Usability preferences of people living with cystic fibrosis about a lung transplant education website

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Abstract
People living with cystic fibrosis (CF) need educational resources about lung transplant prior to engaging in shared decision making with their medical providers. We conducted a usability study to elicit preferences of people living with CF about how didactic and experiential content could be used in an educational resource to learn about lung transplant. We created two prototypes with different design features that participants used in a scenario-based task and evaluated using the System Usability Scale. We interviewed participants and analyzed the data to understand their preferences for educational content and design. Study participants indicated that didactic resource articles were important to understanding their illness trajectory, while experiential patient stories supported fear reduction and knowledge discovery. When learning about lung transplant, participants stated a preference to control the amount of information they receive and preferred a combination of didactic and experiential knowledge.

Introduction
Cystic fibrosis (CF) is a genetic condition that often leads to early death from progressive respiratory failure.[1] Lung transplant is a treatment option for people living with advanced CF lung disease that can improve and lengthen their life -- but many people living with CF die before receiving a transplant.[2] Importantly, it has been demonstrated that people living with CF commonly express ambivalence about lung transplant, which can lead to deferring necessary discussions with healthcare providers until it's too late.[3] Although CF Foundation guidelines recommend education and shared decision making regarding transplant well before the need arises,[4] limited resources to facilitate discussions currently exist. There is an opportunity for informatics support to provide proactive education regarding transplant to people living with CF, therefore reducing ambivalence and increasing the ability to receive this potentially life-saving treatment.

Given the complexities of lung transplant, people living with CF need ample support and time to prepare for lung transplant decisions. Yet most educational resources designed to date have been decision aids designed for point of care consultation.[5,6] Decision aids are designed to help patients become informed and actively participate in shared decision making with medical providers, and have been shown to reduce patient decisional conflict and ambivalence.[7] In contrast to traditional health education material which aims to improve understanding and knowledge, decision aids focus on explicit options and associated outcomes, frequently used in conjunction with clinical consultation. Shared decision-making can be supported through "deliberation" - "a process where patients become aware of their choice, understand their options, and have the time and support to consider 'what matters most to them'" (p. 1365).[8] For a complex and life altering procedure like lung transplant, people living with CF need extensive information and time for deliberation. They express the need for both clinical information about the medical procedure from transplant professionals as well as experiential information about lived experience of lung transplant recipients.[9, 10, 11] Whereas clinical information is traditionally provided to patients in the form of didactic patient education, experiential information in the form of illness narratives offer value through patient stories.[12] While decision aids used during point of care consultation with medical providers have a critical role in shared lung transplant decision making, there is an opportunity for upstream educational tools that explain the complexities of the lung transplant experience and can be used over time in preparation for shared decision making.

To address these gaps, our team is designing an educational website for people living with CF to learn about lung transplant and prepare for timely transplant discussions with their CF medical providers. In our formative work, people living with CF who have received a lung transplant indicated that educational resources should include clinical information, patient stories, and frequently asked questions (FAQ). In this case, **didactic content** refers to clinical information, such as clinical facts and figures about lung transplant that CF patients receive from health professionals like CF physicians.[3] ***Experiential content*** refers to patient stories about the lived experience of lung transplant - people living with CF want to hear other people's personal accounts of lung transplant.[13] In fact, experiential content in the form of narrative stories provides information about the day to day experience as well as emotional support to improve patient knowledge.[14] Our FAQs included both responses from CF patients and CF physicians. When didactic content and experiential content are used together, educational tools are found to be more effective.[15] However, how to design educational tools to best provide these different types of content is underexplored.

We conducted a usability study to investigate how clinical didactic and experiential content are used by people living with CF in an educational website about lung transplant. Our aim was to elicit usability preferences from people living with CF who were prepared to discuss, but hadn't received a lung transplant. We address the following research questions:

RQ1. How do people living with CF, who are prepared to discuss lung transplant, prefer to use clinical didactic and experiential content in an educational website about lung transplant?

RQ2. How do people living with CF, who are prepared to discuss lung transplant, prefer to navigate an educational website about lung transplant?

Prototype Design
We constructed two prototypes to use as design probes to elicit preferences from people living with CF about how they would use an educational resource about lung transplant. The design parameters we explored were the organization of content (i.e., clinical didactic resources, experiential patient stories, and FAQs) and navigational control. The three content types could be organized into separate sections, forcing readers to navigate between sections to use content in siloes. In contrast, the three content types could be integrated on a single page, encouraging readers to more seamlessly use different types of content together. The navigational experience was either designed to lead participants through content in a recommended order based on a self-assessment survey (i.e., **"author-driven"**), or alternatively designed to allow participants to freely browse siloed content (i.e., **"reader-driven"**). In interactive visualization literature, these designs - referred to as "author-driven" and "reader-driven" - provide alternative navigational experiences[16]. We adopt this terminology for our alternative prototypes (Figure 1).

The content for both prototypes consisted of clinical didactic "resource articles", experiential "patient stories", and frequently asked questions ("FAQ") answered by CF clinicians and transplanted patients. FAQs reflected a combination of clinical didactic and experiential knowledge. In total there were 22,218 words of content across 17 webpages with an average Flesch-Kincaid readability grade score of 6.7 (SD=2.5). Table 1 describes the resource articles, patient stories, and FAQs. An answer from a clinician "Dr. Ramos," (KJR) was included in 3 FAQs, whereas the other 5 FAQs focused on the subjective experience of transplant and were answered only by patients.

Table 1. Description of available content in both prototypes

	Number of webpages *Total webpages 17*	Word count *Mean (SD), range*	Flesch-Kincaid readability grade score *Mean (SD), range*
Resource Articles	4	989 (492), 291 - 1419	9.75 (1.5), 8 - 11
Patient Stories	5	2927 (1049), 1475 - 4266	5.2 (1.9), 3 - 8
FAQs	8	453 (167), 280 - 731	6.1 (2.1), 3 - 8

In the *Author-Driven prototype* (Figure 1, top), the participant responded to a 6-question self-assessment survey about their health status. Based on those responses, a personalized home page listed recommended content: 2 resource articles, 2 patient stories, and 2 FAQs. Although only 6 web pages were recommended on the home page, participants were able to access the remaining 11 webpages by viewing any of the 6 recommended webpages. For the purposes of usability testing, the recommended content was the same regardless of survey response to allow for a similar user experience. We pre-filled responses in the self-assessment survey to provide participants with context for the recommended content.

In the *Reader-Driven prototype* (Figure 1, bottom), content was organized separately by type (i.e., resource articles, patient stories, and FAQs), and allowed the participant a free navigational experience to browse through each section of content. The prototype home page provided links to separate sections for resource articles, patient stories and FAQs. Each section listed all content available and included simple controls to filter the list of content. The top navigation of the Reader-Driven prototype contained a link back to the home page and links to navigate between each content type.

Figure 1. Author-Driven (top) and Reader-Driven prototypes (bottom). The Author-Driven prototype has participants submit a pre-filled self-assessment survey,(A) then recommends 6 web pages.(B) The Reader-Driven prototype presents the participant with 3 separate sections,(D) one for each of the three content types, and allows the participant to freely browse a list of articles associated with each content type (E). In the Author-Driven prototype, at the end of every webpage there were additional recommended webpages to read (C), while webpages in the Reader-Driven prototype didn't have this feature (F).

Methods

We conducted a mixed-methods usability study to elicit design preferences for a lung transplant educational website for people living with CF who have not received a lung transplant. We were particularly interested in design input from people living with CF that reported feeling prepared to discuss lung transplant with their CF care team. Prepared patients can reflect on their experience to consider information needs and preferences at different points in the illness trajectory, making this a valuable group to engage. Participant preferences were grounded by completing scenario-based usability tasks with the Author-Driven and Reader-Driven prototypes. Following usability tasks, we assessed participants' design preferences by asking them to rate each prototype with the System Usability Scale (SUS) [17]. To deepen our understanding of design preferences, we then interviewed participants to explain their SUS ratings. Procedures were approved by University of Washington IRB.

Participant Recruitment

We recruited participants through a screening survey that was distributed to adults 18 years or older with CF at the University of Pittsburgh, University of Minnesota, National Jewish Health, and via listserv to members of the CF Foundation's Community Voice, an organization that allows people with CF and their families to engage with and impact CF research. The screening survey collected self-reported health status, demographic information, and Likert ratings of preparedness to discuss and make decisions about lung transplant with their CF care team. Survey respondents were eligible for study participation if they had not received a lung transplant and reported higher levels of preparedness to discuss lung transplant with their providers. Higher levels of preparedness were self-reported on a Likert scale as "very prepared" or "moderately prepared" when asked how prepared they felt to talk to the care team about lung transplant or make decisions about lung transplant as a treatment option. Study staff at the University of Washington recruited a convenience sample of participants from eligible survey respondents. Participants were provided $45 after completing the study.

Data collection

We collected data through 90-minute individual sessions comprising 3 parts: usability tasks, prototype evaluation, and an exit interview. Sessions were conducted and recorded through video conferencing in Zoom. Participants navigated the prototypes through screen sharing in Zoom.

Usability tasks

Participants were asked to search for information about lung transplant using both the Author-Driven and Reader-Driven prototypes as if they were a fictional CF patient. Participants were given up to 15 minutes to complete each usability task by searching for as much information relevant to the fictional CF patient as possible. The order that participants used these prototypes was counterbalanced between participants to reduce order effects. Participants were asked to follow the concurrent think-aloud protocol to provide the research team with insights about their experience.[18]

For the Author-Driven prototype, participants put themselves in the shoes of **"Marco,"** a person living with CF who wants to understand if his CF is worsening and is considering discussing lung transplant with his doctor. For the Reader-Driven prototype, participants were **"Tamika,"** a person with CF who recently had a decline in her health status, is now using supplemental oxygen, and is actively contemplating lung transplant with her doctor. Our usability tasks aimed to elicit preferences at different illness stages - healthier (Marco) and sicker (Tamika) - rather than other characteristics such as age, technology familiarity, or health literacy.

Recordings of each usability task were viewed by two researchers to determine how the prototypes were used. The start and end of each usability task was recorded to determine its duration. To determine what content was viewed during the usability task, we recorded if resource articles, patient stories, or FAQs were viewed at least once and which content was viewed first.

Prototype ratings

After completing each usability task, participants completed the SUS to rate each prototype. SUS is a 10-item measure that produces three scores that range from 1 to 100 (higher scores are better); an overall SUS score, and subscale scores for usability and learnability.[19] SUS Scores greater than 71 are considered "ok", greater than 85 considered "excellent", and above 90 considered "best imaginable."[20]

Exit interview

At the end of the session we conducted an interview to understand participant perspectives about what they valued, and what they found challenging, about the resource articles, patient stories, and FAQs. Additionally we asked participants to compare the Author-Driven and Reader-Driven prototypes by describing what they preferred or found challenging and why.

Data Analysis

Data included quantitative data from usability tasks (i.e., counts of content types viewed) and SUS scores, and qualitative data from usability tasks (i.e., think aloud comments) and exit interviews. We summarized quantitative data with descriptive statistics. We compared SUS scores for the prototypes with paired t-tests.

For qualitative data, we conducted a deductive analysis of comments made during the usability tasks and exit interview. Using the quantitative data from usability tasks and SUS as context, three members of the research team (MRH, JBP, NR) made analytical memos about what participants found valuable or challenging about resource articles, patient stories, and FAQs (RQ1) and what they found valuable and challenging about the Author-Driven and Reader-Driven prototype (RQ2). The three researchers reviewed interview recordings, created, and compared analytic memos to establish reliability. Every interview recording was reviewed by two research team members. Disagreements and conflicting observations between reviewers were noted and resolved by building consensus through reviewing interview recordings together. Resulting memos were discussed with the broader research team to clarify and validate knowledge elicited from study participants.

Results
Fourteen people with CF participated in the study (P1-P14). Participant characteristics are described in Table 2.

The average duration of the Author-Driven usability task was 13:38 min (SD 2:02) and the Reader-Driven task was 12:32 min (SD 3:05). Table 3 shows the types of content viewed by participants during usability tasks. All participants viewed the resource articles with both prototypes. All participants also viewed patient stories with the Reader-Driven prototype, but only 10 did so with the Author-Driven prototype. FAQs were viewed by most but not all participants in each prototype. Resource articles were the first content viewed by the majority of participants with both the Author-Driven and Reader-Driven prototype.

Table 3 Resource articles, patient stories, and FAQs viewed with Author-Driven and Reader-Driven prototypes

	Viewed during task			First viewed during task		
	Resource Articles	Patient Stories	FAQs	Resource Articles	Patient Stories	FAQs
Author-Driven	14/14	10/14	11/14	12/14	1/14	1/14
Reader-Driven	14/14	14/14	13/14	8/14	5/14	1/14

Table 4 summarizes SUS scores for both Author-driven and Reader-driven prototypes. Overall the Author-Driven prototype was rated "ok" whereas the Reader-Driven was rated "excellent". Compared to the Author-Driven prototypes, the Reader-Driven prototype had higher overall SUS (p<0.001) and higher usability subscale scores (p<0.001). The learnability sub-scale scores for both prototypes were identical and nearly perfect (i.e., rated "best imaginable").

Table 4 SUS scores for Author-Driven and Reader-Driven prototypes

	Overall Score	Learnability subscale core	Usability subscale score
	Mean (SD), range, interpretation	*Mean (SD), range, interpretation*	*Mean (SD), range, interpretation*
Author-Driven	81.6 (10.0), 67.5-97.5 "Ok"	99.1 (3.3), 87.5-100 "Best imaginable"	77.2 (12.4), 59.4-96.9 "Ok"
Reader-Driven	90.0 (8.8), 70.0-100 "Excellent"	99.1 (3.3), 87.5-100 "Best imaginable"	87.7 (01.6), 62.5-100 "Excellent"

Table 2. Participant characteristics

Race	
White	14/14 (100%)
Gender	
Woman	11/14 (79%)
Man	3/14 (21%)
Another gender	1/14 (7%)
Age	
20 - 30	3/14 (21%)
30 - 40	7/14 (50%)
Greater than 40	4/14 (29%)
Self-reported health status	
Excellent	1/14 (7%)
Good	4/14 (29%)
Fair	7/14 (50%)
Poor	2/14 (14%)
Self-reported lung function	
Greater than 40%	8/14 (57%)
30% - 40%	3/14 (21.5%)
Less than 30%	3/14 (21.5%)
Self-reported preparedness to discuss lung transplant	
Not prepared	0/14 (0%)
A little prepared	0/14 (0%)
Moderately prepared	4/14 (28%)
Very prepared	10/14 (72%)
Self-reported preparedness to make lung transplant decisions	
Not prepared	0/14 (0%)
A little prepared	0/14 (0%)
Moderately prepared	4/14 (28%)
Very prepared	10/14 (72%)
Primary type of health insurance	
Private insurance	8/14 (57%)
Medicare	4/14 (29%)
Medicaid	1/14 (7%)
Military insurance	1/14 (7%)

RQ1. How do people living with CF, who are prepared to discuss lung transplant, prefer to use clinical didactic and experiential content in an educational website about lung transplant?

Benefits and challenges of **resource articles**
Generally, resource articles were seen as a preparatory resource that "*helps you know what's expected of you, and what to expect*" (P11). Some participants described resource articles as helpful by providing the "*whole picture*" (P4) of lung transplant. Participants said resource articles helped them understand what to expect -- even when information wasn't positive – it helped them "*not get their hopes up*" (P11). P9 valued topics "*no one really wants to talk about,*" such as death and estate planning.

Many participants described the tables and checklists presented in resource articles as particularly valuable for learning what to focus on and encouraging them to discuss lung transplant with their care team. P12 discussed this shorter information as being useful to know what physicians were paying attention to, so "*you can pay attention too.*" P9 described it as:

> "*Having it in a chart felt super useful, so you can see it -- and not play Bingo with it -- but be like 'oh, I have that already'*"

Despite these benefits which participants valued, some participants found the resource articles challenging to absorb because of too much text. P14 said the text was so dense that it "*buried information.*" In general, participants preferred charts and lists that were easier to digest, and suggested adding infographics to help summarize content.

Benefits and challenges of **patient stories**
Similar to resource articles, patient stories were perceived by participants as useful because they provided a description of the lung transplant process but added emotional value that could reduce fear. P4 emphasized that other people's stories illustrated that "*you can do it too*" and that "*stories change scary concepts from resource articles into hope, not scientific jargon.*" P6 described patient stories as useful to validate feelings and explain how the lung transplant process will feel. Patient stories were considered "*emotionally heavy*" (P12), but even difficult experiences were valued, as P5 described:

> "*I don't care if I know that people got better, I want to know what I am in for. If I want happy stories I'll go to Facebook.*"

Authoritative guidance offered by resource articles was valued by participants, and was preferred to "*anecdotal*" (P12) patient stories and FAQs perceived by some. Participants often mentioned that a person's experience with CF varies widely, and some dismissed patient stories and FAQs as "*too broad spectrum*" (P9). Many participants indicated that resource articles are valuable to view first to get objective information that was not provided by the patient stories. For example P2 stated that he wanted subjective phrases in the stories such as "*I got sicker*" to be explained statistically. Other participants felt that the emotion conveyed in patient stories limited the amount of content that could be consumed, while others generally found them to be lacking desired details. As P2 described:

> "*Most people want -- in my opinion, I guess -- the actual information* [facts] *before they want the patient story. I just wanna know, what the actual data is, you know as far as, when I should be getting more serious about it, when my CF is getting worse, rather than a similar patient story.*"

P4, a younger participant in their 20's, remarked not feeling represented in the patient stories, which were frequently about older people living with CF. P4 described patient stories of people who were older or less sick as not helpful because older and less sick people have had experiences younger and sicker individuals have not.

Benefits and challenges of **FAQs**
The variety of answers to FAQs from both the CF physician and other patients was valued by participants. One benefit we heard from participants was that responses to FAQs could reduce fear, similar to patient stories. This was often described in terms of finding perspectives that "*resonate with them*" (P9), and that more diverse respondents increases the value of FAQs. FAQs were valued to help gain perspective on the experience of lung transplant: "*Real*

without sugar coating" (P10). The concrete details embedded in the FAQs were seen by participants as valuable for reducing fear and aiding preparation as described by P4: "*knowing it's [a transplant evaluation test is] a tube going down your throat versus 'this one's [this test is] the worst' and you walk-in terrified.*"

Similar to patient stories, some participants were dismissive of FAQs and felt that resource articles provided more factual information. P1 said they would only read the physician's responses to FAQ, ignoring responses from patients for this reason.

RQ2. How do people living with CF, who are prepared to discuss lung transplant, prefer to navigate an educational website about lung transplant?

*Benefits and challenges of **Reader-Driven** navigation*
Participants expressed a clear preference for the Reader-Driven prototype, which was universally described as easier to navigate than the Author-Driven prototype. Some participants described wanting to be "i*n control of finding information,*"(P3) articulating that controlling how they navigate and iteratively search for and make sense of information is a central use of the website. P11 described that her interests would change while engaging with the educational tool, and she wanted the control to be able to find information and ask new questions as needs emerged.

Participants stated a clear preference for keeping the three different types of content separated. Some participants were confused by the integrated content in the Author-Driven prototype. Some described it as keeping "*social stuff*"(P1) and "*patient perspective*"(P13) separate from resource articles. For example, P4 shared:

> "*Even though it's color coded and all .... it's [the Author-Driven prototype] all over the place. I like it better when it's [content] kept in boxes.*"

Beyond a participant describing the Reader-Driven prototype as "clunky" (P1), the main challenge participants described with the Reader-Driven prototype is that it is less clear where a person should start reading -- this was described as a strength of the Author-Driven prototype described below.

*Benefits and challenges of **Author-Driven** navigation*
Participants thought that the recommendations provided in the Author-driven prototype served as a filtering function to provide a starting point that reduces the work of finding the right information. Participants liked that information could be tailored to meet them where they were and provide high quality information quickly. This feature aided people to "*see where they are*" with respect to needing a lung transplant (P7). P10 worried that having all the information at once would be too much information and that recommendations can "*help someone know where to start*"(P10). For example, P1 thought the recommendations would be helpful for most people because it was "*more guided*" and could help people find quality information, rather than "*clicking around by themselves.*" With the Reader-Driven prototype, P4 described the lack of recommendations as "*flying blind.*"

In contrast to these benefits, some participants described challenges using the Author-Driven prototype. Some participants explained that they didn't like that information seemed to be hidden in the Author-Driven prototype. For example, P4 said:

> "*I would like to have that overall category kinda thing [the Reader-Driven prototype's separated lists of pages] on Marco's [Author-Driven prototype], where I can go look at things on that and try to find any more hidden gems that I wouldn't have gotten in my recommended stuff*"

Other participants didn't trust the recommendations and desired greater control. For example, P8 expressed the following concern:

> "*To me, there's more room for error because, going off the survey, something could be missed. Here is the recommended information, but maybe I didn't answer something right. ... I'd rather be able to go through stuff myself.*"

In addition, some participants mentioned not wanting to initially enter information into a survey before getting to use the website and requested that the survey be optional.

Discussion

Beyond point of care decision aids, people living with CF have few educational resources to learn about lung transplant and prepare for discussions with their providers. Through a usability study, we investigated the preferences of people living with CF for the design of an educational website about lung transplant. We found that clinical didactic content in the form of resource articles was preferred for understanding the process of lung transplant, while experiential patient stories and FAQs were preferred for emotional support, such as reducing fear and gaining perspective (RQ1). Participants preferred to navigate between more clearly delineated (i.e., separated) content by type as presented in the Reader-Driven prototype rather than being guided through multiple integrated content types in the Author-driven prototype (RQ2). Our use of multiple methods offered a nuanced understanding of these preferences. Although controlling navigation was often discussed as preferred, participants also expressed utility in systems that recommend educational content as a starting point for transplant education.

Clinical didactic content was preferred as the initial content type viewed, in a manner that aligns well with the deliberation process in shared decision making – because it can be used to understand available options to create initial preferences and inform preferences.[8] Study participants described using the clinical didactic content in preparation to engage in the transplant process by learning how to start a conversation and building expectations about lung transplant evaluation and treatment. Experiential content also helped with preparation for the transplant process, but the subjective experiences of other patients also served to reduce fear. Online health communities also feature clinical didactic and experiential content, often being discussed as informational support and social support, that complement each other in a sensemaking process.[21] Participants in online health communities report similar tensions between didactic and experiential content, as there are needs for multiple perspectives offering social support but also needs for clear and direct clinical knowledge.[22] Our results suggest that both didactic and experiential content are useful components of educational resources that support lung transplant deliberation, which is similar to the design of educational resources about cancer that increased patient knowledge scores when experiential content was included with didactic content.[15]

Study participants preferred accessing educational resources in an iterative process, supporting prior work on information foraging theory and sensemaking. We found that participants preferred choosing which webpage to view next, rather than satisficing with a predetermined path.[23] Additionally, study participants indicated that educational resources prompted further exploration and collaboration with medical providers, similar to how perceived cues prompts sensemaking in chronic disease self-management.[24] Participants also found recommendations of initial content to be useful. Information technology should look to support a person's search process, rather than constrain it. Examples of supportive recommendations are computer agents to adapt content to a person's health literacy,[25] and methods like information fostering that aims to support the search process.[26] The iterative process that was preferred in our study needs to be explored further to see if allowing more agency is useful when people are making decisions about their health.

Under-preparedness for shared decision making about lung transplant is thought to contribute to ambivalence towards lung transplant among people with CF, which can potentially delay referral and increase the risk of death without transplant.[27] Informatics efforts could focus on supporting the process of deliberation by understanding how educational resources are used at different points of a patient's illness trajectory. Future research should focus on how to provide more agency to the patient. A systematic review of decision aids shows there are more resources with the physician involved than preparatory resources to aid patients having discussions with their doctor.[28] CF is a rare genetic condition, but it is still the 3rd leading indication for lung transplant worldwide. There may be similar information needs for people considering lung transplant to treat other types of advanced lung disease.[29]

Limitations

The limitations of this study primarily relate to generalizability and the limited scope of the prototypes. We recruited individuals with CF who reported feeling moderately or very prepared for discussions and decisions about lung transplant. The design preferences of these prepared participants could differ from people living with CF who feel less prepared. However, because these "prepared patients" were more informed about lung transplant, they were in a position to provide valuable design input when reflecting on their experience. Future work should explore the needs of patients who feel less prepared and those who may be less inclined to participate in research (e.g. those with lower socioeconomic status, lower health literacy, and more diverse with respect to race/ethnicity) to determine whether the findings translate across different populations. Additionally, while our prototype designs had many possible variations, we only evaluated two prototypes each was paid with a specific scenario. How SUS scores and

participant responses would have varied with a different usability scenario or prototypes is uncertain. The prototypes presented in usability testing were limited in scope, with only 5 patient stories and 4 types of resource articles. Some participants wanted more resource articles and others discussed not being represented in the patient stories we shared. Future work should include more comprehensive lung transplant educational resources.

Conclusion

We gathered the preferences of people living with CF about the design of an educational resource to support deliberation about lung transplant, for use prior to engaging in shared decision making with their medical providers. People living with CF preferred clinical didactic knowledge to understand their illness trajectory. Experiential knowledge and FAQs were useful to reduce fear about transplant. Yet, participants wanted control to freely navigate the full library of educational resources, including didactic resources, patient stories, and FAQs. A web-based resource for lung transplant education to support deliberation was well-received and rated highly by people living with CF. These findings fill a critical gap in available educational support for lung transplant.

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