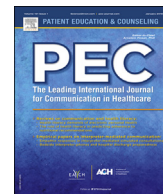




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Development of a patient-centered video series to improve education before kidney transplantation

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ABSTRACT

Background: Inadequate patient knowledge about transplantation can result in low patient satisfaction and contribute to poor clinical outcomes. The purpose of this patient-oriented research project was to develop an educational intervention for patients awaiting kidney transplantation.

Methods: An educational intervention was developed by patients and health care providers, experts in medication adherence, video education, motivational psychology, and cultural education. Project objectives were defined and content was guided by a series of studies conducted with stakeholders. A review process was undertaken with additional patients, external health care providers and ninth grade high school students and edits were applied accordingly.

Results: A set of six educational videos, ranging in length from 3 to 24 min, was created to describe the transplant process. The videos are patient friendly in design, and incorporate animations to explain complex information to accommodate low health literacy, and patient testimonials align the content with principles of adult learning theory. Feedback from external patient reviews [n = 8], external care providers [n = 13] and students [n = 26], indicate that the mini-series is informative and useful.

Conclusion: Patient involvement significantly influenced the development of a video series about kidney transplantation. Practice Implications: Patient engagement is integral for developing high quality and relevant educational interventions.

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1. Introduction

Transplantation is one of the most important developments in the treatment of kidney disease and is considered the treatment of choice for most patients. In comparison to patients undergoing dialysis, kidney transplant recipients live two to three times longer and have a better quality of life [1–4]. The road to transplantation, however, can be difficult. To become active on the transplant waitlist, patients must undergo a multidisciplinary medical evaluation, and navigate tests and appointments in a complex healthcare system. Patients who receive a kidney transplant face a

new set of challenges. They must adapt to lifestyle changes and attend frequent appointments for medical assessments and laboratory testing. The primary risk to transplant success is rejection, which can result in lengthy hospitalizations, transplant loss, shortened lifespan, and a significant cost to the health care system [5]. To minimize the risk of rejection, transplant recipients must adhere to indefinite therapy with immunosuppressive medications, which are complex, often cause side effects [6], and may even reduce quality of life [7]. Information about the transplant process and immunosuppressive medications is generally provided verbally by the transplant team and supplemented with written materials. Nevertheless, inadequate knowledge about transplant medications is a major problem following transplant surgery [8–10]. Studies in transplant recipients have reported a mismatch between expected and actual quality of life outcomes [11,12], patient satisfaction with pre-transplant education has been

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reported to be suboptimal in several studies [13–16], and medication adherence is a major problem [17].

A patient-oriented research project was undertaken to improve education for patients awaiting kidney transplantation. Patient-oriented research aims to apply the knowledge generated from multidisciplinary teams in partnership with relevant stakeholders to improve healthcare systems and practices [18], and has become recognized as integral for improving patient outcomes [18–20]. A needs assessment was conducted with stakeholders to determine the optimal informational content. Seven transplant recipients and 33 health care providers (including nephrologists, surgeons, nurses and pharmacists) shared their insights through qualitative studies. The transplant recipients were generally satisfied with their transplant education, but identified gaps in all areas of the transplant process, including the transplant waitlist, surgery, medications, and life changes post-transplant [21]. Health care provider's perceptions were consistent with the views of transplant recipients. They highlighted patient misconceptions about the assessment process and the surgery, incongruence between patient expectations and outcome, and confusion regarding medications [22].

A mixed-methods study was also conducted to understand the needs of patients listed and waiting for a kidney transplant [14]. Thirty-nine percent of patients (41/106) on the kidney transplant waitlist participated in the study to determine education satisfaction, transplant knowledge, health literacy and beliefs of medicines [14]. While the majority of participants had adequate health literacy (95%, 39/41) and scored high on the knowledge assessment, several patients were unsatisfied about education regarding what to expect after the transplant, and transplant medication (23% and 31%, respectively). This study provided insight on what patients perceived to be important in terms of education, such as frequent updates, highlighting the need for repetitive information (Fig. 1).

In the present manuscript, we describe the subsequent step in the project: development and testing of the educational intervention, and illustrate how the involvement of patients was critical to the intervention.

2. Materials and methods

2.1. Intervention development: video production

A 'creative team' was assembled to develop the intervention. The team consisted of two transplant pharmacists (HM, NR), a nephrologist (RM) and the video director (AKB) (also a community pharmacist). Based in the results of the needs assessment [14,21,22] and literature review on education in transplant, a set of guiding principles was developed. It was determined that the intervention would be delivered in the form of a video series. A pharmacy research summer student, also a kidney transplant recipient, was recruited to provide insight (PT), and medical animator was hired to animate difficult concepts (VN). Objectives were drafted and several preliminary brainstorming meetings were held to identify the best strategies to meet these objectives. A literature search identified evidence-based strategies to facilitate learning and retention. An expert in video education (JW), an expert in motivational interviewing and behavior change (MO), a research chair in patient adherence (DB), an Indigenous scholar with focus on communication, vernacular and metalinguistic detail (GM), and the medical director of the Saskatchewan Transplant Program (AS) were consulted as needed to provide guidance throughout this process. A detailed script was drafted reflecting information that was based on the needs assessments, brainstorming sessions and appropriate clinical information. The script was subsequently revised several times as indicated by the team. A visual storyboard was sketched for each animated

sequence in the script. Real life testimonials from patients and care providers were recorded, and the raw footage was catalogued and uploaded into editing software (Final Cut Pro X(v10.3), Apple Inc.). An additional video editor (RP) was hired to assist with compiling the footage, applying visual effects, designing the sound track, performing color corrections, and creating an initial draft of the mini-series.

2.2. Video review process

An intensive video review process was undertaken to ensure the goals of the project were achieved and that the intervention was perceived to be satisfactory by both patients and health care providers. The initial draft of the mini-series was thoroughly reviewed and revised by the creative team. Once an acceptable draft was available, the videos were sent for review to an external group of patients and project stakeholders. To ensure generalizability to other centers, individuals from other provinces were included in this cohort. Edits to the mini-series were applied based on this feedback. The first two videos were also shared with an external group of ninth grade students within the community, to confirm that the content was understandable and that the videos were appealing to watch. We reasoned that if we could engage a group of students with no interest in transplantation or external motivation, the videos would perform at least as well in a patient population with some healthcare experience and interest in transplantation. The students, who were unknown to the research team, were specifically asked "What did you understand from watching these videos?" and "What feedback to you have to the video developers?" They were asked to supply written, open-ended feedback. Finally, we hosted an in-house viewing of the mini-series. Patients that provided testimonials for the videos were invited to view the videos along with the staff of the Saskatchewan Transplant Program and share their comments with the creative team. Comments were discussed by the creative team and revisions performed accordingly.

3. Results

3.1. Intervention development: video production

The preliminary list of guiding principles developed by the creative team provided the framework for the intervention. It is shown in Table 1.

A set of 6 educational videos ranging in length from 3 to 24 min was created to describe the transplant process in its entirety. The videos are patient friendly in design, and incorporate animations to explain complex information to accommodate potential recipients with low health literacy. In the needs assessment that was conducted prior to script writing, several transplant patients described the transplant process as a 'journey'. To be consistent with this analogy it was decided that the videos would feature a relatable animated main character embarking on a 'transplant journey'. The videos are subsequently chunked into sections, with each video corresponding to a different stage of the transplant process and depicted by a map. The resulting videos are entitled: Video 1: Introduction; Video 2: The Kidney; Video 3: Assessment and Waitlist; Video 4: Operation and Recovery; Video 5: Medications; Video 6: Your New Life. As the animated character 'Marc' progresses through his transplant journey, actual patients and health care providers help to personalize the information and provide context by sharing their perspective and real world advice. These testimonials help to align the content with principles of adult learning theory. In total, thirty-five patients and family members were filmed and/or shared personal stories for the videos. Patients of varying ages, genders, and demographics

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