

Integrating the lived experience of kidney donors and recipients in transplant education sessions to increase the uptake of living donor kidney transplant (LDKT) in the Multi-Care Kidney Clinic (MCKC)

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Background

Humber River Hospital (HRH) is a community hospital with a comprehensive nephrology program encompassing the Multi-Care Kidney Clinic, Transitional Care Unit, Home Dialysis Program, and In-Facility Hemodialysis.

LDKT is the preferred renal replacement therapy for End Stage Renal Disease (ESRD). At HRH, an average of 10 patients per year were referred for pre-emptive kidney transplantation prior to the implementation of the Access to Kidney Transplant (AKT) initiative in 2018.

The AKT Initiative

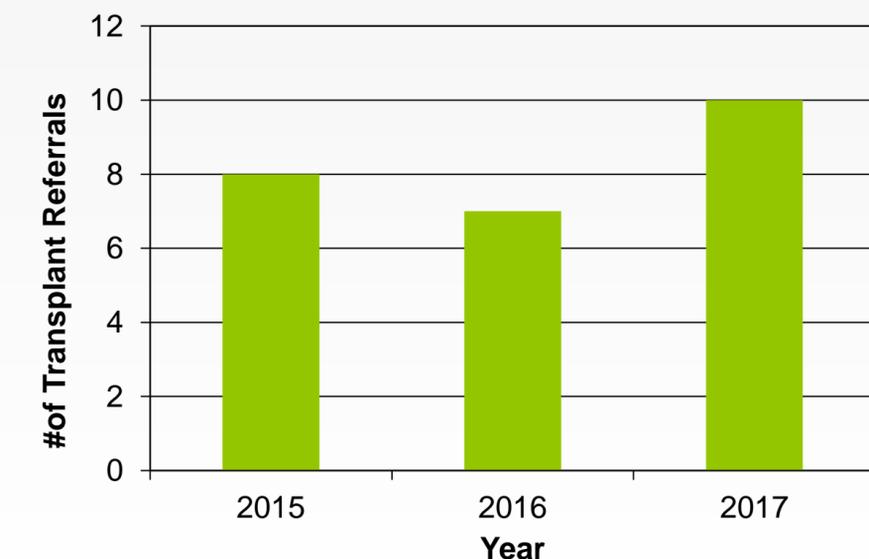
The AKT initiative, started in 2018 by the Ontario Renal Network, is a multicomponent initiative that aims to improve opportunities for, and access to, living donation and kidney transplantation for all chronic kidney disease (CKD) patients in Ontario (Explore Transplant Ontario, 2018).

The initiative is comprised of four main components – data, education, transplant ambassadors and administration – to support Chronic Kidney Disease programs, healthcare providers, patients and their families.

Problem

Prior to implementation of the initiative at HRH, transplant education was provided in an informal manner during pre-dialysis clinic visits either between the patient and/or family member with a nurse or nephrologist.

Transplant referrals were not formally tracked and data for that time period was collected by reviewing transplant referrals completed in the MCKC.



Method

HRH followed rolled out the AKT initiative through implementation of the 4 main components:

1) Data

- Formal template was created to gather data on number of education sessions provided, number of referrals made to transplant centers and number of transplants.
- Data was completed on a monthly basis and reviewed by stakeholders
- Through data collection, areas of improvement were identified and quality initiatives were in place to rectify the issues

2) Education

- Through the data collection, a need was identified for formal transplant education classes to raise awareness for patients and families to the benefits of living kidney transplantation
- Education classes focused on disseminating formal information on transplant work-up process.
- Integrated the Explore Transplant Ontario (ETO) education package to all patients identified by the clinic nurse to be ready or would benefit from receiving the education package
- Health care providers were required to review the education package also

3) Transplant Ambassadors

- Active recruitment of persons with a history of either being a donor or recipient to become an ambassador for HRH

4) Administration

- The leadership team ensured sufficient resources were allocated to the implementation of this initiative and provided facilitation during the monthly transplant meetings

Challenges

Prior to seeing results with the implementation of the AKT initiative at HRH, we recognized several challenges that prevented the successful integration of the above mentioned components:

- Education sessions did not yield a higher amount of referrals to the transplantation centers or garner increased patient interest in LKDT
- Post-session evaluation also showed that patients and families saw low value in the information provided
- The Explore Transplant Ontario education package was not efficiently used by patients and families
- HRH had a difficult time recruiting Transplant Ambassadors due to the time commitment required of the role

New Strategies

The AKT quality initiative team implemented several strategies to mitigate the aforementioned challenges:

- Transplant education sessions were now conducted in a more informal environment
- Recognizing the challenges of recruiting formal transplant ambassadors, we facilitated for previous kidney donors and recipients to join education sessions per their own availability to share their stories
- The sessions were more of a discussion panel where patients and family members were able to listen to the lived experience of donors and recipients and ask questions

Results

We found that with the integration of the lived experience of donors and recipients into the education sessions, there was increased engagement during the transplant education sessions by patients and families. Through collection of post-sessions evaluation data, patients and families expressed high satisfaction with the information provided which vastly differed from the transplant sessions where only transplant process information was provided.

The implementation of the AKT initiative combined with the integration of lived experiences in the transplant education sessions, there was a significant increase in referrals for pre-emptive kidney transplantation.



Lessons Learnt

- Peer support is vital in engaging patients when discussing transplantation; patients and families are interested in the lived experience more so than the process of transplantation
- Formal education sessions were not productive and yielded low engagement.
- Role of transplant ambassadors should offer less commitment to allow for flexible membership
- The ETO education packages were poorly used; it is a good tool but very difficult to follow through the all the videos and questionnaires and keep track of patients who have received the package and whether they were utilized appropriately