



Evaluation of the use of visual storytelling as an educational intervention in the cardiac ICU: reaching parents before they are in crisis



Original Article

Cite this article: Chlebowski MM, Stark C, Khoury PR, Zang H, Baenziger J, and Kasparian NA (2024) Evaluation of the use of visual storytelling as an educational intervention in the cardiac ICU: reaching parents before they are in crisis. *Cardiology in the Young* **34**: 1190–1198. doi: [10.1017/S1047951123004201](https://doi.org/10.1017/S1047951123004201)

Received: 9 February 2023
Revised: 8 November 2023
Accepted: 20 November 2023
First published online: 22 December 2023

Keywords:
Children; CHD; parent education; traumatic stress

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Abstract

Objective: To evaluate the acceptability and safety of educational videos utilising visual storytelling to provide information about the cardiac ICU and post-operative care to parents. Videos were designed to educate, further encourage parents to engage in their child’s cardiac care, and address common sources of distress. **Study Design:** Two educational videos and survey were sent to 29 families of children previously admitted to the cardiac ICU (April 2020–March 2021). Views regarding information quality, quantity, format, and relevance were assessed, as were parents’ emotional responses. Quantitative thresholds for safety and acceptability were set a priori. An inductive approach to content analysis was applied to identify themes in qualitative data. **Results:** Sixteen parents participated (response rate: 55%). All acceptability and safety thresholds were met; 92% of parents rated the videos as helpful and 85% were “very” or “extremely likely” to recommend them to other families of children with CHD. No participants reported significant distress after viewing the videos. Expressions of parental engagement with their child’s care team were common (92%). In qualitative responses, parents perceived the videos as potentially helpful in reducing distress if viewed prior to cardiac ICU admission. **Conclusion:** Visual storytelling to orient parents to the cardiac ICU and address common stressors was found to be safe and acceptable when tested with parents of children previously admitted to the cardiac ICU. Further prospective studies are needed to test intervention effects when videos are viewed before or during cardiac ICU admission, especially for mitigating anxiety and traumatic stress associated with admission.

Paediatric admission to an ICU is associated with anxiety and traumatic stress among children and their parents and caregivers.¹ Post-traumatic stress disorder has been identified in 10–21% of parents of children in the ICU with up to 84% of parents reporting traumatic stress symptoms post-discharge.² While there are mixed findings regarding the association between parental distress and child disease severity, studies consistently report a strong link between parental psychological distress during ICU admission and symptoms of distress in their child.^{2–4} Children with complex CHD are oftentimes admitted to the paediatric or cardiac ICU, placing them and their parents at risk for adverse psychological outcomes. A recent systematic review identified traumatic stress symptoms warranting clinical intervention among 30% of parents of children with complex CHD (CHD requiring cardiac surgery in infancy) and over 80% reported high levels of psychological distress during hospitalisation.⁵ Elevated anxiety is well documented among parents during their infant’s admission for cardiac surgery, with excessive worry being the most common symptom reported.⁶ When surveyed in other studies, parents often reported feeling helpless and frightened during their child’s admission, with common stressors including the sights, sounds, and smells of the ICU environment, seeing their child afraid or in pain, not knowing what to expect, and loss of their parental role.^{3,7}

While several studies have attempted to address parental traumatic stress after ICU discharge^{2,8–10} and have shown the benefit of providing information and anticipatory guidance regarding psychological responses, very few have evaluated proactive strategies to prevent or reduce distress, including in parents of children with CHD. While many ICU admissions are not planned, children with CHD admitted to the ICU for surgery offers a unique opportunity for planned intervention in most cases.

There is a growing need and desire for evidence-based digital health interventions for families of children living with a health condition.¹¹ The use of visual storytelling through video animations, including cartoon animations, is an emerging tool for adult medical education.¹² The use of both images and text enhances understanding by activation of different information processing pathways and also fosters connections between new information and existing

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knowledge to increase recall.^{13,14} Images and videos can also provide unspoken subtext and elicit visceral reactions that may not be conveyed by text alone.¹⁵ There is evidence that animations enhance knowledge and the recall of facts related to specific healthcare interventions.^{16,17} Animations can also highlight important content better than a photographic video¹⁸ and may be more acceptable to adults who do not want to see realistic portrayals of medical interventions.^{18,19} In addition, animations may be especially helpful for adults with limited literacy skills or low confidence engaging with medical information.²⁰

Given the prevalence of anxiety and traumatic stress among parents and caregivers, herein referred to as parents, of children with CHD admitted to the cardiac ICU, we developed an educational intervention utilising visual storytelling to (1) introduce parents to the cardiac ICU environment, (2) provide anticipatory guidance regarding their child's admission and common stressors, and (3) further encourage parents to take an active role in their child's care. Our goal in this initial study was to do user-centred testing of the intervention with parents who already had experience with cardiac ICU admission, as a first step to establishing whether the intervention is safe and acceptable for use with parents. Parental reactions to the newly developed intervention were assessed, including perceptions of intervention safety, quality, quantity, format, and relevance, as well as the perceived potential for the intervention to reduce parental anxiety and traumatic stress, and encourage engagement during their child's cardiac ICU admission.

Materials and methods

Study design

This cross-sectional, mixed-methods study was carried out at a single, tertiary care children's hospital in Cincinnati, Ohio, treating all children with complex CHD (Institutional Review Board Approval: 2021-0203). The initial study incorporated user-centred design²¹ to explore parental use and perceptions of a newly developed educational intervention utilising visual storytelling to convey information to parents about the cardiac ICU.

Intervention development

The educational intervention consisted of two animated videos using visual storytelling. The videos were co-created through collaboration between a cardiac ICU physician, medical educator, and sibling of an infant with CHD and a professional team of creative experts, many of whom were parents or caregivers to family members with chronic medical conditions requiring repeated hospitalisation. Video elements and associated learning principles implemented to maximise information processing and retention²² are shown in Table 1. In accordance with best practice guidelines,²³ all language and conversational audio were set to below fifth-grade literacy level.

Video A (1:08 minutes) showed a school-age child and her family including her mother, father, brother, and grandmother as well as members of the care team. It included introductory information about the different members of the cardiac ICU care team, parents' role as members of the care team, principles of family-centred care, and common stressors in the cardiac ICU environment, including monitoring devices and alarms. Video B (4:16 minutes) showed an infant alongside her mother and father and various members of the care team throughout the video discussing the basics of post-operative care, including ICU

monitoring, use of a breathing tube or ventilator, chest tubes, temporary pacing wires, and common medications. Milestones leading to transfer from the cardiac ICU to the cardiology step-down unit are described to help establish parental expectations. Validation of the parents' important role in their child's recovery and further information on common stressors is provided. Supplementary Figure S1 illustrates exemplar features.

Participants and recruitment strategy

In this first user-centred design study to examine intervention safety and acceptability, parents with experience of cardiac ICU admission were identified via the hospital cardiac ICU database. Parents or grandparents caring for a living child aged 0–18 years who had undergone cardiac surgery for the first time between 1 April, 2020 and 31 March, 2021 were eligible for the study. Parents were aged ≥ 18 years, contactable via e-mail, and able to participate in English. To reduce participant burden, parents with severe or chronic untreated mental illness, intellectual disability, or dementia were not approached, nor were parents of children admitted to the cardiac ICU for organ transplantation. To ensure sample heterogeneity and to ascertain a range of views and experiences from as many different perspectives as possible, purposive sampling was employed.²⁴ Consistent with this approach, chart review was performed to ensure parents represented children with varied surgical and post-operative course complexity, admission duration, prior healthcare exposure (e.g. hospital and ICU admissions, procedures, and surgeries), and health insurance types. Mothers and fathers were invited and encouraged to participate.

Procedures

Parents were asked to watch two videos and complete one survey via the secure survey platform, REDCap. Parents were emailed a detailed study information sheet and a personalised link to the study consent form, educational videos, and survey. If the survey was not completed within 2 weeks, a weekly reminder e-mail was sent over a 2-month period (October–November 2021). Reminder phone calls were made monthly to ensure e-mails had been received and all questions regarding the study had been answered.

Measures

A survey instrument was designed specifically to assess intervention acceptability, incorporating expert consultation, findings from literature review, and our previous research designing educational interventions for use in medical settings.^{25–28} Survey completion time was approximately 10 minutes and included the following items:

1. **Acceptability and Safety** (19 items): Thoroughness of video viewing and perceptions of video quality (0 = "Poor" to 4 = "Excellent"), format, and relevance of information were assessed. To assess safety, parents were asked to indicate their level of distress while watching (0 = "Not distressing at all" to 4 = "Very distressing"), whether the video elicited anxiety or feeling upset (0 = "Strongly disagree" to 4 = "Strongly agree"), as well as self-described emotional responses while watching the videos.
2. **Perceived Helpfulness** (19 items): Participants rated how helpful they perceived the videos to be (0 = "Not at all helpful" to 5 = "Extremely helpful"), the likelihood of

Table 1. Intervention development – description of video topics and associated learning strategies.

Video A topics	Learning strategies
Introduce team members including the family	Matching modality: targeting both visual/pictorial and audio/verbal pathways to maximize information integration without causing overload
Identify common stressors (e.g. alarms, monitors)	Conversational style rather than formal language in multimedia instruction found to positively impact learning
Encourage family engagement	Weeding: removing distracting background images or music that may distract from the high-yield information
	Segmenting: information was broken up between two videos allowing the viewer to start the next section when ready and maximize attention
Video B topics	
Post-operative care components: breathing tube, ventilator, pacing wires, chest tube, and medications	Signaling: using text in the video to highlight high-yield information Shortened video lengths to maximize engagement
Identify common stressors (e.g. alarms, monitors, nursing presence)	Matching modality
Milestones for transfer to the floor (e.g. no longer needing continuous medications)	Utilize narrative voice to speak quickly with enthusiasm

recommending and sharing the videos with family, friends, and other families in the cardiac ICU (0 = “Not at all likely” to 5 = “Extremely likely”), the likelihood of the videos addressing parents’ questions, difficulties, or worries about the cardiac ICU (0 = “Not at all likely” to 5 = “Extremely likely”), and how helpful these videos may be in preparing parents for their child’s cardiac ICU admission (0 = “Not at all likely to help” to 5 = “Extremely likely to help”). Questions assessing perceived helpfulness of the videos in encouraging parents to be further involved in their child’s care, asking questions, reducing stress or anxiety, and setting expectations for transfer to the step-down unit (0 = “Not at all helpful” to 5 = “Extremely helpful”) were also included.

- Dissemination Preferences** (3 items): Parents preferences in terms of when to receive the videos (before admission, when first admitted, after being in the cardiac ICU for a few days, before discharge, or after cardiac ICU discharge), whether to watch the videos alone or with a member of the care team, and additional support needed were assessed.
- Suggestions for Improvement** (7 items): Space was provided throughout the survey for parents to offer suggestions for improving the presentation, story, and characters in the videos as well as any additional ideas for improvement and willingness to assist with future intervention re-design and modification.
- Health Literacy** (2 items): The Brief Health Literacy Screen (BHLS; 2 items²⁹), is a self-report scale assessing parents, adult patients, and siblings’ need for assistance reading health-related materials (0 = “Never” to 4 = “Always”) and level of confidence completing medical forms (0 = “Not at all confident” to 4 = “Extremely confident”). Item 2 is reversed and scores summed, with higher scores indicating greater health literacy.

Demographic characteristics assessed included parent age and gender, insurance coverage, educational attainment, gross annual household income, child gender, and age at time of cardiac surgery. Clinical characteristics were collected via chart review, including primary cardiac diagnosis, cardiac surgical procedure and date, the Society of Thoracic Surgeons-European Association for Cardio-

Thoracic Surgery (STAT) risk category,³⁰ and presence and description of major non-cardiac co-morbidities. Number and description of non-cardiac or cardiac non-surgical procedures (e.g. catheterisation), ICU admissions within 12 months prior to surgery, and cardiology step-down unit or ICU readmissions within 6 months post-surgery were also obtained to better characterise parents’ perceptions and understanding of the cardiac ICU.

Data analysis

Quantitative thresholds for safety and acceptability were set a priori. For acceptability, the following three measures were required: > 75% of participants “agree” or “strongly agree” the videos are helpful, > 75% of participants would be “very” or “extremely likely” to recommend the videos to other families to learn about the cardiac ICU, and < 20% of respondents select, “I did not think the videos were useful and did not want to continue watching.” For the intervention to be deemed safe, the following three measures were required: < 20% of participants rate the videos as “very distressing,” < 20% of participants “strongly agree” the videos made them feel anxious or upset, and < 20% of participants select “I found the videos upsetting and did not want to continue watching.” All statistical analyses were performed using the R statistical program (version 3.6.1, <https://www.r-project.org/>). Median ratings with 25–75th percentiles, or frequencies with percentages, were used to describe parent and child demographics and child clinical characteristics. Comparisons between participating and non-participating families were tested using Wilcoxon rank-sum tests for continuous variables and Chi-square tests for categorical variables. p-Values < 0.05 were considered statistically significant.

Qualitative data provided in free-text survey responses were coded and analysed in four phases using an inductive approach.³¹ Initially, two authors independently read all responses, annotating reflections on salient content. Next, a set of agreed themes was generated. Subsequently, a narrative summary of each participant’s responses was developed identifying overall themes, and these themes were further discussed and interpreted by all authors. This iterative process was repeated until all responses had been

interpreted. Finally, the salient findings across all surveys were represented by a set of descriptive and interpretive themes. These were synthesised, and overarching themes were developed and critically appraised into a final set of themes. Data were managed using Microsoft Excel.

Results

Response rate and sample characteristics

Of the 29 families invited to participate in the study, 16 parents consented (response rate 55%) and 13 parents completed all structured survey items, yielding a survey completion rate of 81%. Twelve participants (all biological mothers of a child with CHD) provided qualitative (written) responses in addition to structured (closed-ended) responses. Participants ranged in age from 23 to 48 years (mean age: 33 ± 7 years), 15 were biological mothers and 1 was a biological grandmother. Demographic and clinical characteristics of participating parents compared with those who declined study participation (i.e. non-participating families) are shown in Table 2. Median child age at cardiac surgery was 6 months (25th–75th percentile: 0.25–13.69). STAT risk categories were evenly distributed across the sample, with at least two patients in each of the five STAT categories.

Intervention use and dissemination preferences

Almost all parents (81%) reported watching both videos from start to finish. Most perceived the length of each video as “just right” (92%). All parents rated the amount of information included in each video as “just right” and described the videos as “professional,” “warm,” and “inviting.” No parents rated the videos as “too plain or boring,” “confusing,” “difficult to follow, too busy or cluttered,” or “worrying or upsetting.” Nearly all parents (92%) “agreed” or “strongly agreed” that the videos included diverse characters. Most parents (85%) indicated a preference for watching the videos before cardiac ICU admission, and most (85%) would prefer to watch the videos on their own but would like a nurse, doctor, or other health professional available to answer any questions.

Acceptability and safety

All a priori thresholds for acceptability and safety were met (Table 3). In total, 92% of parents “agreed” or “strongly agreed” that the videos were helpful and 85% were “very” or “extremely likely” to recommend the videos to other families of children with CHD to learn about the cardiac ICU. Over three-quarters (77%) of respondents were “very” or “extremely likely” to share the videos with family and friends, including siblings, to better understand experiences in the cardiac ICU. In terms of safety metrics, no parents rated the videos as “very distressing,” none “strongly agreed” that the videos made them feel anxious or upset, and no respondents endorsed the statement “I found the videos upsetting and did not want to continue watching.”

Perceived helpfulness of the intervention

Almost all parents (92%) rated the videos as helpful in reducing parental stress and anxiety related to cardiac ICU admission; only one parent perceived the videos as “not at all helpful” in reducing parental stress and anxiety. Five parents viewed Video B, which focused on post-operative care and expectations for transfer to the step-down unit, as “much better at reducing stress” than Video A.

The step-by-step information about what was going to happen to after their child’s surgery and milestones for transfer to the step-down unit were viewed as especially helpful. All but two parents rated the videos as “very” or “extremely helpful” in encouraging parents to be involved in their children’s care during cardiac ICU admission, and almost all (92%) “agreed” or “strongly agreed” the videos supported their role as an important member of their child’s care team during admission.

Qualitative themes

Four major themes were identified in qualitative responses from 12 mothers: (1) *Experiences of the Intervention*, (2) *Improvements*, (3) *Emotional Responses*, and (4) *Sharing with Others* (Table 4).

Experiences of the intervention

All mothers believed the videos would help families to know what to expect during their child’s cardiac ICU admission. Six mothers perceived the videos as conveying information in a concise and easy-to-understand manner: “*It really explained step-by-step what was going to happen and how you are going to get through it and all the people that were going to help you*” (participant identification (ID) number 3). Three mothers mentioned the need for sensitive timing when providing the videos to families and the need for additional family support, considering the emotional impact of the journey ahead: “*They were great, but even better if parents actually had time to emotionally prepare before their stay began.*” (ID 7). Additionally, one mother shared, “*Thank you for having me contribute. This in and of itself helps me feel like a valuable member of the team*” (ID 6).

Suggestions for improvement

Six parents explicitly stated they had no suggestions for intervention improvement and one parent shared “*I liked everything*” (ID 30). Six mothers offered recommendations to improve the videos, including changing the dialogue in Video A to ensure the gravity of the cardiac ICU admission was not downplayed. Other suggestions included adding more realistic images ($n=3$), such as “*real-life illustrations versus animated versions of what families would see in the room*” (ID 17). Two mothers expressed the desire for a video explaining the gravity of the post-surgery and post-discharge experience, and one mother acknowledged the need for a COVID-19-friendly version of the videos. Five mothers found Video B on post-surgical aspects more helpful than Video A introducing the cardiac ICU.

Emotional responses

Eleven mothers viewed the videos as a useful tool for preparing parents and said they would embrace the opportunity to ask questions of health professionals after viewing. One mother mentioned, “*This is still a pretty anxiety-inducing process and the videos may raise more questions than answers BUT it is an incredibly helpful start*” (ID 2). Many of the mothers described cardiac ICU admission as emotionally challenging and perceived the videos as helping parents to navigate this journey. One mother stated the videos, “*would have made me feel less anxious for sure at already a very stressful time*” and “*(the) calmness of the video was great at making me feel everything was going to be ok*” (ID 9). Two mothers mentioned the videos brought back difficult memories of their experience (ID 7,11). One mother described that a folder outlining parental resources had been incredibly helpful for her

Table 2. Demographic differences.

	Participating families (n = 16) ^a	Non-participating families (n = 13)	p-Value ^b
Female sex	8 (50%)	4 (31%)	0.5
Age of child at surgery (months)	6 (0.25-13.69)	3 (0.30-10.45)	0.7
Presence of co-morbidities			
Total ^c	12	9	
22q11 deletion	2 (16.7%)	0 (0%)	0.1979
Trisomy 21	2 (16.7%)	2 (22.2%)	0.7483
Other chromosomal abnormalities	2 (16.7%)	0 (0%)	0.1979
Prematurity (< 37 weeks)	1 (8.3%)	2 (22.2%)	0.3681
Obstructive sleep apnea	2 (16.7%)	1 (11.1%)	0.7188
Airway abnormalities	2 (16.7%)	1 (11.1%)	0.7188
G-tube dependence	1 (8.3%)	0 (0%)	0.3749
Anxiety	0 (0%)	1 (11.1%)	0.2367
Cancer/myelodysplastic syndrome	0 (0%)	1 (11.1%)	0.2367
Seizure disorder	0 (0%)	1 (11.1%)	0.2367
Non-cardiac surgical interventions or caths (within 1 year prior to cardiac surgery)	3 (19%)	1 (7.7%)	0.8
Readmission(s) after cardiac ICU discharge (floor or cardiac ICU up to 6 mos after discharge)	3 (19%)	4 (31%)	0.8
Prior admission to any ICU (within 1 year prior to cardiac surgery)	10 (62%)	7 (54%)	>0.9
STAT category			0.5
1	3 (19%)	1 (7.7%)	
2	2 (12%)	5 (38%)	
3	4 (25%)	2 (15%)	
4	3 (19%)	3 (23%)	
5	4 (25%)	2 (15%)	
Insurance type			
Private insurance	9 (56%)	1 (7.7%)	0.011
Medicaid	5 (31%)	12 (92%)	
Military	1 (6.2%)	0 (0%)	
Self-pay	1 (6.2%)	0 (0%)	
Education			
Some high school	1 (6.2%)		NA ^d
High school	3 (19%)		
Some college	2 (12%)		
College	5 (31%)		
Postgraduate	5 (31%)		
Income			
I prefer not to answer	1 (6.2%)		NA
Less than \$15,000 per year	1 (6.2%)		
\$25,000-\$34,999 per year	2 (12%)		

(Continued)

Table 2. (Continued)

	Participating families (n = 16) ^a	Non-participating families (n = 13)	p-Value ^b
\$35,000-\$49,999 per year	1 (6.2%)		
\$50,000-\$74,999 per year	4 (25%)		
\$150,000-\$199,999 per year	4 (25%)		
\$200,000 and over per year	3 (19%)		
Healthcare worker			
Yes	4 (25%)		
No	12 (75%)		

^aData are presented as medians with 25–75th percentiles and frequencies with percentages.

^bp-Values are calculated using Chi-square test or Wilcoxon rank-sum test.

^cTotal number of co-morbidities accounting for patients who have more than one co-morbidity.

^dNA = not available.

Table 3. Acceptability and safety metrics.

Metric	Response rate
<i>Acceptability</i>	
>75% will “agree” or “strongly agree” that the videos are helpful	92% (12/13)
>75% will be “very likely” or “extremely likely” to recommend videos to other families	85% (11/13)
<20% will select “I did not think the videos were useful and did not want to continue watching”	0% (0/13)
<i>Safety</i>	
<20% will rate the videos as “very distressing”	0% (0/13)
<20% will “strongly agree” that the videos made them feel anxious or upset	0% (0/13)
<20% will select “I found the videos upsetting and did not want to continue watching”	0% (0/13)

and another expressed the desire for support from a psychologist during their cardiac ICU stay.

Sharing with others

Ten mothers expressed a desire to share the videos with families, friends, and/or siblings: “I really hope that these videos are shared ASAP, they are so, so helpful!” (ID 9). They felt the videos could alleviate the burden of having to repeatedly explain their experiences to others. One mother of a 3-year-old son shared, “It would be helpful to explain some things to extended family in a way that would inform but not scare them” (ID 10). Mothers perceived the videos as child-friendly and could help siblings aged 4–17 years to prepare for and adjust to the experience. Most mothers did not think the videos would be appropriate for siblings aged 3 years or younger.

Discussion

To our knowledge, this is the first study to demonstrate the acceptability and safety of visual storytelling in the form of educational videos designed for parents of children previously admitted to the cardiac ICU for cardiac surgery. Key goals of the newly developed educational videos were to: (1) introduce the cardiac ICU environment, (2) provide anticipatory guidance to

parents as they navigate their child’s admission and common stressors, and (3) further encourage parents to take an active role in their child’s care during hospital admission. Given this was the first user-centred test of the intervention, we sought the views and perceptions of parents of children previously admitted to the cardiac ICU, to provide input into intervention relevance and acceptability, as well as any modifications needed, based on their experiences. Overall, results were very positive. Nearly all parents found the videos helpful in providing information on what to expect during their child’s admission and would recommend sharing the intervention with other families as they navigate their child’s journey through the cardiac ICU. Most parents (85%) perceived the videos as “very” or “extremely helpful” in encouraging parents to be involved in their child’s care, and almost all (92%) “agreed” or “strongly agreed” the videos emphasised parents’ central role in their child’s care team. This highlights the way in which simple educational methods, such as videos utilising visual storytelling, may serve as critical tools to foster a strong alliance between parents and the multidisciplinary cardiac ICU care team.

Our findings suggest that visual storytelling may serve as an important educational resource in addressing parents’ information and support needs in the cardiac ICU setting, especially if provided prior to cardiac ICU admission. Parents indicated a clear preference to watch the videos on their own, with opportunities to ask their child’s cardiac care team questions, if necessary. Coupled with provider follow-up and psychological care, it is possible this intervention may serve to reduce parental distress and improve knowledge-sharing and engagement before, during, and after cardiac ICU admission, though this remains a hypothesis to be tested in future studies with larger samples.

Study limitations

Several study limitations warrant discussion. Overall, while participants in the study were representative of diverse socio-economic groups, healthcare experiences, and CHD types, the small sample size and timing of the intervention precluded generalisability of results across experiences throughout a child’s hospitalisation and was limited only to parental recall from prior cardiac ICU admissions. Restrictions placed on in-person research during the study period due to the COVID-19 pandemic limited the research design to an online survey. Survey questions were voluntary, resulting in some missing data. The survey response rate

Table 4. Examples of qualitative feedback from participant mothers.

<i>N</i>	<i>Theme</i>	<i>Exemplar</i>	<i>ID</i>	<i>Child</i>	<i>Child</i>
<i>n</i>	<i>Node</i>	<i>Quotes</i>		<i>Age</i>	<i>Sex</i>
12 Experiences					
11	Roadmap, repetition	I did like the aspect of the post-surgery video where the steps to leave the cardiac ICU were described. Oftentimes, parents don't know exactly what the medical team is checking for and the checklist of milestones to be met by every child leaving the cardiac ICU is helpful to understand the process.	1	6.7 months	female
6	Informative, helpful, concise	They're very informative without being overwhelming.	19	6 days	female
5	Child-friendly, fun, inviting	The videos gave a great intro for what to expect both during and after the procedure. It hit all of the highlights and was on a level that is easy to understand for both children and adults.	9	12 years	male
3	Sensitive to timing	Ahead of time would be great. Once you're in the thick of it, all focus and concentration goes out the window.	7	4 days	female
3	Downplays gravity	I feel the animation downplays the gravity of the ICU in some ways.	10	3.4 years	male
10 Improvements					
6	Nothing	I liked everything.	30	5 days	male
4	Changes in dialogue	Everyone is too happy to be there in #1, in my opinion. I understand that you are trying to lighten things up, but the reality is that this is life and death as you all know. Maybe just tune it down a little with the cheeriness in that story.	6	1.3 months	male
3	Adding illustrations	I would include more illustrations that make it more like what they would actually see – a busy room with lots of machines and medicines.	17	6 months	female
2	Post-surgery, post-discharge information	They do not show how scary post-surgery can feel for parents.	10	3.4 year	male
5	Favoring 'post-surgery' video to 'intro to cicu'	Family part of the care team and the information provided. The videos are overall warm and inviting. The expectations set in the second video was most helpful.	11	2.5 years	female
1	COVID version	Above. There should be a COVID times version with limited family members, face masks, etc., also	6	1.3 months	male
11 Emotional responses					
6	Opportunity for questions, explanations	I would like to watch them on my own and then ask questions if I have questions or concerns	3	9 days	female
3	Emotional regulation	I was thinking back to when my son had open-heart surgery last year. This would have made me feel less anxious for sure at already a very stressful time. The calmness of the video and all of the information was great at making me feel everything was going to be ok.	9	12 years	male
4	Emotional experience	It's a really good set of videos but no amount of videos can completely make that worry go away, it is still open-heart surgery and babies, it's hard, and scary, no amount of videos can make that go away, it is a part of it all.	19	6 days	female
1	Counselor	I think a counselor should be in the room when things are explained. It's very hard to seek out help when your child is also ack. As a parent of a heart patient when I address my own problems, I feel selfish.	30	5 days	male
1	Resource folder	We got a nice little folder with more detailed information about visiting hours, and parent resources, and our child's information/their care team (surgeon etc), and information ON the actual procedure. This was great.	2	8 months	male
10 Sharing with others					
3	Addressing needs of relatives	When we were in the cardiac ICU everyone was always asking lots of questions so this would be really helpful.	2	8 months	male
8	Siblings	I would share it with her older siblings (not the 2 year old) who could understand what was going on.	11	2.5 years	female

N = number of mothers reporting feedback in relation this theme/node.

did exceed the average response rate for online surveys based on a recent metanalysis;³² however, limited qualitative response data may have inhibited the ability to understand all possible themes within this study population. Furthermore, while the study was

offered to all parents irrespective of gender, responses were received only from caregivers who identified as female, thus limiting the available views and perspectives, especially those of fathers who may have different informational preferences.

Similarly, the views of parents without private health insurance were also under-represented. In future studies, we will work to address the limitations identified in the present study to improve diversity and inclusion in this research.

Implications for future research and practice

In term of next steps, the results of the present study and all feedback received will be used to directly inform the refinement of the educational intervention. In addition, this work is complemented by work done to identify vulnerable populations who may benefit from novel educational strategies and emotional support resources for parents in the cardiology step-down unit to improve discharge readiness³³ and further the mission of a multifaceted approach to the education of parents of children with CHD. Seven participants indicated their willingness to serve as parent partners in the re-design and modification of the intervention materials for use in future studies. We also plan to partner with non-English speaking families to develop materials in other languages. Once modifications have been made, we plan to invite parents to participate in a larger, quantitative study of responses to the intervention and to use these findings to guide the design of a longitudinal randomised controlled trial to prospectively test the effects of the intervention on parental anxiety, depression and traumatic stress, as well as engagement during in their child's cardiac ICU admission. We also plan to analyse different subgroups of children undergoing cardiac surgery, such as those with higher medical or surgical complexity, to determine if different anticipatory support is needed. After the educational intervention has been comprehensively tested and validated, we plan to disseminate the resource widely in response to parents' feedback.

Conclusions

This first user-centred design study provides preliminary evidence supporting the use of visual storytelling as an acceptable and safe educational intervention for parents of children previously admitted to the cardiac ICU. The newly developed intervention was perceived by these parents as safe, informative, relevant, and helpful, especially if offered prior to cardiac ICU admission and may serve to complement existing supports and resources to provide anticipatory guidance before families are in crisis. Next steps include refinement of the intervention to incorporate the feedback received and then testing in larger studies to examine the effects of visual storytelling as a possible complementary educational tool in a more diverse sample of parents of children with CHD both before and during cardiac ICU admission.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1047951123004201>.

Acknowledgements. None.

Financial support. Statistical and regulatory support was provided by the Heart Institute Research Core (HIRC), Cincinnati Children's Hospital Medical Center. MMC received HIRC funding for the project. JB is the recipient of an Early Post-doctoral Mobility Fellowship from the Swiss National Science Foundation (SNSF Grant P2LUP1_195091). NAK is the recipient of a National Heart Foundation of Australia Future Leader Fellowship (101229) and support from HIRC and the Additional Ventures Single Ventricle Research Fund. Funders had no role in study design, collection, analysis, or interpretation of data, manuscript preparation, or the decision to submit the article for publication.

Competing interests. None.

Ethical standard. The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation (Title 45 of the Code of Federal Regulations) and with the Helsinki Declaration of 1975, as revised in 2008, and have been approved by the institutional committee (Institutional Review Board Approval: 2021-0203).

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