

How people with cystic fibrosis value didactic and experiential information when learning about lung transplant

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Background

Lung transplant is an underutilized but life saving treatment option for some individuals with advanced cystic fibrosis (CF) lung disease. People with CF report diverse information needs to support shared decision making before lung transplant. In particular, prior work indicated the need for decision aids to include both didactic (patient education resources) and narrative (patient-authored stories) content. To optimize the design of a lung transplant decision aid, we explored the role of lung disease severity in how people with CF value these different types of content.

Methods

We conducted a usability study where CF patients without a prior lung transplant completed scenario-based usability tasks by interacting with a web-based decision aid prototype. In each usability scenario, participants searched for information as if they were a fictional patient with CF. One fictional patient was healthier with higher lung function and thus more removed from the transplant decision, whereas the other was sicker and actively considering lung transplant. After the usability tasks we interviewed participants to understand their preferences for didactic versus narrative content. We qualitatively analyzed session recordings to describe how participants valued each content type.

Results

Fourteen people with CF completed the study. Most felt didactic content was valuable for both healthier and sicker patients - describing didactic content as empowering patients to discuss lung transplant with their doctor. In contrast, narrative content was perceived as valuable for sicker patients as experiential details could aid preparation and reduce fear.

Discussion

Participants identified value in didactic content regardless of disease severity, but described additional value in narrative content for the sicker patient. To better support people making decisions about health care, we need to consider how different types of content - both didactic as well as experiential narratives - can support patients with varying degrees of disease severity.

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