INTRODUCTION

While there have been dramatic improvements in pediatric SOT, adolescents aged SOT recipients demonstrate poor outcomes such as low graft survival, frequent hospitalizations, and higher rates of anxiety and depression. Adolescents who have undergone SOT verbalize that the process of transplant is very stressful and this population has demonstrated low health literacy levels regarding education around their transplants. Healthcare professionals play a vital role in providing education and psychosocial support to patients in this population.

Assessing the acceptability and efficacy of teens taking charge: Transplant—A pilot randomized control trial

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Abstract

Background: Adolescents who have undergone SOT are at heightened risk for graft failure. This pilot randomized controlled trial aimed to determine the feasibility and obtain preliminary estimates of efficacy of the online TTC program.

Methods: TTC is a web-based self-management program for adolescent SOT patients. Participants—kidney or liver transplant candidates or recipients—were enrolled over a 2-year period and randomized to either an intervention group that accessed TTC or a control group that did not access the program. Outcome measures included feasibility, how much the program was utilized, and pre- and post-intervention health-related outcomes evaluating self-management, self-efficacy, mood, use of healthcare services, and knowledge. Semi-structured interviews were conducted with participants post-intervention.

Results: Forty-two participants were enrolled in the study. Participants in the intervention group expressed that they enjoyed learning about other teens’ experiences, but reported barriers to accessing the site, such as being too busy, computer being too slow, and not being able to access the site on their mobile device. Time spent using the website was low for the majority of participants. Patients less than 1-year post-transplant accessed TTC more than patients who had their transplant for longer. No significant differences were found for health-related outcomes between groups.

Conclusions: No differences in health-related outcomes were found between groups. Further studies that examine barriers to engagement with web-based education tools are warranted.

KEYWORDS
adherence, adolescents, kidney transplant, liver transplant, patient education, pilot RCT, self-efficacy, self-management, web-based education tools

1 | INTRODUCTION
Adolescents are expected to adhere to stringent regimes post-transplantation for many aspects of their care, including medication, physical exercise, and diet. Inadequate self-management and coping skills can lead to poor health outcomes in adolescent patients, and unfortunately, these challenges can continue into adulthood. Patients undergoing SOT during adolescence demonstrate poorer long-term graft survival, which may be indicative of the non-linear process of developing self-management skills in this population. Therefore, timely adherence-promoting interventions aimed at improving medical outcomes and quality of life are critical.

Technology is an integral part of adolescent daily life. Studies showing that 95% of adolescents aged 12-17 years in the United States are Internet users underscore the need to develop technology-based interventions for adolescents. Patients with SOT and chronic illness have been shown to be receptive of health technology programs targeting both medication adherence and web-based peer support programs. High school-aged patients regularly access health information online at home and at school, and due to the frequency of Internet use, eHealth programs have the potential to help teen patients better follow their medical regimens and positively impact quality of life, self-efficacy, health education, and overall adherence. For example, a pilot study including patients with juvenile idiopathic arthritis investigated the use of a similar “Teens Take Charge: Managing Arthritis Online” program developed at our institution. They found the program helped to decrease pain, increase knowledge, and improve adherence to exercise compared to attention control group. Our online program was adapted from this previous pilot study.

Thus, there is a clinical need to develop a reliable and comprehensive online program designed to address self-management and target adherence barriers in adolescents who have undergone SOT, which potentially may lead to a reduction in health-related costs. Based on a previously conducted needs assessment and a usability testing study, the TTC program was developed. This pilot study had the following aims:

1. Determine study feasibility in terms of accrual and dropout rates, completion of outcome measures, and usage of TTC program.
2. Obtain preliminary estimates of efficacy of the TTC program among a group of pre- or post-transplant adolescents across the following health-related measures: self-management, self-efficacy, mood, use of healthcare services, knowledge, and medication adherence. We hypothesize that the intervention group (who access TTC) will demonstrate greater gains in these health-related variables compared to the control group.
3. Conduct interviews with participants in the intervention group following study completion to capture their experiences and perceptions regarding acceptability of the program.

2 | METHODS

2.1 | Participants

Eligible participants were identified and recruited at a large tertiary pediatric hospital in Canada. Participants were recruited from ambulatory renal and liver transplant clinics and from the chronic kidney disease and dialysis clinics between September 2014 and July 2016. Initially, patients were only recruited to the study if they were a minimum of 1-year post-transplant. However, following review of Google Analytics data of the enrolled intervention participants approximately halfway through the enrollment, a decision was made to include pre- and recently transplanted patients (i.e., <1 year) into the pilot study. This was due to participants’ website usage being lower than expected; it was hoped that pretransplant and more recently transplanted patients would be more motivated to use the website. Eligibility criteria for the study included: (a) proficiency in the English language; (b) undergone kidney or liver transplant or listed for kidney or liver transplantation; (c) aged 12-18 years; and (d) no significant intellectual or learning delay.

2.2 | Procedure

2.2.1 | Online program development

TTC was developed by an interdisciplinary team of healthcare professionals comprised of nurses, physicians, dieticians, social workers, psychologists, pharmacists, and surgeons, together with medical illustrators and medical content developers at the institution. A needs assessment was completed with transplant recipients, which informed development of the site. At different stages of development, usability testing was performed to generate feedback from patients and caregivers about the website. Feedback helped determine what aspects of the website needed revisions, or could be improved, and if any content was missing. This input was used to improve key features of the program, including navigation, content, and design.

The comprehensive online program consists of the following modules for adolescent liver or kidney transplant candidates or recipients: Introduction, Assessment, Listed and Waiting, Your Transplant Surgery, Going Home and Follow-Up, Medication and Vaccines, Self-monitoring and Potential Complications, Your Diet After Transplant, Your Life After Transplant, Managing Stress, Looking Ahead to Adulthood After Transplant, and Resources (see Figures 1 and 2 for details).

TTC also includes several interactive educational animations and videos of adolescent SOT recipients discussing their experiences before and after having a transplant. Modules are targeted at patients who are wait-listed for transplant, as well as patients who have already received a transplant and/or preparing to transition to adult care facilities. There are two caregiver modules that include content about helping your teen cope with transplant. The program is available in English with the kidney transplant section of the website also available in French. All content was written at a grade-six equivalent reading level.

Institutional REB approval was obtained for this study (REB file number: 1000045608). Written consent was obtained from patients and their parents/caregivers. Baseline demographic and pre-intervention outcome measures were obtained immediately following consent procedures or at a subsequent hospital appointment (outcome measures described below). Enrolled patients were
randomized into either (a) intervention (online TTC program) or (b) control groups (standard patient care), using the web-based randomization program Randomize.net. All participants were in the study for 12 weeks and continued to receive regular care at the hospital. At a regularly scheduled clinic visit approximately 12 weeks post-enrollment, participants completed outcome measures again. Participants received monetary compensation (Tim Horton’s vouchers ($5), parking voucher for visit ($20), and volunteer hours for their role in the study).

Semi-structured interviews were conducted following study conclusion with intervention group participants. Interviews were conducted by the research project coordinator, either face-to-face or by telephone, to obtain feedback about participants’ experience (acceptability) with the online intervention.

2.2.2 | Intervention group

Following group allocation, those randomized to the intervention group were contacted via e-mail with website access instructions. Intervention group participants were assigned a unique login and password to access the TTC online program, which was restricted to intervention group participants and research team members. Participants were instructed to visit the intervention website program for at least 1 h/wk but were encouraged to access the site as much as they liked during the study.

A semi-structured interview guide was used to capture the experiences and perspectives of participants in the intervention group after concluding the 3-month follow-up visit. Questions covered what participant liked the most/least and their impression of specific features of the TTC online program. Interviews were audio-recorded, transcribed verbatim, and subsequently analyzed by three research team members using simple content analysis as described by Sandleowski.20

2.2.3 | Control group

The control group were not given access to the TTC program. Widely available web-based materials (Appendix 1) were provided for control group participants that are routinely provided to all patients undergoing kidney or liver transplant, consisting of health-related websites with information about SOT and self-management. Participants randomized to the control group were told that they had the option of looking at these materials, but it was not mandatory.
2.2.4 | Phone call check-ins

Phone calls at 1- and 2-month intervals were made to participants in both groups to maintain engagement in the research study. Using a standardized script, participants in the intervention group were asked about frequency and duration of online program use and if any barriers prevented them from using the site as per study procedures. Participants in the control group were asked if they had accessed the online materials provided to them or if they had sought any online information related to their health.

2.2.5 | Demographic questionnaire

Participants in both study groups completed a demographic questionnaire including details of their age, gender, type of transplant, and amount of time typically spent on the computer and using the Internet per week.

2.2.6 | Use of the TTC program

Total minutes that intervention participants spent on the TTC website were recorded, with data obtained at three time points using Google Analytics. The differences in total use of the website across intervention group participants who were waiting for transplantation and who had received a SOT were reviewed. Compiled reports included the time spent on a specific web page, total time spent on the website per week, number of sessions per week, and the length of individual viewing sessions. The frequency and duration of visits to the TTC website was used to monitor the participants’ use of the intervention. Participants were informed about the use of Google Analytics during the study, and website activity for each participant was tracked using a unique ID.

2.2.7 | Health-related variables

All outcome measures were self-report.

Medical Self-Management and Transition Readiness Scale

The Medical Self-Management and Transition Readiness scale has been shown to be reliable and valid. Internal consistencies using Cronbach's alpha were high for youth at 0.89. Inter-rater reliability when measured between youth and parent report was \( r = .56 \) (\( P < .1 \)). This questionnaire includes 22 items using a three-item Likert scale where “0” indicates “No, I can’t,” “2” indicates “some but not all,” and “3” indicates “Yes I can.” Domains on this scale included the ability, knowledge, and participation in engaging with healthcare appointments and responsibilities. Scores range from minimum of 0 to a maximum of 66, with higher scores denoting greater independence.

Self-efficacy (Generalized Self-Efficacy Sherer Scale)

The GSE scale is a 12-item Likert format scale that measures self-efficacy relating to general independence. The responses are on a five-point scale ranging from "1" denoting "strongly disagree" to "5" denoting "strongly agree." Higher total scores represent greater levels of self-efficacy. Validity and reliability of the GSE has been explored in previous research. Internal consistency is good for adolescents with \( \alpha = 0.87 \). An example of a statement from this
scale includes: “if I can’t do a job the first time, I keep trying until I can.”

PROMIS pediatric anxiety and depression short form
Two separate eight-item short forms measured the participants’ emotional anxiety, including fear and hyper-arousal, and emotional depressive symptoms, including negative mood, social cognition, and self-perceptions. These scales have been shown to demonstrate sensitivity to change in various populations. Higher score shows higher anxiety or depression. Internal consistency for adolescents is α = 0.85.

Health utilization form
A six-item questionnaire was developed by the research team to collect data on participants’ contact with healthcare centers and medical team members within the past 3 months. Questions asked participants about engagement with the transplant clinic to see their family doctor, transplant team, or emergency department; changes in medications; and use of psychological therapies, such as counseling.

Transplant knowledge questionnaire
The research team created two separate questionnaires (one for kidney and one for liver transplant recipients) to assess the participants’ knowledge of transplant-related health information. The liver questionnaire contained nine multiple-choice questions based on website content, and the kidney questionnaire ten questions, with only one correct answer for each question. Higher total scores (0-10) are indicative of more proficient knowledge.

2.3 | Statistical analyses
Data analyses were performed using SAS 9.4 and Stata 12 Software. Descriptive statistics were used to describe the population, TTC program use, and health-related variable data using means with standard deviation or medians with interquartile range as appropriate.

3 | RESULTS
3.1 | Study population
A total of 58 patients were approached for participation. Of those approached, 14 declined participation due to having: (a) no access to a computer/Internet (two patients); (b) concerns about the time commitment required (two patients); and (c) lack of interest (10 patients). Forty-four participants (50% male) with a mean age of 15.1 years (range = 12-17 years) participated in the pilot study, with three participants subsequently withdrawing post-randomization (total of 19 intervention and 22 control). Six participants in the study group did not complete the interview due to an inability to schedule a time (3) and participants being too busy (3).

Four participants (two in the intervention group and two in the control group) enrolled in the study before receiving transplantation. The two participants in the intervention group were transplanted during their time enrolled in the study. See Table 1 for demographic data and Figure 3 for CONSORT flow diagram.

3.2 | Use of the TTC site
Ten participants spent less than 1 hour on TTC in total, and of that group, four participants did not visit the program at any point during the study. Participants who were less than 1-year post-transplant seemed to have longer cumulative program use. See Figure 4 for graphical representation of TTC website use across study time points.

3.3 | Preliminary estimates of treatment efficacy
After analyzing results descriptively, the self-management and self-efficacy score interquartile ranges were compared between groups at baseline and 3-month follow-up visits (see Figure 5 for box-plot representation). Table 2 shows mean score comparisons between groups at baseline and 3-month follow-up for medical self-management, generalized self-efficacy, depression, and anxiety scales. There were no significant differences in scores within or between groups in these or other measures.

From baseline health utilization scores, 53% (N = 10) of intervention group participants and 25% (N = 5) of control group participants reported accessing health services at least twice in the past 3 months, with 45% of control group participants reporting having accessed no services at this time. At 3-month follow-up, 47% (N = 9) of intervention group participants reported accessing health services at least twice in the previous 3 months and 32% (N = 6) of control group participants reported accessing health services at least twice at this time. On the transplant knowledge questionnaires, intervention group participants scored a mean of 7.1 (pre) and 7.3 (post), while control group participants scored a mean of 6.25 (pre) and 6.2 (post) at baseline and 3-month follow-up, respectively.

| TABLE 1 Demographic characteristics of participants from the intervention and control groups (n = 42) |
|-------------------------------------------------|-------------------------------------|-------------------------------------|
| Intervention group N = 19                       | Control group N = 22                 |
| Type of transplant                              |                                     |
| Kidney                                          | 12 (63%)                            | 15 (68%)                            |
| Liver                                           | 7 (37%)                             | 7 (32%)                             |
| Gender                                          |                                     |
| Male                                            | 8 (42%)                             | 12 (55%)                            |
| Average age at recruitment                      | 15.1                                | 15.2                                |
| Time since transplant (at time of enrollment)   |                                     |
| Not transplanted                                | 2 (11%)                             | 2 (9%)                              |
| Less than 1 y                                   | 9 (47%)                             | 4 (18%)                             |
| More than 1 y                                   | 8 (42%)                             | 16 (73%)                            |
3.4 | Follow-up interviews

Interviews for the initially recruited participants were conducted 1 to 3 months after completing the study, whereas subsequently recruited participants had greater variation of interview time, with some interviews occurring 3 months post-study completion. Scheduling difficulties and participant preferences to do the interview in person versus on the phone delayed the timing of the interview. Two participants from the intervention group who did not access the online program at any time declined being interviewed. Fourteen intervention group participants were interviewed. Themes that emerged from the interviews with study participants centered on the perceived strengths and limitations of the TTC intervention, as well as suggestions for practical revisions to the design of the TTC website. Participants noted that they found the TTC website relatable, stating “I saw one person saying how they often felt tired and I think I relate to that a lot. I wanted to see if people had the same experiences as I did” (Female, 18 years old) and “I knew [difficulties experienced with transplant] was correct because I experienced it myself” (Female, 18 years old).

Participants also commented on the helpfulness of the website as well as the ease of navigating the site and diversity of content. For example, “I would recommend this website to [new patients] because if they are going to have a transplant then they can learn some stuff, what they need to do after transplant, so that they can get used to it and apply it to their daily schedule and everyday life” (Female, 13 years old), and, “it was easy to use. It was easy to find things that you wanted to look at” (Female, 16 years old).

A potential barrier to the usability of the intervention included making time to access the website, as explained by participants who stated, “on school days it would be harder to get on because I had my homework to do, but on weekends it was a bit easier” (Female, 17 years old) and, “reminding myself was a big challenge. It wasn’t super significant, but it was a challenge and reminding myself by putting it into the phone would help me a lot.” (Male, 16 years old).

Participants shared suggestions for revising the website which were intertwined with potential barriers involving accessibility, such as one participant who said, “I think you should make it more...
accessible because, you know how it can only open on laptops, you should develop an app for like, a smartphone and tablets” (Male, 14 years old). Another participant commented on program speed, stating, “I think I would change the loading time to be faster…. Every time I would work on the website it would take five minutes to come up.” (Female, 15 years old).
4 | DISCUSSION

This pilot study sought to determine the feasibility, acceptability, and preliminary estimate of impact of the online TTC transplant program using a randomized controlled trial. While there were high accrual, low dropout rates, and a 95% rate of outcome completion at baseline and post-study period, there were no significant differences in health outcomes measured between groups. There was low usage of the online program. Many of the teenagers involved in the study did not utilize the website during the study for the minimum suggested hours even although in the previous study examining usability testing of the website, teenagers gave very positive feedback regarding the website and said they would use it and recommend it to others. In the qualitative interviews and phone check-in with intervention participants, they shared some reasons why they did not utilize the website, including being busy with school work, slow loading pages, and that they could not access the website on their mobile devices. In addition, patients who had received their transplant more than a year previously (and were relatively medically stable) said they were less motivated to explore information about transplant than those going through assessment and transplant surgery. Several months into the study, we reviewed Google Analytics usage data in the treatment group and determined that many of the recruited patients were not spending much time using the website. Some research has identified reasons for low engagement with eHealth interventions, such as a systematic review by Karyotaki et al who found (a) being male, (b) having a lower educational level, (c) increased anxiety, and (d) younger age was predictive of higher levels of attrition in self-guided studies in adults. Although patients in our intervention group did not report high anxiety, all were still attending high school, 50% were male, and all were of a young age (mean 15 years). Eysenbach suggests that participant dropout may be a natural and typical feature of eHealth studies and that high dropout rates may underestimate the impact of an application on the population that actually continue to use it.

The lack of significant differences in health outcomes between the intervention and control groups may have been due to the low usage of the site and the fact that many of the teens were more than 1-year post-transplant. Thus, it is not clear whether increased usage of the website would have led to an improvement in self-management skills. Mentoring and health coaching have been shown to improve compliance with the use of online programs. In the Teens Take Charge arthritis study, intervention group participants

| Measure                      | Baseline Intervention (N = 19) | Baseline Control (N = 20) | Three months Intervention (N = 19) | Three months Control (N = 20) |
|-------------------------------|--------------------------------|--------------------------|-----------------------------------|-------------------------------|
| Self-Management Scale         | 46.0                           | 44.35                    | 44.6                              | 45.9                          |
| Generalized Self-Efficacy Scale| 23.6                           | 24.4                     | 28.7                              | 27.7                          |
| PROMIS Depression Scale       | 6.7                            | 3.7                      | 4.7                               | 3.0                           |
| PROMIS Anxiety Scale          | 7.0                            | 5.4                      | 7.6                               | 4.8                           |

FIGURE 5 Interquartile ranges for Self-Management Scale and Self-Efficacy Scale outcomes for the intervention and control groups. *Y-axis numbers represent mean raw scores
received weekly health coaching from trained non-healthcare professionals who helped to tailor website content to meet the needs of the teens during the study. Each week the coach reviewed the previous week’s homework, knowledge quiz and goals, determined whether homework had been completed, and provided guidance and problem solving for any issues that had arisen. This study did show higher engagement and improved health outcomes. Having a health coach (healthcare provider or peer mentor) guide the teenager through the program may result in higher engagement with the program, which could improve health outcomes.

Although the teens expressed a number of barriers to use the website, many expressed that they related to the information provided on the website on a personal level. Many teens commented that they enjoyed hearing about the personal experiences of other teens. They felt it was reliable and trustworthy and felt it would be useful to new patients undergoing transplant. Changing the website platform so as it can be accessed on a mobile device may remove a potential barrier to use.

Self-guided exploration of an eHealth platform in an adolescent population may be insufficient to effect change. In the prior eHealth study with adolescents with arthritis group, following study completion the control group were given self-guided access to the website and hits and times on website were monitored by Google Analytics. In a similar timeframe, there were only 156 hits to the website (compared to 6757 during the study) and a total of 6.42 hours logged on versus 436.9 hours logged by study group participants. This suggests that combining an eHealth intervention with health professional coaching/peer mentoring allows users to build a relationship and provides a more individually tailored approach to address knowledge gaps and find information that is important and of interest. Thus, utilizing the website within a positive relationship, as a visual tool to reinforce concepts and ideas discussed in one-on-one teaching sessions, may be more effective in this age-group.

5 CONCLUSION

Adolescents in our study expressed finding the website reliable and would recommend it to others; however, this study did not find any differences between the study groups in health outcomes measured. Further research should examine reasons for non-engagement with adolescents in this population and web-based tools. In addition, other methods for improving engagement (such as health coaching, peer mentoring) need to be studied when using the TTC program. Finally, the value of using TTC as a visual tool during education sessions with adolescents and healthcare professionals could be further examined.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

AUTHORS’ CONTRIBUTIONS

Moira Korus, Anna Gold, Samantha J. Anthony, Rulan S. Parekh, and Jennifer N. Stinson: Advised on research design; Moira Korus, Elizabeth Cruchley, and Masa Calic: Contributed to writing paper; Anna Gold, Samantha J. Anthony, Rulan S. Parekh, and Jennifer N. Stinson: Contributed to editing of manuscript; Moira Korus: Conducted multiple previous studies for background of this research study; Elizabeth Cruchley, Masa Calic, Samantha J. Anthony, Rulan S. Parekh, and Jennifer N. Stinson: Assisted with data analysis; and Elizabeth Cruchley and Masa Calic: Collected the data and coordinated the research study.

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**APPENDIX 1**

**LIST OF TRANSPLANT-EDUCATION ONLINE RESOURCES SENT TO CONTROL GROUP PARTICIPANTS**

- [http://www.kidneypatientguide.org.uk/site/contents.php](http://www.kidneypatientguide.org.uk/site/contents.php)
- [http://www.kidney.org/transplantation/transAction/share.cfm](http://www.kidney.org/transplantation/transAction/share.cfm)
- [www.ablelink.org](http://www.ablelink.org)
- [www.eparent.com](http://www.eparent.com)
- [http://www.uhn.ca/MOT/PatientsFamilies/Clincies Tests/Pages/living_donor.aspx](http://www.uhn.ca/MOT/PatientsFamilies/Clincies Tests/Pages/living_donor.aspx)
- [http://www.kidney.ca/page.aspx?pxml:id=305](http://www.kidney.ca/page.aspx?pxml:id=305)

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