



Explore Transplant Ontario: Adapting the Explore Transplant Education Program to Facilitate Informed Decision Making About Kidney Transplantation

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Abstract

Purpose: In this article, we describe a province-wide collaborative project in which we adapted the Explore Transplant (ET) education program for use in Ontario, Canada, to develop Explore Transplant Ontario (ETO). Kidney transplantation (KT), especially living donor kidney transplantation (LDKT), is the best treatment for many patients with end-stage kidney disease (ESKD), with the best patient survival and quality of life and also reduced health care costs. Yet KT and LDKT are underutilized both internationally and in Canada. Research has demonstrated that patients with ESKD who receive personalized transplant education are more likely to complete the transplant evaluation process and to receive LDKT compared with patients who do not receive this education.

Sources of information: Research expertise of the lead authors and Medline search of studies assessing the impact of education interventions on access to KT and LDKT.

Methods: The ET program, developed by Dr Amy Waterman, has been used in thousands of patients with ESKD in the United States to enhance KT and LDKT knowledge. To adapt this program for use in Ontario, we convened a working group, including patient representatives, nephrologists, transplant coordinators, dialysis nurses, and patient educators from all Ontario KT centers and selected dialysis units. In an iterative process concluding in a consensus workshop, the working group reviewed and edited the text of the original ET program and suggested changes to the videos.

Key findings: The adapted program reflects the Ontario health care environment and responds to the specific needs of patients with chronic kidney disease (CKD) in the province. The videos feature Ontario transplant nephrologists, transplant coordinators, and patients, representative of the ethnic diversity in Ontario, sharing their transplant experience and expertise. Despite the changes, ETO is consistent with the quality and style of the original ET program. At the end of this article, we summarize subsequent steps to test and utilize ETO. Those projects, specifically the ETO pilot study and a multicomponent quality improvement initiative to increase utilization of KT and LDKT across Ontario, will be described in full in future papers.

Limitations: This article describes a provincial initiative; therefore, our findings may not be fully generalizable without further considerations. The adapted education program has not yet been tested in large trial for effectiveness.

Implications: As a program grounded in the theoretical model of behavior change, ETO places patients with ESKD at the center of a complex process of navigating renal replacement therapy modalities and acknowledges a broad range of patient values, priorities, and states of readiness to pursue KT.

Abrégé

Contexte: L'article présente un projet collaboratif provincial qui visait à adapter le programme éducatif états-unien Explore Transplant (ET) au contexte ontarien pour créer Explore Transplant Ontario (ETO). La transplantation rénale (TR), particulièrement la transplantation d'un rein avec donneur vivant (TRDV), s'avère le meilleur traitement pour de nombreux patients atteints d'insuffisance rénale terminale (IRT) sur le plan de la qualité de vie, des perspectives de survie et des coûts des soins de santé. Néanmoins, la TR et la TRDV demeurent sous-utilisées tant au Canada qu'ailleurs dans le monde. La recherche a démontré que les patients atteints d'IRT qui reçoivent un enseignement personnalisé au sujet de la greffe rénale sont plus susceptibles de procéder à l'évaluation et de recevoir une TRDV que les autres patients.

*Both authors contributed equally to the manuscript.



Sources: Au-delà de l'expertise de recherche détenue par les principaux auteurs, on a consulté les études publiées sur Medline qui évaluaient le fruit porté par des interventions éducatives sur l'accès à la transplantation rénale et sur la greffe avec donneur vivant.

Méthodologie: Élaboré par la D^{re} Amy Waterman pour mieux informer les patients sur la TR et la TRDV, le programme Explore Transplant a servi à des milliers de patients états-uniens atteints d'IRT. Un groupe de travail a été formé pour adapter ce programme au contexte ontarien : les participants compaient patients, néphrologues, coordonnateurs en transplantation, personnel infirmier en dialyse et intervenants éducateurs en provenance de l'ensemble des centres de transplantation rénale en Ontario et de certaines unités de dialyse. Dans le cadre d'un processus itératif qui s'est conclu par un atelier de consensus, le groupe de travail a révisé et adapté le texte original du programme Explore Transplant, en plus de suggérer des modifications à apporter au contenu des vidéos.

Principales constatations: Le programme adapté reflète bien le milieu de la santé en Ontario et répond adéquatement aux besoins particuliers des patients atteints d'IRT de cette province. Les vidéos mettent en vedette un ensemble d'intervenants représentatif de la diversité ethnique de la province : des néphrologues transplantologues, des coordonnateurs en transplantation et des patients qui y partagent leurs expériences et leur expertise. Bien qu'adapté, ETO est demeuré fidèle à la qualité et au style du programme original. Dans la dernière partie du présent article, nous résumons les prochaines étapes à entreprendre pour tester et mettre en œuvre le programme ETO; ces projets feront l'objet d'articles subséquents – plus précisément l'étude pilote du programme ETO et l'initiative d'amélioration de la qualité multicomposantes qui vise à accroître le recours à la TR et à la TRDV partout en Ontario.

Limites de l'étude: Cet article concerne une initiative provinciale; de ce fait, nos résultats pourraient ne pas être généralisables sans autres considérations. De plus, l'efficacité du programme éducatif adapté n'a pas encore fait l'objet d'un test à grande échelle.

Conclusion: En tant que programme fondé sur un modèle théorique de changement comportemental, ETO place les patients atteints d'IRT au centre d'un processus complexe d'exploration des modalités de thérapie de remplacement rénal. Le programme tient également compte du large éventail de valeurs, de priorités et de niveaux de cheminement des patients à l'égard de la greffe rénale.

Keywords

donation of organs and tissues, kidney failure, chronic, surgery, kidney transplantation, utilization, education, psychology, decision making, patient education, living donors

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What was known before

The Explore Transplant (ET) program is a comprehensive, patient-centered kidney transplant education program designed to assist health care providers in American dialysis centers and nephrology clinics in educating patients about their kidney transplantation (KT) options. The use of ET improved transplant-related knowledge and attitudes.

What this adds

Explore Transplant Ontario (ETO) reflects the Ontario health care environment and responds to the specific needs of patients

with chronic kidney disease (CKD) in the province. The program is ready to be tested for efficacy and effectiveness.

Background

Chronic Kidney Disease: A Rapidly Growing Global Burden

The increasing health care burden of chronic kidney disease (CKD) and the underutilization of kidney transplant (KT) are important concerns both in Canada and globally.^{1,2} The increase in end-stage kidney disease (ESKD) prevalence and the utilization of maintenance dialysis are outpacing

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population growth worldwide. The demand for transplantable kidneys exceeds the available supply from deceased donors; therefore, the international nephrology community is seeking ways to increase deceased donation, expand the deceased donor pool, and increase living donor kidney transplantation (LDKT).³⁻⁵ Despite these efforts, however, many patients with ESKD remain on maintenance dialysis and do not consider KT or LDKT as treatment options, or those options are not available for them.^{6,7} Waiting time for KT is increasing in developed countries, and many dialysis patients will die on the waiting list before a suitable donor becomes available for them.⁸⁻¹⁰ The reasons for this are diverse, but research has consistently demonstrated that a lack of knowledge and awareness regarding the benefits of transplantation among patients and in the general public is an important, potentially modifiable factor contributing to the underutilization of KT.¹¹

Benefits of KT for Canadians With ESKD

At the end of 2013, the majority (57.5%) of the nearly 42 000 Canadians with ESKD received some form of dialysis, whereas only 42.5% were living with a functioning KT.⁸ The advantages of KT over long-term dialysis treatment have long been established. First, patients with ESKD who receive KT have reduced morbidity and mortality compared with those who remain on dialysis.¹² The unadjusted 5-year survival rate for Canadian patients on hemodialysis was only 41%, compared with 81.4% for adult patients who received a deceased donor kidney transplant (DDKT) and 90.8% for those who received a living donor transplant (LDKT).⁸ In other words, many patients gain 10 or more additional years of life with KT compared with long-term dialysis. Second, KT has clear quality-of-life benefits for both affected individuals and their families.¹³⁻¹⁶ Finally, KT is associated with substantially reduced long-term health care costs compared with lifelong dialysis.^{8,17} For example, over a 5-year period, every 100 KTs performed save the Canadian health care system well over \$20 million in averted hospital-based dialysis costs.^{18,19}

However, the majority of Canadians with ESKD are treated with lifelong dialysis and never receive KT, a pattern that is consistent both at the national and provincial levels.⁸ Of the 24 114 Canadians on dialysis in 2013, only 3382 (14%) were waitlisted for kidney or simultaneous kidney-pancreas transplant.⁸ Furthermore, a recent analysis in Ontario showed that only 10% to 18% of the approximately 11 000 dialysis patients across all renal programs were waitlisted for KT, and there was a significant variation in waitlisting, referral, and transplantation rates across the regional CKD programs.²⁰ In an analysis of more than 400 000 patients on dialysis in the United States, KT referral rates among patients healthy enough to undergo transplant were also variable, while a significant proportion of patients with less than 5 years of estimated life expectancy got waitlisted.²¹

All this suggests that factors other than medical or surgical concerns may contribute to the observed practice variations and that the low proportion of waitlisted patients in Ontario may not be fully explained by an aging and more comorbid dialysis population alone.

Given the anticipated demographic trends, the need for transplantable kidneys in Canada will grow in coming years. From 2004 to 2013, the number of Canadians living with ESKD rose by 35% from 30 953 to 41 931.⁸ As the Canadian population ages and the rates of obesity, diabetes, hypertension, and other CKD-associated conditions grow, the prevalence of ESKD is set to rise and to fuel a consequent increase in disease burden and health care costs.²²

Explore Transplant: Transplant Education for Patients in American Dialysis Centers

Similar to Canada, a majority of patients with ESKD in the United States receive dialysis rather than KT, with approximately 63% of all patients with ESKD treated with some form of dialysis.²³ It is well established that minority groups such as African Americans and Hispanics experience significantly lower access to transplantation, which, among other things, has been attributed to disparities in their transplant knowledge and in the quality of transplant education they receive.²⁴⁻²⁷

Research has suggested that both health care system-level and individual factors can hinder American patients' access to KT and LDKT. For instance, a lack of knowledge about the benefits of KT, of transplant expertise among renal care providers, and of understanding of transplant eligibility criteria among both patients and health care providers have all been identified as barriers that may prevent patients from pursuing transplant.²⁸⁻³⁰ Dialysis centers often have insufficient resources to provide transplant information and to dispel misconceptions, as frontline staff may themselves lack transplant-related training, access to transplant education resources, or time to deliver transplant patient education.^{31,32} At an individual level, patients contemplating LDKT are often uneasy about initiating conversations with potential living donors, given their reluctance to coerce donors, their concerns about perioperative and long-term risks of donating, and a tendency to overestimate the risks of transplant surgery to both themselves and donors.³¹⁻³³ Furthermore, the transplant evaluation procedure for potential KT recipients and donors requires multiple appointments and tests, a process that may not be patient-centered or simple to navigate.³⁴

Deciding about the renal replacement therapy (RRT) modality that best suited to one's needs, personal goals, and preferences is a highly complex process. Evidence indicates that transplant education both improves patients' knowledge and helps them to develop the self-efficacy required to take steps toward transplant.³⁵⁻⁴² Furthermore, some of these studies showed that patients who received personalized KT

Table 1. Stages of Patient Readiness to Pursue Kidney Transplantation.³²

| SOC | Associated behavior |
|------------------|---|
| Precontemplation | Not considering or not ready to pursue DDKT or LDKT |
| Contemplation | Considering pursuing DDKT or LDKT |
| Preparation | Planning to pursue DDKT or LDKT |
| Action | Have contacted the transplant center, or are being evaluated for KT or having 1 or more living donors evaluated |
| Maintenance | Have already contacted the transplant center and have been waitlisted or have found a matching living donor |

Note. SOC = Stage of Change; DDKT = deceased donor kidney transplantation; LDKT = living donor kidney transplantation.

education were more likely to receive a KT or LDKT compared with those who have not.³⁹⁻⁴¹ In an additional study, Rodrigue et al³⁷ found numerically more LDKT among patients receiving home-based transplant education compared with other education methods. The difference, however, was not statistically significant. Personalizing and tailoring transplant education to patients' stage of readiness is vital. Patients who are undecided about KT often need further information to help make up their minds, whereas individuals in later decision-making stages require information on how to progress through the transplant referral process.^{27,43} The Explore Transplant (ET) program, developed by Dr Amy Waterman in the United States, aims to address these knowledge and decision-making needs.^{26,31,32,34}

The ET program is a comprehensive, patient-centered KT education program designed to assist health care providers in American dialysis centers and nephrology clinics in educating patients about their KT options.⁴⁴ Importantly, ET was developed to provide education customized to the patients' present stage of readiness to pursue transplantation. The program was also designed to address the specific information and support needs of African American patients, with the aim of reducing existing racial inequities in accessing KT and LDKT.^{26,36} The content and structure of ET are based on the Transtheoretical Model of Behavioral Change (TTM), which defines 5 Stages of Change in relation to individuals' readiness to modify complex health-related behaviors.⁴⁵

The 5 stages defined by the TTM are useful in illuminating patients' thought processes regarding KT (Table 1) and have been shown to be accurate measures to guide patient educators in assessing the information patients with ESKD are ready to hear.^{33,43} The ET package consists of a series of 4 education videos and accompanying information brochures designed to guide patients with ESKD through their transplant decision-making process, helping them to decide whether to remain on dialysis or to pursue DDKT or LDKT.

Table 2. Explore Transplant: Themes of Educator-Patient Visits.³²

| Visit | Theme | Conversation focus |
|-------|-------------------------------|---|
| 1 | Exploring Transplant | Could transplant add anything to the patient's quality of life? |
| 2 | Considering Deceased Donation | What would it be like to pursue a transplant from a deceased donor? |
| 3 | Considering Living Donation | What would it be like to involve a living donor? |
| 4 | Deciding What to Do | Developing an action plan appropriate for the patient |

The videos include personal testimonials from transplant recipients and donors, who share their experiences of dialysis, personal motivations informing their decision making about RRT, questions or concerns they had as they contemplated KT, and the impact KT or LDKT had on their life. The videos do not evade the difficulties patients may face in coping with a diagnosis of ESKD or in approaching potential living kidney donors. Alongside successful KT and LDKT stories, the videos also feature patients with failed transplants, as well as patients who opt not to pursue KT. The transplant professionals featured in the videos provide a balanced discussion of medical and technical aspects of transplantation and dialysis and emphasize the range of choice in RRT modalities. The brochures support patients in exploring KT, understanding why patients choose to get transplants, and deciding on treatment options suited to their circumstances and preferences.

The ET program is most often administered by trained transplant educators (renal nurses, nephrology technicians, social workers) in dialysis centers and predialysis clinics.^{31,32} Educators participate in a 1-day training session in which they expand their transplant knowledge and learn how to customize the program delivery based on patients' stages of readiness to pursue KT.³² The conversations between the educator and the patient are structured around the theme of the corresponding video (Table 2). Patients are encouraged to take the ET videos and brochures home to share with family members, friends, and potential living donors.

The ET has been tested in the United States in 4 randomized control trials.^{34,36,46,47} The first (published only as abstract) included 293 patients at 20 dialysis centers. The use of ET led to improved transplant-related knowledge, protransplant attitudes, and more referrals to begin transplant evaluation.⁴⁶ The other 3 trials (only protocols published, analysis of the data is under way) tested ET in various settings, enrolling about 1900 patients with ESKD. To date, ET has also been used broadly throughout the United States to educate more than 4000 American dialysis and nephrology providers and more than 28 000 patients and potential living donors.⁴⁴

KT in Ontario, Canada: Needs and Barriers

Patient education delivered by Ontario's regional CKD programs has not focused on transplant education, but rather on selecting a dialysis modality, promoting best body access practices and managing life with dialysis. In 2015, the Ontario Renal Network (ORN) and the Trillium Gift of Life Network (TGLN) partnered to form an education task group that conducted a province-wide needs assessment that surveyed frontline health care providers in Ontario's regional CKD programs, including patients, nephrologists, and dialysis and renal clinic nurses.⁴⁸ The aim was to identify barriers to the delivery of KT education and to inform the selection or development of suitable educational resources.

The needs assessment found that frontline CKD program staff not only faced severe time constraints limiting their opportunities for meaningful transplant-related discussions with patients and family members, but a majority also did not feel empowered to discuss LDKT with their patients. The assessment also found that prior to the initiation of dialysis, approximately one-third of patients in advanced CKD clinics were not adequately informed about KT as a treatment option.⁴⁸ Thus, the findings of this assessment supported the need to better educate frontline staff including nurses about KT and LDKT, as well as to provide improved educational resources for patients with ESKD and their families.

Based on the experience with the ET program in the United States, a working group was convened to adapt the program for use in Ontario, to provide Ontario patients and their families, as well as frontline health care staff, with personalized resources on KT and LDKT; to address their questions, concerns, and knowledge gaps; to improve professional training about KT for CKD health care providers in Ontario; and to improve transplant knowledge and education for patients and their families. This working group included patient representatives, nephrologists, transplant coordinators, dialysis nurses, and patient educators from all Ontario KT centers and selected dialysis units.

Adapting the ET for Use in Ontario: Development of Explore Transplant Ontario

In early 2015, members of the ET adaptation working group were invited to review the ET program, including the text and video and also the training manuals for patient educators. The working group began its adaptation work by identifying differences in practice between renal programs in the United States and Ontario, as well as system-level differences in health care delivery, funding, and insurance in the 2 countries. The group identified local sensitivities in Ontario in relation to religious references in the original ET material and recognized the need for the Ontario content to

reflect more fully the ethnocultural diversity in the province (to include Indigenous peoples and East Asian and South Asian Canadians). It was also necessary to update the ET content to reflect new knowledge about the risks of living donation. Once the sections of the videos, brochures, and booklets that needed changes were identified, these were rewritten and were subsequently subject to extensive discussion review during regular teleconferences in the summer of 2015.

The working group's revisions formed the basis for a full-day consensus meeting in Toronto on September 10, 2015, where transplant nephrologists, transplant coordinators, patient educators, and patient representatives finalized the changes necessary to adapt ET to the Ontario health care environment and for the specific needs of patients with CKD in the province. To produce Ontario-specific segments of the ET video materials, the project core team then recruited patient volunteers, family members, living donors, and health care professionals. In late 2015, the production team and the project core group collaborated to produce videos featuring Ontario transplant nephrologists, transplant coordinators, and patients, representative of the ethnic diversity in Ontario, sharing their transplant information and expertise. During this production phase, participants also finalized the content of patient brochures, educator training manuals, and program slide decks. During and after production, Dr Waterman and her team provided their professional expertise to ensure that the new Ontario materials were consistent with the quality and style of the original American version of the ET program. Following a second round of revisions to the draft version of the videos and brochures, the Explore Transplant Ontario (ETO) package was finalized in the Spring of 2016.

ETO Launch and Training Session

After the ETO program was finalized, a full-day pilot training session was held at Toronto General Hospital, University Health Network (UHN) in May 2016. Its purpose was to present the ETO package to the physicians, nurses, and other health care providers who had participated in the adaptation process and to show them how to implement the education program with their patients with ESKD. A secondary purpose was to train dialysis nurses, research students, and volunteers to use ETO with patients with ESKD at Humber River Hospital (HRH) in Toronto, in preparation for the ETO pilot study (described below). The session was moderated by Dr Amy Waterman and Ms Christina Goalby, a master trainer from the ET nonprofit organization based in the United States. Fifty-four participants attended; in addition to professionals from Ontario, nurses, coordinators, and nephrologists from Alberta, Saskatchewan, and Quebec also participated in this full-day training event.

Next Steps

ETO Pilot Study

Our research team conducted a pilot study in Toronto from June 2016 to June 2017 to test the efficacy of the ETO education program in increasing transplant knowledge and readiness among patients on maintenance dialysis.⁴⁹ This prospective, nonrandomized, parallel-arm study was conducted in the hemodialysis units at UHN Toronto General Hospital and at HRH among 229 patients undergoing maintenance hemodialysis. Participants at both sites went through identical procedures except that participants at HRH (the intervention site) were given an ETO education package to take home, whereas UHN participants (control site) received care as usual with no additional KT education. In addition, at HRH, research assistants from our team were present to support local renal nursing staff in delivering and tracking KT education. The ETO videos were made available for viewing on the central video platform of HRH during dialysis sessions. At both sites, research assistants also assessed the participants' readiness to pursue KT before, during, and after the education period using self-report questionnaires. Preliminary results, presented at the annual meeting of the Canadian Society of Transplantation, supported acceptability and efficacy.⁵⁰ The results will be published in full at a later date.

Access to KT Education Initiative

To improve access to KT and LKDT in Ontario, ORN and TGLN have initiated a multicomponent quality improvement project called "Enhance Access Kidney to Transplantation-Living Kidney Donation" (ENAKT-LKD; NCT03329521) (details of the initiative and the full protocol will be the focus of separate forthcoming manuscripts). This cluster randomized trial will implement educational and process interventions to improve access to KT and LDKT in Ontario. Outcome measures assessed will include CKD program-level KT referral rate, rate of living kidney donor candidates who contact the transplant center for evaluation, and transplant rate. Thirteen of Ontario's 26 regional CKD programs began participation in the fall of 2017, and the remaining 13 will join in the fall of 2019. The study will conclude in 2021. The 4 "pillars" of ENAKT-LKD are (1) data sharing, audit, and feedback; (2) a peer-mentoring (Transplant Ambassador) program; (3) transplant education for frontline staff and patients; and (4) administrative support from ORN.

The education pillar includes the development and implementation of a province-wide KT "core curriculum" for frontline renal staff and providing patients and staff with a curated KT education portfolio, of which ETO is an important component. A public ETO website (<https://etontario.org/>) developed for ENAKT-LKD went live in October 2017 and gives an overview of the program. (Online access to the

full ETO videos and brochures through the website is presently limited to patients and clinicians in the 13 Ontario CKD programs participating in the first wave of ENAKT LKD, during 2017-2019.)

Although delivering basic KT patient education is within the scope of work and continuing professional education for frontline CKD program staff, the ORN-TGLN partnership will monitor the impact on frontline staff of this intervention. Another potential unintended consequence of efforts to increase KT is an increase in the rate of referrals, including potentially "inappropriate" referrals for transplant assessment. However, with the increased awareness about transplant among nephrology nurses and clinicians, and also improved communication between transplant centers and renal programs, appropriate screening mechanisms can be implemented to mitigate that effect. Finally, some patients may become enthusiastic about KT, but eventually may be deemed not a candidate for transplant, and this may cause emotional distress. These patients will need to be identified and supported primarily by their home renal programs.

Psychosocial and Ethnocultural Barriers to LDKT

Factors related to ethnocultural background represent a significant barrier to KT and LDKT in Canada. We have recently confirmed earlier reports suggesting that access to KT is significantly lower among African and Asian Canadians, compared with Caucasian Canadians.⁵¹ This inequitable access was especially substantial concerning LDKT.⁵¹ Culture-specific health beliefs, religious and cultural concerns, socioeconomic deprivation, poor social support, disconnection from social networks, family and friends' health literacy disparities, language barriers, and mistrust in the Canadian health care system may all contribute to the observed differences. With these factors in mind, our research group is completing a mixed methods study to better understand the complex social, cultural, and psychological barriers that patients from various ethnocultural communities may face when considering LDKT. We collect quantitative information through self-report questionnaires from patients with ESKD about patients' social networks, attachment styles, KT knowledge, and readiness to pursue KT in the face of various challenges. We are also conducting focus group discussions with patients with ESKD, as well as members of their families and communities, to assess specific, culturally relevant attitudes, barriers, and education needs. This research is done in close collaboration with patient representatives, family members, religious leaders, and community organizations. Based on our improved understanding of the cultural barriers at play, we will develop culturally and linguistically competent education programs, initially for larger groups within Ontario (eg, South and East Asians), to serve as companions to ETO. The results of this study will be reported in separate manuscripts at a later date.

Conclusion

The ETO adaptation process brought together representatives from all Ontario transplant centers, as well as selected CKD program staff and patients, to create a consensus-based KT education program. As a program founded on theoretical models of behavior change and on adult education principles, ETO places patients with ESKD at the center of a complex process of navigating RRT modalities and acknowledges a broad range of patient values, priorities, and states of readiness to pursue KT. Its learning materials encompass both factual information on KT and RRT, and importantly, the experiential knowledge of patients, families, and live kidney donors. This program has the potential to provide a core of agreed-upon information to help patients with CKD to improve their understanding and their capacity for shared, informed decision making about RRT modalities. The ETO will also be useful to inform frontline renal clinic and dialysis staff about transplant. We hope to answer questions about efficacy and utility of ETO after our Pilot study and the provincial roll-out will have been completed.

Members of the ETO Adaptation Working Group

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Author contributions

All authors participated in drafting and finalizing the article.

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References

- Hill NR, Fatoba ST, Oke JL, et al. Global prevalence of chronic kidney disease - a systematic review and meta-analysis. *PLoS One*. 2016;11:e0158765. doi:10.1371/journal.pone.0158765.
- Thomas B, Wulf S, Bikbov B, et al. Maintenance dialysis throughout the world in years 1990 and 2010. *J Am Soc Nephrol*. 2015;26:2621-2633. doi:10.1681/ASN.2014101017.
- Jones B, Bes M. Keeping kidneys. *Bull World Health Organ*. 2012;90:718-719. doi:10.2471/BLT.12.021012.
- Zhang QL, Rothenbacher D. Prevalence of chronic kidney disease in population-based studies: systematic review. *BMC Public Health* 2008;8:117. doi:10.1186/1471-2458-8-117.
- Garcia-Garcia G, Harden P, Chapman J, et al. The global role of kidney transplantation. *Nephrology (Carlton)*. 2012;17:199-203. doi:10.1111/j.1440-1797.2012.01564.x.
- Vamos EP, Novak M, Mucsi I. Non-medical factors influencing access to renal transplantation. *Int Urol Nephrol*. 2009;41:607-616. doi:10.1007/s11255-009-9553-x.
- Vamos EP, Csepanyi G, Zambo M, et al. Sociodemographic factors and patient perceptions are associated with attitudes to kidney transplantation among haemodialysis patients. *Nephrol Dial Transplant*. 2009;24:653-660. doi:10.1093/ndt/gfn660.
- Canadian Institute for Health Information. *Canadian Organ Replacement Register Annual Report: Treatment of End-Stage Organ Failure in Canada, 2004 to 2013*. Ottawa, ON: Canadian Institute for Health Information; 2015.
- Hart A, Smith JM, Skeans MA, et al. OPTN/SRTR 2015 annual data report: kidney. *Am J Transplant*. 2017;17(suppl 1):21-116. doi:10.1111/ajt.14124.
- Pippias M, Kramer A, Noordzij M, et al. The European renal association - European dialysis and transplant association registry annual report 2014: a summary. *Clin Kidney J* 2017;10:154-169. doi:10.1093/ckj/sfw135.
- Waterman AD, Rodrigue JR. Transplant and organ donation education: what matters? *Prog Transplant*. 2009;19:7-8.
- Ortiz F, Aronen P, Koskinen PK, et al. Health-related quality of life after kidney transplantation: who benefits the most? *Transpl Int*. 2014;27:1143-1151. doi:10.1111/tri.12394.
- Evans RW, Manninen DL, Garrison LP Jr, et al. The quality of life of patients with end-stage renal disease. *N Engl J Med*. 1985;312:553-559. doi:10.1056/NEJM198502283120905.
- Neipp M, Karavul B, Jackobs S, et al. Quality of life in adult transplant recipients more than 15 years after kidney transplantation. *Transplantation* 2006;81:1640-1644. doi:10.1097/01.tp.0000226070.74443.fb.
- Pinson CW, Feurer ID, Payne JL, et al. Health-related quality of life after different types of solid organ transplantation. *Ann Surg*. 2000;232:597-607.
- Molnar MZ, Novak M, Mucsi I. Sleep disorders and quality of life in renal transplant recipients. *Int Urol Nephrol*. 2009;41:373-382. doi:10.1007/s11255-009-9527-z.
- Kidney Foundation of Canada. *Facing the Facts About Kidney Disease 2017*. Montreal, QC: Kidney Foundation of Canada; 2017.
- Kidney Foundation of Canada. *Facing the Facts about Organ Donation*. Montreal, QC: Kidney Foundation of Canada; 2018. <https://www.kidney.ca/facing-the-facts>.
- Klarenbach SW, Tonelli M, Chui B, et al. Economic evaluation of dialysis therapies. *Nat Rev Nephrol*. 2014;10:644-652. doi:10.1038/nrneph.2014.145.

20. Naylor KL, Dixon SN, Garg AX, et al. Variation in access to kidney transplantation across renal programs in Ontario, Canada. *Am J Transplant*. 2017;17:1585-1593. doi:10.1111/ajt.14133.
21. Schold JD, Srinivas TR, Kayler LK, et al. The overlapping risk profile between dialysis patients listed and not listed for renal transplantation. *Am J Transplant*. 2008;8:58-68. doi:10.1111/j.1600-6143.2007.02020.x.
22. Arora P, Vasa P, Brenner D, et al. Prevalence estimates of chronic kidney disease in Canada: results of a nationally representative survey. *CMAJ*. 2013;185:E417-E423. doi:10.1503/cmaj.120833.
23. United States Renal Data System. *USRDS Annual Data Report: Epidemiology of Kidney Disease in the United States*. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; 2016.
24. Churak JM. Racial and ethnic disparities in renal transplantation. *J Natl Med Assoc*. 2005;97:153-160.
25. Kucirka LM, Segev DL. The other half of informed consent: transplant education practices in dialysis centers. *Clin J Am Soc Nephrol*. 2015;10:1507-1509. doi:10.2215/CJN.08280815.
26. Waterman AD, Peipert JD, Hyland SS, et al. Modifiable patient characteristics and racial disparities in evaluation completion and living donor transplant. *Clin J Am Soc Nephrol*. 2013;8:995-1002. doi:10.2215/CJN.08880812.
27. Weng FL, Brown DR, Peipert JD, et al. Protocol of a cluster randomized trial of an educational intervention to increase knowledge of living donor kidney transplant among potential transplant candidates. *BMC Nephrol*. 2013;14:256. doi:10.1186/1471-2369-14-256.
28. Delmonico FL, Dominguez-Gil B, Matesanz R, et al. A call for government accountability to achieve national self-sufficiency in organ donation and transplantation. *Lancet*. 2011;378:1414-1418. doi:10.1016/S0140-6736(11)61486-4.
29. Rodrigue JR, Paek MJ, Egbuna O, et al. Readiness of wait-listed black patients to pursue live donor kidney transplant. *Prog Transplant*. 2014;24:355-361. doi:10.7182/pit2014337.
30. World Health Organization. *Fifty-Seventh World Health Assembly Resolution WHA57.18—Human Organ and Tissue Transplantation*. Resolution. May 22, 2004. Geneva, Switzerland: World Health Organization; 2004.
31. Waterman AD, Barrett AC, Stanley SL. Optimal transplant education for recipients to increase pursuit of living donation. *Prog Transplant*. 2008;18:55-62.
32. Waterman AD, Hyland SS, Goalby C, et al. Improving transplant education in the dialysis setting: the “explore transplant” initiative. *Dial Tran*. 2010;39:236-241. doi:10.1002/dat.20452.
33. Waterman AD, Robbins ML, Paiva AL, et al. Measuring kidney patients’ motivation to pursue living donor kidney transplant: development of stage of change, decisional balance and self-efficacy measures. *J Health Psychol*. 2015;20:210-221. doi:10.1177/1359105313501707.
34. Waterman AD, Robbins ML, Paiva AL, et al. Your path to transplant: a randomized controlled trial of a tailored computer education intervention to increase living donor kidney transplant. *BMC Nephrol*. 2014;15:166. doi:10.1186/1471-2369-15-166.
35. Massey EK, Gregoor PJ, Nette RW, et al. Early home-based group education to support informed decision-making among patients with end-stage renal disease: a multi-centre randomized controlled trial. *Nephrol Dial Transplant*. 2016;31:823-830. doi:10.1093/ndt/gfv322.
36. Waterman AD, McSorley AM, Peipert JD, et al. Explore transplant at home: a randomized control trial of an educational intervention to increase transplant knowledge for Black and White socioeconomically disadvantaged dialysis patients. *BMC Nephrol*. 2015;16:150. doi:10.1186/s12882-015-0143-0.
37. Rodrigue JR, Paek MJ, Egbuna O, et al. Making house calls increases living donor inquiries and evaluations for blacks on the kidney transplant waiting list. *Transplantation*. 2014;98:979-986. doi:10.1097/TP.000000000000165.
38. Rodrigue JR, Pavlakis M, Egbuna O, et al. The “house calls” trial: a randomized controlled trial to reduce racial disparities in live donor kidney transplantation: rationale and design. *Contemp Clin Trials*. 2012;33:811-818. doi:10.1016/j.cct.2012.03.015.
39. Rodrigue JR, Cornell DL, Lin JK, et al. Increasing live donor kidney transplantation: a randomized controlled trial of a home-based educational intervention. *Am J Transplant*. 2007;7. doi:10.1111/j.1600-6143.2006.01623.x.
40. Rodrigue JR, Cornell DL, Kaplan B, et al. A randomized trial of a home-based educational approach to increase live donor kidney transplantation: effects in blacks and whites. *Am J Kidney Dis*. 2008;51:663-670. doi:10.1053/j.ajkd.2007.11.027.
41. Garonzik-Wang JM, Berger JC, Ros RL, et al. Live donor champion: finding live kidney donors by separating the advocate from the patient. *Transplantation*. 2012;93:1147-1150. doi:10.1097/TP.0b013e31824e75a5.
42. Boulware LE, Hill-Briggs F, Kraus ES, et al. Effectiveness of educational and social worker interventions to activate patients’ discussion and pursuit of preemptive living donor kidney transplantation: a randomized controlled trial. *Am J Kidney Dis*. 2013;61. doi:10.1053/j.ajkd.2012.08.039.
43. Waterman AD, Robbins ML, Paiva AL, et al. Kidney patients’ intention to receive a deceased donor transplant: development of stage of change, decisional balance and self-efficacy measures. *J Health Psychol*. 2010;15:436-445. doi:10.1177/1359105309351248.
44. Waterman AD. Explore transplant & living donation: current & past trainings. 2016. <https://exploret transplant.org/explore-transplant-trainings/>. Accessed September 10, 2017.
45. Prochaska JO. Decision making in the transtheoretical model of behavior change. *Med Decis Making*. 2008;28:845-849. doi:10.1177/0272989X08327068.
46. Waterman AD, Hyland SS, Stanley S, et al. *Improving Education Increases Dialysis Patients’ Pursuit of Transplant: Explore Transplant RCT Findings*. Boston, MA: American Transplant Congress; 2009.
47. Weng FL, Brown DR, Peipert JD, et al. Protocol of a cluster randomized trial of an educational intervention to increase knowledge of living donor kidney transplant among potential transplant candidates. *BMC Nephrology*. 2013;14:256. doi:10.1186/1471-2369-14-256.
48. Network OR; and Network TGoL. *Access to Kidney Transplantation & Living Donation: Transplant Education Needs Assessment Report*. Toronto, ON: Ontario Renal Network and Trillium Gift of Life Network; 2017.

49. ClinicalTrials.gov. *Implementing "Explore Transplant" - A Pilot Study*. Identifier NCT03046732. 2017. <https://ClinicalTrials.gov/show/NCT03046732>. Accessed September 19, 2017.
50. Belenko D, Richardson C, Gupta V, et al. Kidney transplant education using the Explore Transplant Ontario package increases transplant knowledge in patients on maintenance dialysis. Paper presented at the Canadian Society of Transplantation and the Cell Transplant and Regenerative Medicine Society Joint Scientific Meeting 2017; September 26-29, 2017; Halifax, NS.
51. Mucsi I, Bansal A, Famure O, et al. Ethnic background is a potential barrier to living donor kidney transplantation in Canada: a single-center retrospective cohort study. *Transplantation*. 2017;101:e142-e151. doi:10.1097/TP.0000000000001658.