






RESEARCH

Open Access



Adapting user-centered design principles to improve communication of peer parent narratives on pediatric tracheostomy

Haoyang Yan^{1,2*} , Stephanie K. Kukora³ , Kenneth Pituch³ , Patricia J. Deldin^{1,4} ,
Cynthia Arslanian-Engoren⁵  and Brian J. Zikmund-Fisher^{6,7} 

Abstract

Background: Parents who have to make tracheostomy decisions for their critically ill child may face forecasting errors and wish to learn from peer parents. We sought to develop an intervention with peer parent narratives to help parents anticipate and prepare for future challenges before making a decision.

Methods: To ensure that the intervention reflects parents' needs (rather than experts' opinions), we adapted a user-centered design (UCD) process to identify decision-critical information and refine the presentation format by interviewing parents who had tracheostomy decision making experience. **Phase 1** ($n = 10$) presented 15 possible forecasting errors and asked participants to prioritize and justify the problematic ones. It also asked participants to comment on the draft narratives and preferred delivery mode and time of the intervention. **Phase 2** ($n = 9$ additional parents and 1 previous parent) iteratively collected feedback over four waves of user interviews to guide revisions to the informational booklet.

Results: **Phase 1** revealed that parents wanted information to address all forecasting errors as soon as tracheostomy becomes an option. They also highlighted diverse family situations and the importance of offering management strategies. The resulting prototype booklet contained five sections: introduction, child's quality of life, home care, practical challenges, and resources. Feedback from **Phase 2** focused on emphasizing individualized situations, personal choice, seriousness of the decision, and caregiver health as well as presenting concrete illustrations of future challenges with acknowledgement of positive outcomes and advice. We also learned that parents preferred to use the booklet with support from the care team rather than read it alone.

Conclusions: A UCD process enabled inclusion of parental perspectives that were initially overlooked and tailoring of the intervention to meet parental expectations. Similar UCD-based approaches may be valuable in the design of other types of patient communications (e.g., decision aids).

Keywords: Patient education as topic, User-centered design, Narratives, Decision making, Pediatric tracheostomy

Introduction

With advances in medicine, tracheostomy placement has been increasingly performed in critically ill pediatric patients to enable long-term breathing support [1]. However, making a tracheostomy decision for a critically ill child is challenging for parents in various ways. Many tracheostomy decisions imply serious and

*Correspondence: haoyangy@umich.edu

² Present Address: Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, 625 N Michigan Avenue, 21st Floor, Chicago, IL 60611, USA

Full list of author information is available at the end of the article



irreversible outcomes, entailing a choice among options such as accepting a life-support-dependent future for the child, prioritizing the child's comfort and allowing death, and indefinite hospitalization [2]. Risks and benefits of each option preclude this from being a straightforward decision and each has significant long-term implications for the child and the family [2, 3].

However, parents may not always receive desired information to evaluate and prepare for tracheostomy [3, 4]. This makes them vulnerable to forecasting errors (i.e., inaccurate estimation of future experiences and/or emotions) [5–7], which may result in dissatisfaction with the decision process and outcomes [8]. Many parents perceive that learning the perspectives of other parents who have been in the same situation will provide informational and emotional support, but they often do not have an opportunity to talk with such peers [4, 9]. To correct this problem, we sought to create an intervention that used parent narratives to *inform* parents about important considerations (challenges in particular) of quality of life and typical life experiences with a child with a tracheostomy. The secondary purpose of the intervention was to *comfort* parents by normalizing emotional and practical challenges during and after tracheostomy decision making.

Recognizing experts' limited ability to understand parents' perspectives, we turned to a user-centered design (UCD) process, in which the iterative product development is guided by end users' feedback (e.g., users' goals, needs, and interactions with the prototype) so that the final product will be effective for intended users [10–12]. According to ISO 9241-210 (2010) as cited in [12], UCD embodies the following principles: "(1) The design is based upon an explicit understanding of users, tasks and environments; (2) Users are involved throughout design and development; (3) The design is driven and refined by user-centered evaluation; (4) The process is iterative; (5) The design addresses the whole user experience; (6) The design team includes multidisciplinary skills and perspectives." User-centered design has been applied and recommended in many domains, for instance, website [13] and software development [14], new product development [15], education [16], and health care such as health information technology and tool development [17–19].

Our primary goal of this UCD study was to optimize the usefulness of the intervention, i.e., to create representative narratives based on real experiences that specifically address different forecasting errors. Its secondary purpose was to improve usability. In this paper, we report how we adapted these UCD principles in two distinct phases to develop our intervention to aid pediatric tracheostomy decisions with maximal parental input.

Phase 1 aimed to identify important information needs to address in the intervention and obtain feedback on draft narratives. **Phase 2**, which consisted of four waves of 2–4 individual user interviews each, focused on eliciting feedback on the prototype intervention. The Standards for Reporting Qualitative Research (SRQR) checklist [20] was included as Additional file 1: Appendix A.

General methods

Application of user-centered design principles

We leveraged our knowledge of pediatric tracheostomy decisions and parents' needs through literature review, clinical experience, and our prior research including semi-structured interviews of parents who made a tracheostomy decision [21] and a survey experiment on narratives [22] to start the design process. We sought input from parents to better understand their needs and use context of the intervention and involved them in content identification and organization of the intervention via direct contact with the materials and in-depth semi-structured user interviews. We used an iterative design process (i.e., two design phases and four iterations in **Phase 2**), allowing us to repeatedly incorporate parents' feedback and update the intervention for more feedback. We did not aim to develop a complete decision aid for parents to make tracheostomy decisions, but we were open-minded about what to include for informing parents about the tracheostomy option. The design team included the following personnel with diverse expertise that would benefit this research: (1) decision scientists (HY, BZ-F), who have decision making expertise, research experience with parents making tracheostomy decisions (HY), and design expertise (BZ-F); (2) a neonatologist (SK) and a pediatric and palliative care physician (KP), who have rich experience working with parents, critically ill children, and tracheostomy decisions; (3) a clinical psychologist (PD), who has substantial research experience with parents who made a tracheostomy decision via previous interview research; (4) a nurse scientist (CA-E), who has extensive expertise in patient and provider decision making as well as nursing, a critical part in long-term care of patients with tracheostomy, and previously analyzed interviews of parents who made a tracheostomy decision.

Participants and data procedures

The study was declared exempt research by the University of Michigan Medical School Institutional Review Board (IRBMED).

Participant eligibility

To recruit parents who were experienced with preference-sensitive tracheostomy decisions and could offer

diverse perspectives, we sought to recruit parents who met the following eligibility criteria: (1) were fluent in English and were at least 18 years of age at the time of enrollment; (2) had made a tracheostomy decision for their child, with or without chronic mechanical ventilation, between about six months and three years prior to the interview; and (3) considered themselves knowledgeable about the child's condition and services, both at the time of the tracheostomy decision and afterwards. The child whose tracheostomy decision had been made should have met the following criteria: (1) was less than 18 years of age at the time of decision making; (2) had a life-limiting illness, in which either a decision to pursue or a decision not to pursue tracheostomy would be ethically appropriate; and (3) was a current patient or had been a patient at the time of tracheostomy decision making at a large Midwestern academic children's hospital and regional referral center for tracheostomy and home ventilation. The current state of the child could be one of the following: (1) if a tracheostomy was pursued: alive, subsequently decannulated, or deceased (more than six months ago prior to the interview, in order not to interrupt the bereavement process); (2) if a tracheostomy was declined at that time of decision making: alive or deceased (more than six months ago prior to the interview).

Participant recruitment

Eligible parents were recruited by one of the following ways: (1) clinicians' recommendations of parents who would potentially meet the above criteria by medical chart review; (2) a mass email to a group of parent volunteers sent by a volunteer coordinator at the study site; (3) flyers and brochures distributed on the study site. For potentially eligible and interested parents, their children's relevant medical information and their responses to the screening questions were reviewed before enrollment to ensure their eligibility and suitability for the study.

Data collection

We conducted 20 semi-structured user interviews ($n = 10$ for each design phase) between September 2019 and February 2020 at convenient mutually agreed-upon locations by the parents and interviewer. In addition to the interviewer, an undergraduate research assistant was present to take notes to facilitate data analysis. Each participant was compensated \$50 for the study plus travel incentives. The first author (HY) conducted all the user interviews. She did not have in-depth interactions with the participants prior to the user interviews, except for a few interactions with four of the participants in the previous interview study and recruitment of participants

for this study. The undergraduate research assistants did not interact with the participants directly during the user interviews. They all strictly followed the interview guide and note-taking protocol to minimize any potential bias.

Data analysis and reporting

The audio recordings were transcribed verbatim, de-identified, and checked by two research assistants for completeness and accuracy. The first author (HY) organized interview notes after each user interview. Given the goals of this study, the analytic process focused on critical feedback insights rather than a broader thematic analysis. Our reporting of data was focused on key takeaways rather than quotes. **Phase 1** data were analyzed to develop the prototype intervention. In **Phase 2**, we analyzed and discussed feedback to revise the intervention after each wave of user interviews. This process continued until the team was confident about the intervention's purposes, its design, and its applicability to this population.

Phase 1

The first phase aimed to identify important information to include in the intervention. Specifically, we asked parents to identify which forecasting errors they perceived to be problematic for informed decision making and to give feedback on five narratives of issues that they considered the most problematic.

Materials

Forecasting errors and narratives

Based on our review of the literature, clinical experience, and previous research [21, 22], we developed 15 single-sentence descriptions of forecasting errors in four key domains where forecasting errors might be common and more information support is warranted: quality of life, home care skills, material constraints, and impact on family life (Additional file 1: Appendix B). These descriptions represented candidates of problems for participants to help us identify important issues to address.

To begin with, parents reported valuing quality of life when making medical decisions for their children [23], but they may encounter *focusing illusion* (i.e., overemphasizing certain considerations and overlooking others) [24] and *misconstrual* of what the future may entail (as discussed in [25]) when evaluating the child's quality of life. We constructed five descriptions to illustrate potential biases, such as focusing on survival rather than other consequences for critically ill children [2, 26], anticipating regret and guilt if they had not tried everything for survival [27], and being overly optimistic about the long term [9, 28, 29].

In addition, parents assume a natural caregiving duty for their child and underestimate challenges of their child's complex home care needs [29]. Parents do not feel fully prepared for transitioning the care to home, handling emergencies and complications, and coordinating health care visits [4, 30]. Accordingly, we constructed three items to illustrate underestimation of the burden of home care commitment.

Professional and social support is important to sustain the care for a child with tracheostomy needs. However, resources may not be as easily accessible as parents expect, for example, a lack of suitable housing [31] and support from the community [9]. Parents may also overestimate the quantity and quality of home nursing care, as they feel stressed about inadequate nursing coverage to maintain their own well-being [30, 32, 33]. We constructed four items to describe these forecasting errors.

Furthermore, caring for a child with a tracheostomy has impact on the family's income, relationships, and social life. Some families experience employment and financial struggles [30, 32, 34]. Strained family relationships (i.e., marriage, parent-child) and social isolation were found associated with caregiving responsibilities of a child with a tracheostomy [9, 31, 35]. We created three items to describe these issues.

For each of the 15 forecasting errors, we constructed a short narrative. According to the Narrative Immersion Model [36], a constructed narrative can be as effective as a real story as long as it appears realistic, credible, and engaging. Experts including decision scientists (HY, BZ-F) and clinicians who are involved in pediatric tracheostomy decisions (SK, KP) reviewed the narratives to ensure that they captured the core ideas of the corresponding forecasting errors and presented accurate medical knowledge and realistic patient experiences without medical jargon.

Interview guide

The interview guide included four steps. Step 1 asked parents about their tracheostomy decision experience to prepare them for the study. It contained questions that asked about any difficulties during the decision process and their information needs. The tracheostomy decision process can be stressful and overwhelming to talk about. Therefore, we designed these questions to not only understand the decision making environment (the context in which the intervention will be used), but also guide parents to think about their challenges when making the decision.

Steps 2 and 3 primarily focused on improving the usefulness of the future intervention. Step 2 was a card sorting task in which parents were asked to think aloud and comment on how problematic these 15 forecasting

errors, if occurred, would be for parents to make informed decisions. We asked them to sort the forecasting errors into three categories: very problematic, somewhat problematic, and not problematic. After card sorting, parents were given opportunities to revise their sorting and comment more on each category of the cards. We further asked them if these issues were realistic and if we missed any problematic forecasting errors. While all of these forecasting errors are possibly relevant to tracheostomy decisions, our goal was to identify which errors were viewed by parents as the most critical to address. This step sought to understand parents' experiences and involve them in the identification of suitable content for the intervention.

In Step 3, we showed parents narratives that corresponded to the forecasting errors they perceived to be the most problematic and asked them whether they thought the narratives conveyed the core issues. We also elicited actionable feedback about what they would keep or change in the narratives. This step was designed to include parents in developing narratives for the prototype intervention.

In Step 4, we sought feedback about how and when such information should be delivered. This would help us set the tone and format of the prototype intervention, further understand the task environment, and increase usability.

Procedure

We asked parents for their consent to participate in the study and started the interview. At the end, parents filled out a demographics and experiences survey.

Data analysis

For Steps 1 and 4, the first author (HY) organized notes of every participant's response to each question. For Step 2, she reviewed the sorting and comments for each forecasting error. For Step 3, she summarized each participant's main comments and feedback on wording for each narrative and edited the narratives. Taking all the analysis, she made a summary of important things to focus on and prepared narratives for developing the prototype. She discussed the findings and made the initial versions of the prototype booklet with the senior author (BZ-F) through a series of meetings and email exchanges. A summary of key findings and the prototype booklet were emailed to the design team members, who made wording edits and offered suggestions over email until the prototype was deemed ready for [Phase 2](#).

Results

Ten parents were interviewed for [Phase 1](#). Parent and child characteristics are reported in [Tables 1 and 2](#).

Table 1 Participants' Demographics (N = 20)

Demographics	Phase 1 (n = 10)	Phase 2 (n = 10)*
<i>Relation to patient, n (%)</i>		
Biological mother	8 (80)	8 (80)
Biological father	1 (10)	1 (10)
Legal guardian/adoptive mother	1 (10)	1 (10)
<i>Age, median (range)</i>		
	37 (28–64)	41.5 (28–45)
<i>Race, n (%)</i>		
White	10 (100)	8 (80)
Mixed (Black or African American with one other race)	0 (0)	2 (20)
Hispanic, n (%)	0 (0)	1 (10)
<i>Marital status, n (%)</i>		
Single	1 (10)	1 (10)
Married	8 (80)	7 (70)
Single/Partnership	1 (10)	0 (0)
Divorced	0 (0)	1 (10)
Separated	0 (0)	1 (10)
<i>Education, n (%)</i>		
High school	1 (10)	0 (0)
Some college or post-high school education	1 (10)	5 (50)
College graduate	5 (50)	4 (40)
Master's degree or higher	3 (30)	1 (10)
<i>Household income, n (%)</i>		
< \$30,000	2 (20)	1 (10)
\$30,000–\$59,999	2 (20)	3 (30)
\$60,000–\$89,999	2 (20)	1 (10)
> \$90,000	4 (40)	4 (40)
Rather not say	0 (0)	1 (10)

* One parent also participated in [Phase 1](#)

Overall, parents reflected that all 15 forecasting errors were realistic issues that might be problematic for making an informed tracheostomy decision. Based on their feedback, we identified the following key components that should be reflected in the content and tone of the prototype intervention:

First, parents acknowledged that they should consider factors other than survival but emphasized that the decision should be made based on the child's best interest rather than convenience and needs of the parent caregivers. They reported diverse expectations and perceptions of a child's best interests. Some valued tracheostomy as a means for their child to thrive while others considered tracheostomy as a threat to their child's comfort and current active life. Either way, parents wished to know both positive and negative outcomes at the time of decision making.

Second, parents considered insufficient preparation regarding home care very problematic. Parents reported that the caregivers ought to be prepared for routine tasks. Otherwise, the caregivers would be stressed and the

child's life may be at great risk due to inadequate care. Parents also reported the lack of competent and reliable nurses to provide care.

Third, parents reminded us that some forecasting errors might be more consequential for some patients' families than for others. For instance, having a child with a tracheostomy might significantly impact household income if both parents used to work, but might have little or no influence, if one parent already stayed at home. Family relationships and social life could also depend on how strong the relationships were.

Fourth, parents described that both making the decision and taking care of a child with tracheostomy could be scary and emotional. They said it would be important to get emotional support and know that other parents have similar feelings. They would not only want to know the challenges, but also support and solutions for those issues to preserve some positivity in life.

Fifth, most parents preferred to get information about tracheostomy and its influences on everyday life as soon as it became an option. Parents appreciated ample time

Table 2 Parent-Reported Children's Information (N = 20)

Characteristics*	Phase 1 (n = 10)	Phase 2 (n = 10)†
Age, range‡	3 months–15 years 4 months	3.5 months–10 years
Age of tracheostomy decision, range	1 month–14 years 6 months	At birth–about 10 years
Duration of tracheostomy if applicable, range	3 months–1 year ongoing	1 year and 9 months–3 years ongoing
Sex, n (%)		
Boys	7 (70)	4 (40)
Girls	3 (30)	6 (60)
Race, n (%)		
White	9 (90)	6 (60)
Black	1 (10)	0 (0)
Mixed (White with one other race)	0 (0)	3 (30)
Hispanic	0 (0)	1 (10)
Final decision, n (%)		
Tracheostomy with ventilator	4 (40)	5 (50)
Tracheostomy without ventilator	2 (20)	0 (0)
No tracheostomy	4 (40)	5 (50)
Current condition, n (%)		
Tracheostomy with ventilator, alive	3 (30)	4 (40)
Tracheostomy without ventilator, alive	2 (20)	0 (0)
Tracheostomy removed, alive	0 (0)	1 (10)
No tracheostomy, alive	3 (30)	1 (10)
Deceased more than 6 months ago	2 (20)	4 (40)

*Parents reported that their children had diverse diagnoses, including chromosomal disorders (e.g., trisomy 18), musculoskeletal syndromes, rare genetic conditions, brain malformations and injury (e.g., cerebral palsy), and pulmonary pathology (e.g., bronchopulmonary dysplasia and malacia)

†One child was also included in Phase 1

‡birth to date of interview or date of death

to digest the information before doctors let them know it is necessary to make a decision. Having information prior to the family meeting would help them ask the right questions, whereas having information after the consultation would enable parents to ponder over their most relevant issues. They preferred multiple ways to deliver the information, such as a short video, pamphlet, website, and app.

Discussion

We decided to make a short booklet because it is a simple and efficient way to present information and it could be adapted to other formats relatively easily. Our findings shaped the content and design of the prototype booklet. First, parents wanted to make the decision for the child's best interest, not theirs, which is consistent with one of the good-parent beliefs—"putting the child's needs above my own" [23]. While the caregivers' physical and mental health is important, we realized that the booklet needed to reflect a delicate balance of describing different types of challenges and not frame the situation as a tradeoff between the interests of the

child and parent caregivers. Second, since parents worried most about not knowing specific details of tracheostomy home care, we decided to provide more detailed narratives on this topic to fulfill the identified needs. Third, there appeared to exist an issue of balance of positive and negative information. As the impact of forecasting errors may depend on the family's situations, we decided to acknowledge and describe different levels of impact explicitly in the narratives. Moreover, while a focus on negative aspects of lived experiences validated parents' feelings, it could be overwhelming to learn about all the challenges without knowing ways to deal with them. Therefore, we decided to present not only the challenges, but also useful advice shared by parents. Fourth, we learned that parents wanted information as early as possible, so we strove to frame the information using an open-minded tone and to focus on getting parents think about these issues. These takeaways addressed user experience (usefulness) by attending to parents' urgent needs for diverse perspectives and solutions.

Phase 2

The second phase focused on eliciting feedback on the prototype intervention. The first three waves each included individual user interviews of two parents and the final wave included four.

Materials

Booklet

The prototype booklet of narratives (Table 3) consisted of five sections. To make it easy for parents to understand and follow, each section was organized by key takeaway points with narratives in simple vocabulary and large prints. The initial concept is that parents could read the booklet before a meeting and take home as appropriate. The goal of Phase 2 was to revise the booklet iteratively based on parents' and professionals' feedback.

Interview guide

Step 1 was the same as that in Phase 1. Step 2 aimed to obtain parents' perceptions of important, concerning, and unnecessary parts of the booklet so that we would know what to keep, change, or add. These questions were designed to improve the usefulness of the booklet, acquiring an explicit evaluation and understanding of whether the booklet adequately conveyed parents' experiences and held value for helping future parents understand these topics. We also asked parents about their perception of the length of the booklet and welcomed them to edit the booklet to increase usability as well. In the second and third waves, we focused more on probing less important points that could be removed and the third wave added one question about whether to take out or combine stories in the "support from schools and public" section. Step 3, which asked more specifically about the booklet, was similar to Step 4 in Phase 1.

Procedure

Similar to Phase 1, after obtaining informed consent, we started the interview. (Step 1 was omitted for the parent who had participated in Phase 1.) At the conclusion of

the interview, parents completed a survey of demographics and tracheostomy-related experiences.

Data analysis

The first author (HY) noted important feedback on the prototype booklet, made edits, and presented them to the senior author (BZ-E, via meetings or emails) and the design team (via emails) for further revision after each wave until a new version was ready for the next wave of user interviews.

Results

Parent and child characteristics for Phase 2 are reported in Tables 1 and 2. Below, we summarize the iterative revision process by wave (See Additional file 1: Appendix C for the details of changes). Overall, parents found the booklet easy to follow and at the right length despite it being 15 pages. They considered this booklet useful to have as soon as tracheostomy becomes an option.

Wave 1 (n = 2)

Positive feedback Both participant parents found the booklet easy to understand, realistic, and useful. They valued informing parents about the downsides and risks of tracheostomy because the challenges of tracheostomy should not be underemphasized and it would be important to be prepared for life changes. They appreciated diverse perspectives of child's quality of life and the information about the uncertainty of the length of tracheostomy. Both of them found the sections about home care and other practical matters useful, because they addressed realistic challenges and caregivers' own needs, which were often neglected.

Constructive feedback Both participant parents expressed the concern that the introduction made tracheostomy sound elective and recommended that a tracheostomy should be presented as essential for survival at the beginning of the booklet. Therefore, we emphasized that tracheostomy provides "a stable airway" and without it "some patients may not live long" in the first paragraph of the introduction. One parent recommended reiterating that the best choice is at the individual family's

Table 3 Sections of the Booklet

Section title	Major content
Introduction	Introduction of the aims and content of the booklet
What is my child's best interest?	Diverse perspectives of long-term quality of life
What should I expect with a tracheostomy?	Home care skills and home care nursing
What else should I know?	Home environment, financial impact, support from schools and public, changes in family dynamics
What if I have more questions?	Support group resources

Final version of the booklet is freely downloadable from <https://deepblue.lib.umich.edu/handle/2027.42/154713>

discretion after the quality-of-life narratives, because parents might doubt themselves after reading perspectives that conflicted with their values. Given all the challenges in finding support, these parents recommended telling parents who would face a tracheostomy decision that this decision would change caregivers' life and that they should be comfortable taking care of the child first before relying on other resources to support the care. They provided suggestions to make the narratives more concrete and vivid, so we added those details.

Wave 2 (n = 2)

Positive feedback Both participant parents found all the content useful. They considered the introduction helpful because it laid out technical pros and cons, main tasks, and important questions parents should think about during decision making. Both of them acknowledged the importance of diverse perspectives and individual choice. They considered the home care challenges realistic and liked the idea that parents should accept the care responsibilities first.

Constructive feedback Regarding the "life-and-death" nature of tracheostomy, one parent found our previous revision unsatisfactory, as we made "death" without a tracheostomy sound probabilistic. Thus, we used "last resort to optimize the chances for long-term survival" to illustrate the importance of this decision. One parent recommended emphasizing that the decision could be "life-altering" rather than just "you may not be able to work" as what we added in the previous wave.

Another salient issue was the balance of positive and negative narratives. While one parent had more negative perceptions of getting support and suggested adding more details about financial difficulties and family relationship changes, the other parent in this wave perceived these narratives too negative and suggested adding positive stories about home health care nurses and family's support. As our booklet focused on describing challenges, we added positive scenarios in the narration but not as an individual story. Both parents, however, provided some advice to deal with these challenges.

One parent suggested that parents should have a team (palliative care in particular to discuss goals of care) with them to go through the booklet rather than read it alone. This was an important suggestion about how this booklet should be used, so we added this message at the end of the introduction.

Wave 3 (n = 2)

Positive feedback Again, the participant parents applauded the descriptions of upsides and downsides of a tracheostomy and parents' thought process. The messages that every child is different and that finding a team

to go through the process together were well received. Both parents considered home care and other practical challenges realistic.

Constructive feedback The balance of positive and negative aspects was still an issue. In particular, one parent had quite positive experiences. They appreciated different perspectives, but disliked the focus on negative outlook of quality of life, as some children with tracheostomies could enjoy many aspects of life. Similar to the previous wave, while these parents described more challenges, they suggested adding some advice and illustrating the adaptation for balance.

In addition to revising based on parents' feedback, we focused on generalizing key ideas in the narratives. We removed various detailed statements that parents had controversies about and details about the specific hospital they attended.

Wave 4 (n = 4)

Positive feedback The participant parents noted that the narratives not only captured peer parents' voices and tone, but were also to the point. The narrations summarized key points well. They valued different perspectives of quality of life and individual choice.

Constructive feedback As for the issue of balance, one parent suggested adding the idea that nurses could be good partners in care and some advice such as home schooling and couples counseling. Another parent suggested taking out the concrete details of home health care nurses' behaviors and including some hope (e.g., "you will have good support"). Although we could not guarantee a good outcome, we illustrated the idea of adaptation in the revision.

Our booklet was designed to give parents information about tracheostomy early in the decision process. One parent shared her experience and pointed that later tracheostomy might not be an option anymore. We thought it would be worth presenting the idea that tracheostomy might not always be an option.

Discussion

The UCD process deepened our understanding of parents' needs for messages and information and led to numerous specific changes in the tone and content to better align with parents' experiences. From [Phase 1](#), we learned that families could make different choices depending on their values and judgments of their child's conditions and used this tone in the prototype booklet. However, parents in [Phase 2](#) pointed out that this message should be conveyed even more strongly than our original design did. For instance, parents recommended reiterating this point at the end of the "best interest" section and reflecting more details about different kinds

of positive and negative experiences in the narratives. Moreover, while we tried to avoid presenting a tradeoff between the child's and family caregivers' interests, parents in [Phase 2](#) helped us find a way to state the importance of caregivers' physical and mental health because the patients would suffer if the caregivers were too stressed to manage the care. Furthermore, emphasizing diverse individual situations and presenting the tracheostomy option in a nonforceful way came at the cost of downplaying serious outcomes of this decision: life and death for the child, and life alteration for the caregivers. Parents pointed out this downside and provided a solution that we could emphasize these points in certain narrations.

In addition, by interviewing parents with different experiences and backgrounds, we were able to include diverse perspectives and add details to the booklet. Parents' emphasis on concrete details forced us to make intentional choices about when to be specific and when it would be better to generalize details to make the narratives more broadly representative of key ideas. Including a variety of enriched narratives helped with the balance issue. While our goal was to focus on conveying challenges and making parents not feel alone, acknowledging positive outcomes and providing advice in the meantime appeared to be helpful for parents to digest information and feel supported.

In terms of usability, parents confirmed that the booklet was easy to understand and efficient to use. One point that emerged in this process was that although parents wanted a lot of information, it could be overwhelming to read the booklet alone without other support. Therefore, we explicitly designed the booklet as informing future conversations with providers rather than as a standalone information resource.

General discussion

Although the UCD process required both time and a willingness to repeatedly modify drafts in response to feedback, it enabled us to gain a direct understanding of how parents perceived forecasting errors in tracheostomy decision making and how they viewed the tone and content of the booklet. We incorporated constructive feedback based on our understanding of the literature and other parents' experiences in multiple rounds of revision. Parents regarded the intervention easy to follow and at the right length.

As we theorized that many forecasting errors were due to incomplete understanding of the challenges, most narratives described negative consequences. Parents offered firsthand information regarding quality of life and their difficulties with emergencies, home health care nurses,

the community, and other family members. These examples increased concreteness of the narratives and, therefore, may help parents facing these decisions accurately envision everyday life with a child with a tracheostomy.

It was also useful to obtain parents' feedback about emphasizing the uniqueness of each case, the importance of adaptation strategies, and the need for acceptance. For instance, research shows diverse outcomes (e.g., discharge, death, decannulation, differences in developmental progress) in tracheostomy- and ventilator-dependent children [37–39]. Parents would become experts of their own children [40, 41], although not all have increased confidence and acceptance of their child's underlying condition and caring needs over time [35].

Another key goal of our booklet was to make parents not feel alone in the process by presenting challenges and strategies. Participant parents suggested that it would be crucial to maintain caregivers' well-being and establish trusting relationships with other professional parties such as home health care nurses and medical supply companies [35]. Well-being is often poor in parent caregivers of children with tracheostomies [30, 42, 43] and it is unrealistic that parents care for the child without any help. Seeking emotional support, resources, and information from professionals may share parents' care burden and increase confidence [40].

The design and development of this booklet successfully captured several key steps of UCD. Our approach scored 7 on the UCD-11 (a descriptive measure of user-centeredness of the design and development of personal health tools) [44] and also had a few additional elements in the DEVELOPTOOLS Reporting Checklist [45]. Our method (e.g., as illustrated by the numbers of development steps and iteration that involved users) was comparable to those of the studies included in a systematic review of UCD in patient decision aids and health tools [46]. Bearing the purposes and use context of the intervention in mind, we sought to involve parents in most stages of the iterative development of the intervention, from understanding their needs to refining the intervention. Given our focus on the usefulness of the intervention and parents' input, we have yet to observe how parents actually use the booklet. While we did not seek feedback on the booklet from health professionals outside our team, our team did include a few health professionals who actively counsel parents about this decision in their clinical work. In the future, we can involve an advisory panel of more stakeholders, facilitate perspective sharing between clinicians and parents, and translate the booklet into other languages.

Our approach may be applicable to other health care contexts where researchers aim to help patients and caregivers understand experiences of treatment options and

considerations during decision making. Although the use of UCD is recommended for enhancing user experiences, many studies do not involve stakeholders (e.g., patients, clinicians) in developing health decision aids and technologies [47, 48]. Engaging stakeholders in research can be time consuming. However, when there is a lack of understanding of stakeholders' needs and goals, it is worthwhile considering involving them in the process of design and development of patient education to ensure usefulness and usability of the materials.

Our study had several limitations that may affect its generalizability. Participants were limited to English-speaking parents from a single study site. Although we strove for recruiting parents from diverse backgrounds and interviewed parents with different education and income levels, most of them were Caucasian and likely had access to the substantial resources needed to manage a child with complex medical needs. In addition, they offered their own experiences with home care and life in a Midwestern state, but different states and regions may have different regulations, resources, and cultures. The generalizability of the findings and the booklet in diverse populations and different states needs to be further tested. Moreover, patients for whom a tracheostomy could be considered have diverse underlying conditions, yielding a full spectrum of prognosis. Our study was limited to more serious cases in which the children were anticipated to have motor and cognitive impairment. Other studies need to be done to investigate the information needs of parents who make tracheostomy decisions for children who are expected to be decannulated and fully recover. Nevertheless, these parents enriched our understanding of their experiences and needs and substantially improved the prototype intervention.

Our user-centered process yielded a parent-tested tracheostomy information booklet that is ready for implementation in clinical settings. The final version is available for free download (<https://deepblue.lib.umich.edu/handle/2027.42/154713>). Nonetheless, further work is needed to evaluate the impact of using the booklet on improving informed decision making and decision satisfaction. We are seeking to incorporate the booklet into goals-of-care consultations for critically ill children. We will first ask clinicians who are doing these consultations to review the booklet and to discuss feasible ways to use it. As the booklet was designed to be used as early in the decision process as possible, clinicians may consider asking parents whether they would be willing to receive such information prior to family conferences to get prepared for the consultation. Clinicians may also discuss key points in the booklet during the consultation or provide it to parents after the consultation as an additional source of information. We encourage both providers and parents

who are facing discussions of such difficult tracheostomy decisions to use this booklet when appropriate. We also appreciate feedback from providers and parents who have used it.

Conclusion

While developing an informational intervention for parents about the quality of life and typical life experiences with a child with a tracheostomy, we found that using a two-phase process informed by UCD principles enabled inclusion of parental perspectives that were initially overlooked and tailoring of the intervention to meet parental expectations. Our research demonstrates the potential value of UCD-based approaches in the design of patient communications (e.g., decision aids).

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12911-022-01911-9>.

Additional file 1: Appendix A. Standards for Reporting Qualitative Research (SRQR). **Appendix B.** 15 Forecasting Errors (Phase 1). **Appendix C.** Booklet Revision Summary (Phase 2).

Acknowledgements

We thank research assistants in the Judgment and Decision Making Lab (Danielle Abraham, Akram Albeer, Ameenah Cameron, Joshua Gruber, Benjamin Hershfeld, Saleen Picard, Ishraq Rahman, Brittany Rivera, David Song, Yiwen Zhong) for their assistance, especially assistance with the interviews and transcription. We thank the clinicians and staff for assistance with logistics of participant recruitment and data collection, including Abbey Skrzypek (MHA), Anita Johnson (MS), and Jamie Villalobos at the Michigan Institute for Clinical and Health Research (UL1TR002240), Nancy Kuemin (JD) in the Office of Patient Experience, Ann Marie Ramsey (RN, MSN, CPNP-PC) in the Pediatric Ventilator Program, Kate Hill (MA) in the Family Center, and Rachel Kolar Anderson and Aurora Stienstra (RN) in the Pediatric Otolaryngology Clinic at the C.S. Mott Children's Hospital, Michigan Medicine. We deeply appreciate parents who provided valuable input to inform this research.

Author contributions

HY and BZ-F designed the study with critical feedback from SK, KP, PD, and CA-E. SK and KP assisted HY with participant recruitment. HY conducted the user interviews and analyzed the data. HY created the initial booklet under the guidance of BZ-F and revised the booklet drafts with critical input from SK, KP, PD, CA-E, and BZ-F. HY wrote the first draft of the manuscript with guidance from BZ-F. All authors read and approved the final manuscript.

Funding

The study was funded by the Rackham Graduate Student Research Grant, University of Michigan. The funding source had no role in designing the study, interpreting the data, writing, or publishing the report.

Availability of data and materials

The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study was declared exempt research by the University of Michigan Medical School Institutional Review Board (IRB/MED). All methods were carried out in accordance with relevant guidelines and regulations. Written informed consent was obtained from all participants.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

Author details

¹Department of Psychology, University of Michigan, 530 Church Street, Ann Arbor, MI 48109, USA. ²Present Address: Department of Medical Social Sciences, Northwestern University Feinberg School of Medicine, 625 N Michigan Avenue, 21st Floor, Chicago, IL 60611, USA. ³Department of Pediatrics, C.S. Mott Children's Hospital, Michigan Medicine, 1540 E Hospital Drive, Ann Arbor, MI 48109, USA. ⁴Department of Psychiatry, University of Michigan, 1500 E Medical Center Drive, Ann Arbor, MI 48109, USA. ⁵Department of Health Behavior and Biological Sciences, School of Nursing, University of Michigan, 400 North Ingalls, Ann Arbor, MI 48109, USA. ⁶Department of Health Behavior and Health Education, School of Public Health, University of Michigan, 1415 Washington Heights, Ann Arbor, MI 48109, USA. ⁷Department of Internal Medicine, University of Michigan, 2800 Plymouth Road, Ann Arbor, MI 48109, USA.

Received: 11 February 2021 Accepted: 21 June 2022

Published online: 25 July 2022

References

- Yaneza MMC, James HP, Davies P, Harrison S, McAlorum L, Clement WA, et al. Changing indications for paediatric tracheostomy and the role of a multidisciplinary tracheostomy clinic. *J Laryngol Otol*. 2015;129(9):882–6.
- Nageswaran S, Golden SL, Gower WA, King NMP. Caregiver perceptions about their decision to pursue tracheostomy for children with medical complexity. *J Pediatr*. 2018;203:354–60.e1.
- Hebert LM, Watson AC, Madrigal V, October TW. Discussing benefits and risks of tracheostomy: what physicians actually say. *Pediatr Crit Care Med*. 2017;18(12):e592–7.
- McCormick ME, Ward E, Roberson DW, Shah RK, Stachler RJ, Brenner MJ. Life after tracheostomy: patient and family perspectives on teaching, transitions, and multidisciplinary teams. *Otolaryngol Head Neck Surg*. 2015;153(6):914–20.
- Gilovich T, Griffin D, Kahneman D. *Heuristics and biases: the psychology of intuitive judgment*. New York: Cambridge University Press; 2002.
- Wilson TD, Gilbert DT. Affective forecasting. In: Zanna MP, editor. *Advances in experimental social psychology*. CA: Academic Press; 2003. p. 345–411.
- Wilson TD, Gilbert DT. Affective forecasting: knowing what to want. *Curr Dir Psychol Sci*. 2005;14(3):131–4.
- October TW, Jones AH, Greenlick Michals H, Hebert LM, Jiang J, Wang J. Parental conflict, regret, and short-term impact on quality of life in tracheostomy decision-making. *Pediatr Crit Care Med*. 2020;21(2):136–42.
- Carnevale FA, Alexander E, Davis M, Rennick J, Troini R. Daily living with distress and enrichment: the moral experience of families with ventilator-assisted children at home. *Pediatrics*. 2006;117(1):e48–60.
- Karat J. Evolving the scope of user-centered design. *Commun ACM*. 1997;40(7):33–8.
- Ritter FE, Baxter GD, Churchill EF. User-centered systems design: a brief history. In: Ritter FE, Baxter GD, Churchill EF, editors. *Foundations for designing user-centered systems: what system designers need to know about people*. London: Springer; 2014. p. 33–54.
- Schneidermeier T, Maier F, Schrickler J. Human-centered communication planning: a conceptual approach. In: Marcus A, editor. *Design, user experience, and usability. Web, mobile, and product design*. Berlin, Heidelberg: Springer; 2013. p. 94–102.
- Corry MD, Frick TW, Hansen L. User-centered design and usability testing of a web site: an illustrative case study. *ETR&D*. 1997;45(4):65–76.
- Kangas E, Kinnunen T. Applying user-centered design to mobile application development. *Commun ACM*. 2005;48(7):55–9.
- Veryzer RW, Borja de Mozota B. The impact of user-oriented design on new product development: an examination of fundamental relationships. *J Prod Innov Manag*. 2005;22(2):128–43.
- McKnight C, Dillon A, Richardson J. User centered design of hypertext and hypermedia for education. In: Jonassen D, editor. *Handbook of research on educational communications and technology*. New York: Macmillan; 1996. p. 622–33.
- LeRouge C, Wickramasinghe N. A review of user-centered design for diabetes-related consumer health informatics technologies. *J Diabetes Sci Technol*. 2013;7(4):1039–56.
- Maher M, Kaziunas E, Ackerman M, Derry H, Forringer R, Miller K, et al. User-centered design groups to engage patients and caregivers with a personalized health information technology tool. *Biol Blood Marrow Transplant*. 2016;22(2):349–58.
- Taylor DP, Bray BE, Staggers N, Olson RJ. User-centered development of a web-based preschool vision screening tool. *AMIA Annu Symp Proc*. 2003;2003:654–8.
- O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med*. 2014;89(9):1245–51.
- Yan H. Aiding difficult and high-stakes medical decision making—research on parental tracheostomy decisions for critically ill children [dissertation]. [Ann Arbor (MI)]: University of Michigan; 2020. Chapter 1, Parent experiences and considerations when facing tracheostomy decisions for a critically ill child: p. 19–39. Available from: <https://deepblue.lib.umich.edu/handle/2027.42/162973>.
- Yan H, Deldin PJ, Kukora SK, Arslanian-Engoren C, Pituch K, Zikmund-Fisher BJ. Using narratives to correct forecasting errors in pediatric tracheostomy decision making. *Med Decis Mak*. 2021;41(3):305–16.
- Feudtner C, Walter JK, Faerber JA, Hill DL, Carroll KW, Mollen CJ, et al. Good-parent beliefs of parents of seriously ill children. *JAMA Pediatr*. 2015;169(1):39–47.
- Schkade DA, Kahneman D. Does living in California make people happy? A focusing illusion in judgments of life satisfaction. *Psychol Sci*. 1998;9(5):340–6.
- Gilbert DT, Pinel EC, Wilson TD, Blumberg SJ, Wheatley TP. Immune neglect: a source of durability bias in affective forecasting. *J Pers Soc Psychol*. 1998;75(3):617–38.
- Michelson KN, Koogler T, Sullivan C, Ortega Mdel P, Hall E, Frader J. Parental views on withdrawing life-sustaining therapies in critically ill children. *Arch Pediatr Adolesc Med*. 2009;163(11):986–92.
- Sharman M, Meert KL, Sarnaik AP. What influences parents' decisions to limit or withdraw life support? *Pediatr Crit Care Med*. 2005;6(5):513–8.
- Demke J, Bassim M, Patel MR, Dean S, Rahbar R, van Aalst JA, et al. Parental perceptions and morbidity: tracheostomy and Pierre Robin sequence. *Int J Pediatr Otorhinolaryngol*. 2008;72(10):1509–16.
- Kirk S. Negotiating lay and professional roles in the care of children with complex health care needs. *J Adv Nurs*. 2001;34(5):593–602.
- Hopkins C, Whetstone S, Foster T, Blaney S, Morrison G. The impact of paediatric tracheostomy on both patient and parent. *Int J Pediatr Otorhinolaryngol*. 2009;73(1):15–20.
- Edwards EA, O'Toole M, Wallis C. Sending children home on tracheostomy dependent ventilation: pitfalls and outcomes. *Arch Dis Child*. 2004;89(3):251–5.
- Hefner JL, Tsai WC. Ventilator-dependent children and the health services system. Unmet needs and coordination of care. *Ann ATS*. 2013;10(5):482–9.
- Meltzer LJ, Boroughs DS, Downes JJ. The relationship between home nursing coverage, sleep and daytime functioning in parents of ventilator-assisted children. *J Pediatr Nurs*. 2010;25(4):250–7.
- Thyen U, Kuhlthau K, Perrin JM. Employment, child care, and mental health of mothers caring for children assisted by technology. *Pediatrics*. 1999;103(6):1235–42.
- Flynn AP, Carter B, Bray L, Donne AJ. Parents' experiences and views of caring for a child with a tracheostomy: a literature review. *Int J Pediatr Otorhinolaryngol*. 2013;77(10):1630–4.
- Shaffer VA, Focella ES, Hathaway A, Scherer LD, Zikmund-Fisher BJ. On the usefulness of narratives: an interdisciplinary review and theoretical model. *Ann Behav Med*. 2018;52(5):429–42.
- Edwards JD, Kun SS, Keens TG. Outcomes and causes of death in children on home mechanical ventilation via tracheostomy: an institutional and literature review. *J Pediatr*. 2010;157(6):955–9.e2.
- McPherson ML, Shekerdemian L, Goldsworthy M, Minard CG, Nelson CS, Stein F, et al. A decade of pediatric tracheostomies: indications, outcomes, and long-term prognosis. *Pediatr Pulmonol*. 2017;52(7):946–53.

39. Rane S, Shankaran S, Natarajan G. Parental perception of functional status following tracheostomy in infancy: a single center study. *J Pediatr*. 2013;163(3):860–6.
40. Kirk S, Glendinning C. Supporting 'expert' parents—professional support and families caring for a child with complex health care needs in the community. *Int J Nurs Stud*. 2002;39(6):625–35.
41. McNamara DG, Dickinson AR, Byrnes CA. The perceptions and preferences of parents of children with tracheostomies in a study of humidification therapy. *J Child Health Care*. 2009;13(3):179–97.
42. Gong S, Wang X, Wang Y, Qu Y, Tang C, Yu Q, et al. A descriptive qualitative study of home care experiences in parents of children with tracheostomies. *J Pediatr Nurs*. 2019;45:7–12.
43. Hartnick CJ, Bissell C, Parsons SK. The impact of pediatric tracheotomy on parental caregiver burden and health status. *Arch Otolaryngol Head Neck Surg*. 2003;129(10):1065–9.
44. Witteman HO, Vaissou G, Provencher T, Chipenda Dansokho S, Colquhoun H, Dugas M, et al. An 11-Item measure of user-and human-centered design for personal health tools (UCD-11): development and validation. *J Med Internet Res*. 2021;23(3):e15032.
45. Witteman HO, Maki KG, Vaissou G, FINDERUP J, Lewis KB, Dahl Steffensen K, et al. Systematic development of patient decision aids: an update from the IPDAS collaboration. *Med Decis Mak*. 2021;41(7):736–54.
46. Vaissou G, Provencher T, Dugas M, Trotter MÈ, Chipenda Dansokho S, Colquhoun H, et al. User involvement in the design and development of patient decision aids and other personal health tools: a systematic review. *Med Decis Mak*. 2021;41(3):261–74.
47. Searl MM, Borgi L, Chemali Z. It is time to talk about people: a human-centered healthcare system. *Health Res Policy Sys*. 2010;8(1):35.
48. Coulter A, Stilwell D, Kryworuchko J, Mullen PD, Ng CJ, van der Weijden T. A systematic development process for patient decision aids. *BMC Med Inform Decis Mak*. 2013;13(Suppl 2):S2.

Publisher's Note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

Ready to submit your research? Choose BMC and benefit from:

- fast, convenient online submission
- thorough peer review by experienced researchers in your field
- rapid publication on acceptance
- support for research data, including large and complex data types
- gold Open Access which fosters wider collaboration and increased citations
- maximum visibility for your research: over 100M website views per year

At BMC, research is always in progress.

Learn more biomedcentral.com/submissions

