

A Mixed Methods Assessment of Home-Based Video Pretransplant Lung Education

Holly Mansell, PharmD¹ , Mark E. Fenton, MD², Julian S. Tam, MD², Nicola Rosaasen, BSP³, Louise Cardinal, BSP³, and Nicole Nelson⁴

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Abstract

Introduction: Patients awaiting lung transplantation must learn new information to successfully navigate the transplant process. A supplemental video series was piloted to patients at home during the Covid-19 pandemic to improve pre-transplant education. **Methods:** A mixed methods study was undertaken to assess patient experiences with this method of education, confirm the ideal timing of the education, and identify gaps that require further attention. Semi-structured interviews were conducted with 17 one-on-one or dyadic (patients and caregivers) who viewed the video series at home. A third-party researcher (not involved in creation of the educational materials) conducted the interviews by phone, which were audio recorded and then transcribed verbatim. NVivo 12 Pro for Windows software was used to code the data and identify emerging themes. **Results:** Participants indicated that home-based videos were applicable, and informative and helpful (4.7 on 5-point Likert scale) and appreciated the advice and experiences of real patients. They were satisfied with their transplant education (4.2/5). While there were few aspects that the participants disliked about the videos, the interviews elicited outstanding questions about the transplant process (eg, logistical aspects of travel) and transplant concerns (eg, medications, expenses, and precautions in daily life). **Conclusion:** Patients being assessed or listed for lung transplant valued the novel electronic video education, and we will implement the home-based process into standard of care after the patient's initial visit with the transplant respirologist. Pre-transplant education will be tailored to help address the outstanding gaps identified in this program evaluation.

Keywords

lung transplant, video education, remote, COVID-19, waitlist

Introduction/Background

The pretransplant period is a vulnerable stage in the lung transplant journey. Patients and caregivers face the stressors of coping with a progressive illness, the loss of autonomy, and anxiety from waiting for an organ.^{1,2} Education is fundamental; patients must learn skills for navigating the healthcare system and the lifestyle changes required after the transplant. The pre-transplant education process within our center currently involves a series of one-on-one consultations with the local transplant respirologist, and a trip to the transplanting center for education and pulmonary rehabilitation. During the Covid-19 pandemic many of these appointments have been performed virtually or by phone, rather than in person.

Recently, our interdisciplinary team collaborated with Lung Saskatchewan and patient stakeholders to develop a 6-part video series that describes the lung transplant process. The English videos, which were adapted from previous work³⁻⁵ according to best practice for education for patients pursuing transplants,⁶ are intended to supplement the first education session provided by the transplant respirologist. This initial meeting includes basic information about the transplant process (eg, what a lung transplant is, the process involved, potential risks and benefits, and what the expectations are

before and after the transplant). The session lasts between 30–90 min depending on the situation and is tailored to the patient's needs and understanding. The videos are 72 min in length, and feature an animated character and caregiver progressing through the transplant process interlaced with testimonials from patients and healthcare providers. The first two videos introduce the viewer to the series and to the impacts of lung disease; videos 3-6 describe the workup, waitlist, operation, recovery, posttransplant medications and required lifestyle changes. The videos are not intended to provide new information; rather they provide visual context and other patient's

¹ College of Pharmacy and Nutrition, University of Saskatchewan, Saskatoon, SK, Canada

² Division of Respiriology, Critical Care, and Sleep Medicine, College of Medicine, University of Saskatchewan, Saskatoon, SK, Canada

³ Saskatchewan Transplant Program, Saskatchewan Health Authority, Saskatoon, SK, Canada

⁴ Patient Advisor, Saskatchewan, SK, Canada

Corresponding Author:

Holly Mansell, BSP, PharmD, Associate Professor, College of Pharmacy & Nutrition, University of Saskatchewan, Health Sciences Building (Room 3208), 104 Clinic Place, Saskatoon, SK, S2N 2Z4, Canada.
Email: holly.mansell@usask.ca

actual experiences to supplement a process that may seem abstract when described verbally by the physicians. Patients and caregivers were invited to watch the videos. Coinciding with the Covid-19 pandemic, the completion of this project provided an opportunity to pilot and evaluate the education delivered to patients electronically (rather showing the videos in a clinic setting). The objectives of this program evaluation were to 1) determine the patient satisfaction with this new electronic home-based education; 2) confirm the ideal time for the supplemental education; and 3) identify gaps in education and issues that remain.

Design/Methods

Design

This mixed-methods study was approved by the local Behavioural Ethics Board (Beh ID#2143). All participants provided informed consent prior to participation.

Setting

Telephone interviews were conducted with patients from a single center adult-only satellite program in Canada. Patients at this program receive the workup and follow-up care at the home institution. They must also travel out-of-province to the transplanting center for pretransplant pulmonary rehabilitation and the transplant surgery.

Population

All eligible pretransplant lung patients were identified by the study physicians. At the time of the study, the target population consisted of 63% men, the mean age was 61 years, and 77% identified as Caucasian and 17% Indigenous. The top two reasons for transplant referral were interstitial lung disease and Chronic Obstructive Pulmonary Disease (COPD) (46% and 42%, respectively).

Sampling

Criterion sampling was used, whereby all participants who met the criteria (being assessed or listed for lung transplant) were mailed an invitation. Patients who had previously received a lung transplant were excluded. The research associate followed up with the potential participant by phone at least one week later.

Data Collection

Interviews were conducted by a third-party qualitative research associate from the Canadian Hub for Applied and Social Research (CHASR) by telephone using a semi-structured interview guide (drafted a priori by the team, which included patient input). (See Supplemental material) As a quantitative measure, participants were asked to rate statements pertaining to the educational value of the videos on a Likert scale of 1 = lowest to 5 = highest. The qualitative questions explored two unrelated

topics: a) those pertaining to this video appraisal (program evaluation) and b) the experience of Covid-19. These analyses were conducted separately. The program evaluation results are described in this manuscript.

Demographic data including residence, diagnosis, stage of process, age, gender, marital status, education, and ethnicity were collected. The interviews were audio-recorded, and field notes were taken to aid in interpretation of the data. Participants were invited to review the transcripts and were provided with a \$25 gift card after the interview.

Data Analysis

Quantitative results were reported descriptively. Qualitative inquiry used the principles of phenomenological inquiry⁷ to learn about the direct experiences of patients and was analyzed using the techniques of Braun & Clarke⁸ with NVivo 12 Pro (QSR International, 2021). Data were collected and analyzed by the third-party research associate.

Broad-based categorization was first applied to establish collections of data pieces (initial codes to digitally flag that which was deemed meaningful to the research questions) that could be further interrogated and determined as substantively connected or not. A secondary review consisted of scanning and locating poignant quotes driving the conversation applicable to the research question(s). Final coding involved taking the initial broad categories and reorganizing, splitting or submerging themes or sub-themes and placing data instances in their most appropriate categories.⁹ The aim was to remain inductively close to the data and the constructed and social meanings that cultivate from individual experiences.⁷

Procedure

The video series were hosted on the internet. Patients were mailed access to the password-protected videos and the qualitative research associate followed up to confirm interest and schedule a mutually convenient time for the interview after the videos were viewed in their entirety.

Results

Of 48 people approached, 22 participants interviewed for this project, 17 participants and 3 caregivers (spouses) watched the entire video series and are included in this manuscript. Being too busy or misplacing the video links were the most common reasons for not viewing the videos. The interviews lasted between 10–60 min (mean 35) and occurred between February–May 2021.

Patient Demographics

The majority of the participants (76%) were male and at least 60 years old (65%). Self-reported demographics are presented in Table 1. Figure 1 depicts a word cloud with the most frequently occurring words about previous research/learning on lung

hopeful nature, and practical insights as to what was critical throughout the process.

Negative aspects about the videos. Many participants had difficulty articulating what they liked least about the videos and a third (6/17) could not name anything when directly asked. Participant 4 said, “I don’t think there was anything I liked the least... I found it all very informative.” Another participant described the content as “right on the money” (participant 7). Stylistic or technical issues were mentioned by two participants, such as not being able to expand the videos to watch them full screen (participant 14), and the cartoons (participant 16). One participant indicated a desire for more specific information about impending experience at the transplanting center.

Objective 2: Timing

Most participants indicated that the videos should be watched early in the workup process, since this meant there was “time to process the information that we were given, before it became critical that we understand it.” (Participant 1). There were caveats to this such as ensuring videos were not watched at the time of diagnosis (to avoid potential psychological distress) and perhaps watching the videos more than once to reinforce education. Some participants indicated that it was useful to watch the videos after initial conversations with doctors had taken place, since the videos reinforced concepts introduced by medical professionals.

Objective 3: Gaps

Transplant concerns. Participants expressed their fears about aspects of the transplant process, including medications, expenses, and precautions in daily life. Some indicated that the content presented was not necessarily what they were expecting. According to participant 15: “Well it was easy to understand [videos] but kind of hard to swallow knowing that I’d eventually have to go through with that.” Some participants felt intimidated by the medications (eg, nomenclature, mechanism, number of pills, cost), but recognized that clinical situations vary. The thought of life after the transplant was anxiety provoking for some. Participant 1 said, “I think those testimonials sort of really reinforced the fact that the surgery is great, but it’s only the first step. There’s a lot of work that goes in afterwards, just as much as before a transplant.” The inherent risks involved in the surgery were intimidating, as well as the impact on other stakeholders involved in the donation process, and on caregivers.

Questions unanswered. Participants had some remaining questions about transplantation even after viewing the videos. These included questions about what happens logistically during the out-of-province trips to the transplanting center (n = 6) (eg, what you need to take/pack, how you might get there, cost, accommodations, the role of the caregiver, and what the trip involves). Lingering questions revolved around health status and what is meant by being healthy

enough for transplant or how having a lung transplant may impact a co-occurring condition or vice versa (n = 5). Financial supports (n = 2), post-surgery recovery and restrictions (n = 2), the surgery (n = 1), and whether to proceed with the surgery itself or its timing (n = 1) were also discussed. Demographic intake questions posed by the researcher revealed other unanswered questions. For example, 8 participants were not completely sure whether they were listed for transplant or for how long they might have been on the list.

Discussion

Quantitative and qualitative feedback from participants in this program evaluation confirmed that the electronic video series was a timely method for improving pretransplant knowledge during the Covid-19 pandemic. Participants perceived the videos to be helpful and they appreciated the insights of fellow patients, knowing their successes, or feeling their hope. This is not to say there was no emotional struggle in hearing about the risks, medications and aftercare involved, but rather that the videos helped inform in a way that provided a psychological preparedness for what is to come. Participants indicated that the videos would be most useful earlier in the process (ie, after a patient has some pre-existing knowledge, but has not yet been to the transplanting center).

While most participants did not explicitly offer suggestions for improving the videos, this endeavor uncovered valuable information for improving the pretransplant experience. Participants expressed concerns regarding medications, expenses, and day-to-day precautions, and articulated lingering questions about the logistical aspects of transplant, the role of a caregiver, financial issues, and health before and after the surgery. Uncertainty was also discovered regarding placement on the waitlist. These misunderstandings speak to a need for clearer communication between healthcare professionals and patients and increased areas for focused education.

This qualitative study provided rich feedback from participants who viewed the video series, but more study is needed to investigate barriers and reasons from those who did not. The participants were primarily Caucasian, and diverse perspectives are required. Furthermore, the results of this single-center program evaluation are not generalizable to other settings.

Conclusion

Supplemental home-based video education was valuable for providing education information during the Covid-19 pandemic and will be implemented as standard of care within our institution permanently. Based on the success of this program evaluation, the videos will be provided electronically to patients after their first visit with the transplant respirologist. One-on-one visits with the healthcare team will be focussed to address the outstanding gaps identified in this program evaluation, such as placement on the waitlist, and logistical aspects of the transplant process. A resource will also be created to highlight financial supports available to patients.

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ORCID iD

Holly Mansell  <https://orcid.org/0000-0002-6405-4775>

Supplemental material

Supplemental material for this article is available online.

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