conclusion

Patients have successfully developed and led a key component of a quality improvement intervention to enhance access to kidney transplant. Patient partners were involved throughout the study, from quality improvement intervention development to manuscript preparation, which has undoubtedly enriched the research and has ensured that the research is meaningful to patients and healthcare professionals. HQ

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