

## Original Article

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# Post-operative discharge education for parent caregivers of children with congenital heart disease: a needs assessment

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## Abstract

**Objective:** Children with congenital heart disease (CHD) have complex unique post-operative care needs. Limited data assess parents' hospital discharge preparedness and education quality following cardiac surgery. The goals were to identify knowledge gaps in discharge preparedness after congenital heart surgery and to assess the acceptability of an educational mobile application to improve discharge preparedness. **Methods:** Telephonic interviews with parents of children with two-ventricle physiology who underwent cardiac surgery 5–7 days post-discharge and in-person interviews with clinicians were conducted. We collected parent and clinician demographics, parent health literacy information and patient clinical data. We analysed interview transcripts using summative content analysis. **Results:** We interviewed 26 parents and 6 clinicians. Twenty-two of the 26 (85%) parents felt ready for discharge; 4 of the 6 (67%) clinicians did not feel most parents were ready for discharge. Fifteen of the 26 parents (58%) reported receiving the majority of discharge teaching on the day of discharge. Eight parents did not feel like all of their questions were answered. Most parents (14/26, 54%) preferred visual educational learning aids and could accurately describe important aspects of care. Most parents (23/26, 88%) and all 6 clinicians felt a mobile application for post-operative care education would be helpful. **Conclusions:** Most parents received education on the day of discharge and could describe the information they received prior to discharge, although there were some preparedness gaps identified after discharge. Clinicians and parents varied in their perceptions of the readiness for discharge. Most responses suggest that a mobile application for discharge education may be helpful for transition to home.

Children who have undergone cardiac surgery require specific and sometimes complicated care from their parental caregivers once they are discharged home.<sup>1</sup> Inadequate education, and therefore, an inadequate transfer of skill and knowledge, may leave caregivers unprepared for care at home.<sup>2</sup> After children with congenital heart disease (CHD) are discharged, they may still experience post-operative complications and are at risk of readmission and/or mortality in an outpatient setting.<sup>3,4</sup> Although there are studies assessing caregiver readiness for discharge after paediatric cardiac surgery, little is known about the adequacy of the information that is understood and retained during this process.<sup>2,5–9</sup> Identifying this information will support the development of interventions seeking to improve discharge education for this complex population.

Children with CHD who undergo surgical repair or palliation have complex needs and require special post-operative care, including incision care, pain management, medication administration and parent knowledge of signs and symptoms of heart failure.<sup>1,5,7,10</sup> Parents and other non-professional legal guardians (hereafter “caregivers”) who care for these children are critical members of the medical team.<sup>7,11</sup>

Safe discharge after surgery for children with CHD requires that caregivers master complex post-operative care during a time of high emotional stress. The post-operative care at home may be compromised by caregiver fatigue.<sup>1,5,11,12</sup> Caregivers must understand their child's critical and complex needs and have the knowledge necessary to take care of their child once discharged from the hospital.<sup>2</sup> Understanding knowledge gaps of caregivers of children discharged following congenital heart surgery may highlight areas for improvement in the discharge education process. Furthermore, little is known about caregivers' preferences about how they receive their education for post-operative cardiac care (via handouts, electronically via mobile applications, etc.).<sup>5,7</sup> Some data suggest that using a mobile application and/or other technology-based support systems may serve as a potential way to reduce knowledge gaps and enhance discharge readiness of caregivers whose children are discharged postoperatively from cardiac surgery.<sup>13</sup>

The goals of this project were to (1) identify gaps in caregivers' knowledge and skills regarding the care of their child prior to discharge home from the perspectives of parents and clinicians and (2) assess acceptability of using an educational mobile application as an adjunctive modality for discharge preparation. This information will support the development of interventions seeking to improve discharge education for this complex population.

## Materials and methods

This project was conducted at a university-based tertiary care 44-bed cardiac care unit. The hospital cares for patients with all forms of CHD and has a robust heart transplant population. The hospital's institutional review board approved this project.

### Patients

We recruited a convenience sample of caregivers whose children underwent recent surgical CHD repair. The caregiver patients in this study were defined as either the parents or legal guardians of children discharged after surgical repair of their CHD. Only caregivers who spoke English or Spanish, who had children with two-ventricle physiology, and whose child had a recent surgical procedure defined as within 30 days of discharge were included. We excluded caregivers of children with single ventricle physiology or children discharged >30 days after surgery because those patients are more medically complex and merit separate study.

The clinicians who participated were a convenience sample of healthcare professionals that provide inpatient care to patients with the above-mentioned criteria. These clinicians included physicians (faculty members of the cardiac care unit), registered nurses and advanced practice registered nurses. Clinicians were required to have at least 6 months' experience to ensure they had a clear understanding of the discharge process.

### Patient recruitment

The primary investigator contacted caregivers via telephone 5–7 business days post-discharge and prior to their first follow-up outpatient surgical visit. The primary investigator was not involved in the care of the children of any enrolled caregivers. The first caregiver listed in the electronic medical record was contacted. A second caregiver was contacted if the first did not answer. Only one caregiver per patient was interviewed. Caregivers provided informed consent prior to the interview.

The primary investigator recruited clinicians based on their experience and active involvement with the patient discharge process, approached them during working hours and obtained consent for all patients.

### Interviews

The primary research team and experts in the perioperative care of infants and children undergoing congenital heart surgery, including cardiac care unit doctors and surgical advanced practice registered nurses, defined important aspects of care that caregivers should know prior to discharge. The aspects of care identified were: who to call in an emergency, comfort with pain management, medication administration, incision care and comfort with scheduling follow-up appointments. The research team then developed an interview guide (Appendix A) that addressed the following domains:

- (1) sense of caregiver preparedness and/or discharge readiness,
- (2) how the discharge process occurred,
- (3) general gaps in preparedness,
- (4) caregiver knowledge of the pre-identified important aspects of care that caregivers should understand for discharge,
- (5) suggestions for improvements in the discharge process,
- (6) input on a mobile application for discharge teaching,
- (7) input on other technology-based support systems for discharge teaching.

Telephonic interviews were approximately 15–20 min. All caregivers received a \$10 Visa gift card after completing the interview. Interviews were conducted until no new themes or domains emerged as determined by the interviewer.

The primary investigator conducted in-person semi-structured interviews with clinicians using a guide (Appendix B) developed similarly to the caregiver interview guide by the primary research team with input from the institution's cardiac care unit leadership (physicians including the medical director, advanced practice registered nurses, and registered nurses). These interviews were conducted in a private room without distractions. The interview guide contained questions asking about what clinicians feel caregivers should know at the time of discharge, if caregivers are prepared to go home the day of discharge, what kind of learning tools are used, and specific information caregivers receive from the above-mentioned important aspects of care that parents should understand prior to going home.

### Transcription of interviews

All interviews were audio-recorded and transcribed verbatim using a transcription service. Transcripts were de-identified prior to analysis.

Interviews with Spanish-speaking caregivers were conducted with a certified Spanish language interpreter via telephone. Only the English portions of the interviews were transcribed. The principal investigator (who is proficient in Spanish) reviewed the audio recordings to ensure the accuracy of the English translation by the interpreters during the interview.

### Data collection

From the patient's electronic medical record, we obtained: age, Society of Thoracic Surgeons–European Association for Cardio-Thoracic surgery mortality category; a measure of risk of mortality depending on the type of cardiac surgery, with higher scores indicating a higher risk of mortality, number of previous cardiac surgeries (excluding cardiac catheterisations and minor procedures), presence of a genetic syndrome, day of the week discharge occurred, medications prescribed at discharged and hospital length of stay.<sup>14</sup> We also recorded information about post-operative complications including clinically relevant bleeding (defined as haemoglobin drop of 20 g/L or more or requiring two or more separate transfusions of packed red blood cells, or bleeding that required medical or surgical intervention, not including menstrual bleeding), neurological complications and arrhythmias. These additional data was collected since such events could impact the amount of information conveyed to caregivers at discharge and could impact caregiver cognitive load.<sup>15</sup>

Information collected about the caregivers included their relationship to the patient, prenatal knowledge about their child's CHD diagnosis, relationship status (single or married couple),

living distance from the hospital, insurance information (i.e., private versus public) and preferred language.

Health literacy data were recorded to examine the correlation of health literacy and knowledge gaps after discharge.<sup>16</sup> Health literacy was determined by using a three-item hospital-registered, nurse-administered admission screening tool validated in adults consisting of questions about difficulty performing reading tasks, understanding written information and highest level of education.<sup>17,18</sup> We transformed responses into levels of health literacy as previously described by Chew et al.<sup>18</sup>

We inputted all patient and caregiver data into the Research Electronic Data Capture data management system.<sup>19</sup>

### Data analysis

We used a summative content analysis approach. A summative content analysis approach, as described by Hsieh and Shannon, "... involves counting and comparisons, usually of keywords or content, followed by the interpretation of the underlying context".<sup>20</sup> Two members of the research team used the above-mentioned domains (i.e., sense of caregiver preparedness and/or discharge readiness, how the discharge process occurred, general gaps in preparedness, caregiver knowledge with the pre-identified important aspects of care, suggestions for improvements and input on mobile application for discharge teaching) as initial coding categories.<sup>20,21</sup>

After reviewing the transcripts from the clinicians and the caregivers, the categories and definitions were identified and redefined as necessary. Any potential subcategories were developed in a subsequent review of the transcripts. Any other portion of the transcript that was not initially categorised with the initial coding schema but were agreed upon to be significant were given new codes, allowing new concepts to develop. The same two members of the research team (i.e., the reviewers) used Dedoose® coding software only for the coding on the transcripts.<sup>22</sup> The reviewers also determined if the answers to questions targeting caregiver comprehension of the specific areas demonstrated sufficient knowledge of each area and coded as such.

The reviewers met regularly to discuss codes, ensure reliability of the coding data by going over each transcript and discussing why each code was given and resolve any coding discrepancies from the transcripts. The coding schema was updated as necessary until a final coding dictionary was developed. After this initial process, the reviewers then re-coded the data with the revised codes in the final coding dictionary.

Descriptive statistics were used to analyse demographic data using Excel.

### Results

We screened 77 patients. A total of seventeen patients were not eligible because: (1) the child had single ventricle physiology ( $n = 7$ ), (2) the child was discharged without having had CHD surgery ( $n = 9$ ) or (3) the parent did not speak English or Spanish ( $n = 1$ ). Of the remaining caregivers, 8 (13%) declined an interview and 26 (43%) did not answer phone calls. Twenty-six caregivers participated in a telephonic interview. All telephonic interviews were approximately 15–20 min.

Six clinicians participated in a one-on-one in-person interview: three registered nurses, two advanced practice registered nurses and one faculty physician.

**Table 1.** Patient demographics and clinical characteristics  $n = 26$

Median Age	5 months IQR: 4 months–3.5 years
Sex	
Male	13 (50%)
Female	13 (50%)
STAT mortality category <sup>a</sup>	
1	16 (62%)
2	6 (23%)
3	2 (8%)
4	2 (8%)
Previous heart surgeries	
0 surgeries prior	23 (88%)
1 surgery prior <sup>b</sup>	2 (8%)
2 surgeries prior	1 (4%)
CHD diagnosed prenatally	
No prenatal diagnosis	16 (62%)
Genetic syndrome <sup>d</sup>	6 (23%)
No genetic syndrome	20 (77%)
Length of the hospital stay in days	
(Median)	IQR: 6–8

IQR: Interquartile Range

<sup>a</sup>Society of Thoracic Surgeons–European Association for Cardio-Thoracic surgery (STAT) mortality categories and types of surgeries included (number of patients in parenthesis): STAT mortality category 1: Atrial Septal Defect (ASD) repair (6), coarctation repair with end-to-end anastomosis (2), partial AVSD repair (1), Tetralogy of Fallot (TOF) repair with Dacron patch and ventriculostomy (3) and Ventricular Septal Defect (VSD) repair (4)

STAT mortality category 2: TOF repair with trans annular patch (2), total anomalous pulmonary venous return (TAPVR) repair (1), VSD with Patent Foramen Ovale (PFO) and ASD repair (1), partial AVSD repair with repair of mitral cleft and PDA (1) and VSD, PFO and Patent Ductus Arteriosus (PDA) repair (1)

STAT mortality category 3: Complete Atrioventricular Septal Defect (AVSD) repair (1) and D-Transposition of the great arteries (1)

STAT mortality category 4: TOF repair with RV-PA conduit (1) and Right Ventricle–Pulmonary Artery (RV-PA) conduit replacement for history of common arterial trunk (1)

<sup>b</sup>Description of the two patients and their previous heart surgeries: (Patient 1) – patient with a history of TOF with pulmonary atresia and major aorta to pulmonary collaterals (MAPCAs) with prior Blalock–Taussig (BT) shunt presenting for three out of four vessels' uni-focalisation, VSD closure, right ventricular outflow tract resection and RV-PA conduit. (Patient 2) – patient with a history of a common arterial trunk s/p VSD and RV-PA conduit repair in 2017 presenting for RV-PA conduit replacement with 16mm conduit and primary closure of PFO

<sup>c</sup>Description of one patient and the two previous surgeries: patient had a history of mixed partially obstructed TAPVR s/p partial repair of left common pulmonary vein to the left atrium in 2014, and then repair of partial anomalous pulmonary venous with modified Warden procedure in 2015 presenting for suture less repair of right pulmonary veins

<sup>d</sup>Genetic syndromes: five patients with trisomy 21 and one patient with chromosome deletion abnormality

### Patient demographics and clinical characteristics

The patient demographics and clinical characteristics are noted in Table 1.

Most patients (22/26, 85%) were in the Society of Thoracic Surgeons–European Association for Cardio-Thoracic surgery mortality categories 1 or 2. The most common day of discharge was on Tuesday (six children). Eighteen patients (69%) were discharged during the weekday (defined as Monday through Thursday) while eight patients were discharged during the weekend (Friday through Sunday). Common medications prescribed at discharge were furosemide (22/26, 85%), acetaminophen (18/26, 69%), ibuprofen (8/26, 31%), bowel regimen medications such

**Table 2.** Demographic of caregivers n = 26

Mothers	22 (85%)
Fathers	4 (15%)
Legal guardians	0
Relationship status	
Single	6 (23%)
Married	20 (77%)
Race	
White	11 (42%)
Hispanic	8 (31%)
Black	3 (11.5%)
Asian	3 (11.5%)
Preferred not to say	1 (4%)
Living distance from the hospital in miles (median)	22 (range 1.8–121)
Insurance	
Private	18 (69%)
Public	8 (31%)
Primary language:	
English	22 (85%)
Spanish	4 (15%)
Health literacy*	
High school	20 (77%)
7th–8th grade	2 (8%)
<6th grade	0

\*Four caregivers did not have their health literacy data filled out

as docusate or polyethylene glycol (10/26, 38%), aspirin (4/26, 15%) and beta-blockers (5/26, 19%).

The study sample included caregivers of children who experienced post-operative complications in each predefined area of bleeding, neurological complications and arrhythmias. One child had clinically relevant non-major bleeding (i.e., overt bleeding requiring blood product administration).<sup>15</sup> One child had a neurological complication associated with surgery, a small intraventricular hemorrhage with restricted diffusion in the corpus callosum seen on magnetic resonance imaging. Four children had significant arrhythmias (one had supraventricular tachycardia and three had ectopic atrial tachycardia). One child went home on anti-arrhythmic medications.

### Caregiver demographics

Caregivers demographics are noted in Table 2.

The majority of caregivers interviewed were mothers (22/26, 85%), White (11/26, 42%), married (20/26, 77%) and had private insurance (18/26, 69%). Many families lived within the city or surrounding suburban regions of the hospital (median 22 miles). Four caregivers' primary language was Spanish. Most caregivers (20 of the 22 who reported their health literacy) were identified to have high-school-level health literacy. Of note, the two caregivers with 7th–8th-grade health literacy identified as Hispanic, one

an English-speaking single mother and the other a married, Spanish-speaking father.

### Caregiver content areas

Caregivers described a range of experiences regarding discharge readiness, explained feeling rushed from the discharge process and provided thoughts on a mobile application for discharge teaching and/or other technology-based support systems. Key quotes describing each of these areas are found in Table 3.

#### Discharge readiness

Twenty-two of the 26 (25%) caregivers felt very or generally prepared by the time their child was discharged. Of the 4 caregivers that did not feel prepared, 3 of the caregiver's children were discharged on a weekend (Friday through Sunday).

Twenty-five of the 26 (96%) caregivers mentioned that the majority of the information they received came from handouts. Twenty-two of the 26 (85%) caregivers said that the nursing staff did most of the teaching and 14 caregivers mentioned that a clinician also explained the information. Eighteen of the 26 (69%) caregivers felt all questions were answered before discharge.

Fourteen of the 26 (54%) caregivers preferred visual learning tools (e.g., handouts) and 5 caregivers mentioned they used videos to supplement their learning. Six caregivers mentioned hands-on training as an education preference. Caregivers also mentioned seeking other sources for information about their children: 3 caregivers searched the Internet, 1 caregiver used her insurance company website as a resource and 1 caregiver asked a pharmacist for questions about medications.

Three caregivers also described age-specific mobility issues to consider for their child after surgery and at home that impacted the caregivers' discharge readiness. For example, caregiver #21 stated: "[The nurse] also went through any medications that he needed to take once he was discharged, any type of holding procedures, such as you know scooping, how he should not do tummy time, various things like that. I mean, a lot of it was also things that didn't pertain to an eight-month-old and would be pertinent to someone who is more mobile, such as walking, or lifting, or carrying a backpack." In addition to mobility issues, one of the caregivers (#19) also described how stress may have made it difficult to feel ready for discharge: "So, one of the things that I can think of is around mental health and stress and all those things that you need to deal with when you see a, you know, child in pain . . . So, maybe a little bit around how to manage the stress for the child that's involved may also help along, you know, with the medication and instructions."

#### Caregiver feeling rushed

Eight caregivers described that they wished information was given sooner. Most (15 out of 26, 58%) commented that they received the discharge teaching the day of discharge. For example, caregiver #14 stated: "So, I think it's more a matter of giving written information earlier, so that the parents can take notes and ask questions as early as possible, as opposed to kind of waiting till the end."

#### Gaps in preparedness

Eight caregivers stated they did not feel like all of their questions were answered when asked. The information they would have liked to have received included: help with medication scheduling for their child (1/26), assessment of pain at home (1/26), questions regarding appropriate form of medicine such as a tablet versus



**Table 3.** Key caregiver quotes

Theme	Caregiver number and key quote
Discharge process and readiness	Caregiver # 1: "Everybody was asking a lot of questions along the way to make sure that I didn't have any questions that were overlooked and that I had all the information that I needed."
	Caregiver # 4: "Like I mean I don't think anyone can prepare for having a child that had surgery and like what does it look like? Like the discharge paperwork was kind of like what we've sort of set aside as like, the like kind of bible for going home. Like it's got these phone numbers. It's got the next appointments. It's got sort of the after care and then it's got next steps."
	Caregiver # 11: "Everything that they said what could really happen, I mean yeah, I'm very, very careful with the medicine, the times and all these things, but as I told you, I get it for my husband. He's not a doctor, so he wants really clear everything [sic] and no problems. Everything that they said is what happened. Everything was really, really clear and some question that I asked to the nurses and they couldn't have the answers right away when I asked, they asked the doctors, or I asked by myself. No, everything was clear and be answered."
	Caregiver # 18: "... you know, of course, like I said, this is going back to giving us information about how to, you know, care for him, you know, to make sure that when it came to him, you know, going back to his daily routine, you know, the approximate, like an estimate of like you know when it may happen. But like I said, overall, they just always made sure that they kept us in the know and gave us all the information that we needed."
	Caregiver # 26: "I felt that they told me everything I needed to know... I get it, and I think if he probably would have had some complications, I'd probably be more on top of what I should be looking for. Because he's been well, I haven't looked for much, you know what I mean?"
	Caregiver # 24: "So, I thought that they went through a very thorough discharge. Some of it was pertinent to my son who is eight months old. Some of it was not. And we probably could've gotten out of there two, three hours earlier. But the information they gave us was fine. It was valid information. It was clear and concise."
	Caregiver # 16: "And then when I got home, I had so many questions that I had to Google, that I felt weren't reviewed, especially in regards to [sic] the dressing change, because she had had like the chest tube and things like that. Like I had even had to like to vocalise, they had taken out her chest tube, maybe like a couple days before that. I think like a day before that. I was like okay. Can you guys change the dressing? And I really wasn't given like any instructions. It would vary slightly, but I guess maybe it was just my inadequate [sic] that I felt about how to change them, because I've never had to deal with anything like that."
Caregiver feeling rushed	Caregiver # 2: "One thing is that we kind of felt like rushed out of the room once we got the discharge approval which I completely understand like it's a very high priority room and, you know, I'm sure there's a sick child waiting to go. But I think that maybe having a clear timeline saying like, okay, you're discharged and, you know, we're going to give you 30 minutes or an hour to finalise getting your things out of the room."
	Caregiver # 14: "Again, I think it's just helpful to get that information sooner, rather than later. I am the type of person who likes to be able to be really prepared, you know. And if I had had – you know, a lot of times in the hospital, you're sitting there. You're sitting there not doing much. And that would've been a great time for me to review like how to take care of her and, you know, like any supplies that we might need when we went home or that kind of thing. And because it was kind of given right at the end, I was trying to read it but also trying to ask questions and make sure that we had everything packed up."
Thoughts on a mobile application for discharge teaching and/or other technology-based support systems	Caregiver # 17: "So, I think everything that we received on paper, in the app would be beneficial, whether it's like a CPR guide and the NG tube, you know, if they get sent home with NG tube, like a video on that, just if you needed like a refresher course while you're home."
	Caregiver # 20: It would be helpful to have on the mobile phone, because like if things are in the home and you go into the doctor's office or something, it'd be more accessible if you have it over the phone. So, that would be completely acceptable."

suppository (1/26), not receiving a cardiopulmonary resuscitation class they asked for (1/26), incision care (including for other sites such as an old intravenous line site) (5/26) and medication frequency concerns (1/26). In addition, 2 out of 26 caregivers were concerned that the clinicians did not check their understanding of the discharge information.

#### *Caregiver knowledge with the pre-identified content topics important for discharge*

Most caregivers responded correctly to questions asking about their knowledge of the pre-defined areas identified as important

for discharge which included: who to call in an emergency (24/26, 92%), correct understanding (based on investigator consensus) about what a given cardiac medication discharged to home is for (24/26, 92%), signs and symptoms of infection (23/26, 88%), how to monitor incision sites for infection (25/26, 96%) and how to manage pain and discomfort (22/26, 85%). Nineteen of the 26 (73%) caregivers said they felt comfortable calling the number provided if questions arose regarding specific issues and who to call in an emergency.

The two caregivers with 7th–8th-grade health literacy both answered that they felt prepared and were able to identify comfort

with pain management, comfort with giving medications and could describe what the medications were for, appropriate incision signs to monitor, and were comfortable with follow-up appointments. One of the caregivers, however, was unable to identify who to call for an emergency. During both interviews, neither noted having questions that the team should have answered before discharge.

#### *Thoughts on a mobile application for discharge teaching and/or other technology-based support systems*

Twenty-five caregivers answered that they preferred handouts to supplement their learning and 23 caregivers agreed that using a mobile application to help supplement their education would be helpful. When asked what caregivers would want in a mobile application, suggestions were making a mobile application that includes all the information printed and provided to parents before discharge and that provides a mechanism for caregivers to easily communicate with clinicians (doctors, registered nurses and advanced practice registered nurses) as questions or issues arise.

#### *Clinician content areas*

Key clinician quotes are found in Table 4, including questions caregivers commonly ask (regarding medications, pain management, signs and symptoms of infection, incision care), common teaching points, problems with the discharge process itself and thoughts on a mobile application for discharge teaching and/or other technology-based support systems.

All mentioned providing paper handouts for discharge teaching, however, other resources such as videos or hands-on instructions varied as these resources were sometimes forgotten (for example, clinician #6 mentions forgetting there are video resources available for families to view). When asked the open-ended question “how prepared are caregivers to go home with their child the day of discharge,” four of the six clinicians volunteered a range of overall preparedness. Clinician # 1 stated “maybe 75%” while clinician #2 stated “3–4 out of a 5,” and clinician #3 stated: “mediumly prepared.” All six clinicians mentioned their concerns that families may feel rushed since the majority of the discharge teaching is done on the day of discharge.

The clinicians also commented on other issues with the discharge process including uncertainty at times when the child will go home and the use of generic discharge materials. For instance, clinician # 2 stated: “Typically, a lot of the times, I feel like we aren’t quite sure exactly what they’re going home with... then I feel like it just keeps getting pushed back or we think patients are going to be here for an extended period of time, and then the providers are like, oh, you want them to go home in three days, but we weren’t aware of the previously to get things done and scheduled... they’re supposed to get a post-op surgical pamphlet, but I feel like it’s a little out of date.”

All six clinicians agreed that a mobile application to deliver discharge information could be helpful.

## **Discussion**

This study elicited caregiver perceptions of discharge readiness, how the current discharge process occurs, general gaps in preparedness and caregiver knowledge in pre-identified knowledge domains for children with CHD who underwent surgical repair within 30 days of discharge. By design, most children were in the Society of Thoracic Surgeons–European Association for

Cardio-Thoracic surgery mortality categories 1 or 2 with minimal post-operative complications.<sup>23</sup> Caregivers that were interviewed preferred to receive discharge information through visual learning tools (e.g., handouts and videos) and hands-on training. Clinicians and caregivers differed in their perception of the readiness of families for discharge: most caregivers felt comfortable with post-discharge care while clinicians expressed a range of perceptions of parental readiness for discharge. Caregiver responses suggested that a mobile application for discharge education may be helpful as they transition to home.

Although this was a convenience sample, most caregivers had higher health literacy. Overall, caregivers felt well prepared even though most received discharge information only on the day of discharge. Of the four caregivers that did not feel prepared, three patients (two in the Society of Thoracic Surgeons–European Association for Cardio-Thoracic surgery mortality category 1 and one Society of Thoracic Surgeons–European Association for Cardio-Thoracic surgery mortality category 2 case) were discharged on the weekend. This difference in preparedness may be due to the difference in staffing (less front-line clinicians to provide education to caregivers although instructions and handouts received would be the same) on the weekend than during the weekday. Additionally, completing discharge teaching on the day of discharge may adversely impact parent learners if deficiencies are identified since there would be less of an opportunity to address those deficits and could further delay the discharge throughput for the cardiac care inpatient unit.

Although most caregivers overall felt prepared to go home with their child, our study identified potential educational gaps in discharge understanding. Eight caregivers had questions that were not answered before discharge. Caregiver responses for pre-identified content topics were not 100% correct, especially for how to manage pain and discomfort and who to call if there are specific issues. Additionally, some caregivers discussed not having enough information for discharge such as sternal precautions and other mobility limitations. Even with less complex cardiac surgeries (i.e., lower Society of Thoracic Surgeons–European Association for Cardio-Thoracic surgery mortality category patients), caregivers still had gaps in knowledge.

Our study also identified how caregivers prefer to receive information (handouts and other visual aids). Furthermore, the majority of the clinicians and caregivers interviewed felt a mobile application could help enhance discharge education. A mobile application has the potential to enhance medication knowledge and administration techniques through the use of videos, track administration and adherence, provide reinforcement and review of information given at the time of discharge, and/or tailor education to the specific disease, age, etc. Our findings will help inform the development of a mobile application and/or other technology-based support systems. We hope to explore this innovation in a future study as a potential way to address knowledge gaps, enhance discharge readiness of caregivers whose children are discharged postoperatively from cardiac surgery.

Discharge readiness assessments and checklists to help standardise discharge procedures have been described in general paediatric inpatient units, centres for women with breast cancer, neonatal intensive care units, and for children who are tracheostomy and ventilator dependent without CHD.<sup>8,24–27</sup> In patients without cardiac disease discharged from the neonatal intensive care unit or children with seizure disorders, simulation tools and educational mobile applications are used to help caregivers address knowledge gaps and enhance discharge readiness.<sup>25,28–31</sup> As we move to

**Table 4.** Clinician key quotes

Theme	Clinician number and key quote
Questions caregivers commonly ask	Clinician #1: "... bathing and incision care; I get a lot of question about, because I teach CPR to the families, so I get a lot of questions about well, what about their incision? Should we give CPR? And I have to like, you know, educate them on, yes, it's an emergency. CPR is life or death, basically."
	Clinician # 2: "But yeah, I feel like it really just comes down to scheduling, who to call, when to call, and medication issues... They ask a lot about support groups, too."
	Clinician #5: "For the younger babies, how to take care of the incisions, what sternal precautions are. When they – they want to know when they're going to come back to see us and who they're going to see. Us via the surgeons, a lot of them assume they're going to see the surgeons, which is not true in our case"
Common teaching points	Clinician # 1: "... how to properly drop the meds, give meds at the right time, and kind of stressing the importance of that, and administering them appropriately."
	Clinician # 2: "I do feel like there are common questions that I hear, that they get outpatient, that we could've done a better job of teaching an inpatient. So, a lot of questions, again, about mixing formula, about adjusting medications and feed schedules...I feel like medication refills, we get a lot of questions on. Like we hear that people have some difficulty with knowing who to call, I get a lot of questions about, and I am not even that sure... And I feel like it's very difficult for them to navigate who I'm supposed to reach out to and when. We get a lot of questions with the meds, too, about vomiting and redosing, and that's a big problem. I feel like the simple cardiac surgeries aren't too complicated, and their questions, they're like how long am I going to be on Lasix? How long do I have follow-up appointments? Can my kid ever play sports, like that kind of stuff."
	Clinician # 5: "Typically, a lot of the times, I feel like we aren't quite sure exactly what they're going home with. And people, I don't mind doing unnecessary teaching, but people are saying, oh, I don't want to teach then about Diuril if they might only go home on Lasix. Or you know, maybe they're pick up their PO, and I don't need to do this NG teaching. And then I feel like it just keeps getting pushed back or we think patients are going to be here for an extended period of time, and then the providers are like, oh, you want them to go home in three days, but we weren't aware of the previously to get things done and scheduled. I feel like that's the window where we start really genuinely discussing what one needs to know for home, and so I feel like we can do a better job of anticipating that window and maybe starting sooner." Clinician # 6: "... But maybe creating a little more of a roadmap for us and like the last push to go home, because I find a lot that you're like oh, that kid's supposed to go home tomorrow, and they're like no education was charted on or whatever, so that happens a lot."
Problems with the discharge process	Clinician # 1: "... maybe having like a mobile med schedule or a mobile, not even just a schedule, but like knowing why we're giving this medicine, and what the dose is, and what the milliliters are, because that way, like when they're getting readmitted or having other issues, we can potentially like have them just show a provider the app... But I for sure think [a mobile application] would help."
	Clinician # 2: "Post-surgical patients: they're supposed to get a post-op surgical pamphlet, but I feel like it's a little out of date. You can't tailor it to the child, and those instructions end up being put in any way into the discharge instruction information."
Thoughts on a mobile application for discharge teaching and/or other technology-based support systems	Clinician # 2: "I feel like it would actually be amazing if we could have all those materials that we, here's the sheets of paper and sheets of paper, if some of those could be in the app, because I feel like parents have so much paper when they go home, and they don't even know how to organise it. They don't keep it."
	Clinician # 3: "I think it would be awesome if it had like, you know like I can think the most common questions we get, like some of the answers to that, like you know when to be concerned. I think it would be helpful, like a little bit more detailed of pain medication 'cause [sic] I find sometimes kids you know they'll be on round the clock Tylenol when they still see me a week later, which is not necessary... You know it would be awesome if there was more than one language just because you know Spanish is probably our most common one, but I think that would be helpful in some of the – and the other thing is that there's different reading levels, and I'm not sure that everybody can read what we give them. So, pictures would be helpful. Like this is, you know I think that's important. Like I think reminders of like you know you're going to, like almost like just milestones, like you saw your post-op visit. That was great, check. Like people like that. You know you saw your cardiologist, check. You saw your pediatrician, check."
	Clinician #5: "I think that a mobile application would be a really great resource, and I think that the vast majority of our families seem to have a smartphone. It could probably, particularly if it's free to them, which I would imagine it would be, they could download this app and make use of it."

improve the discharge education process in cardiac care units, one approach may be to introduce a discharge checklist to standardise some of the information caregivers receive and evaluate these strategies in future research.

Discharge readiness for medically complex children is an important aspect of care and, in some cases, linked to readmissions and increased length of stays.<sup>8,26,32–34</sup> Children with CHD discharged after a surgical intervention are at risk of hospital

readmission and post-discharge complications, such as sternal wound infections and/or failure to thrive.<sup>7,12,35,36</sup> Future studies evaluating discharge readiness for caregivers after their children's congenital heart surgery are needed to see if this will improve outcomes such as reducing readmission rates and length of stay.

Our study was not able to comprehensively assess the relationship between health literacy and discharge readiness. Overall, the population of caregivers had at least high-school-level health literacy taking care of children with the majority of the Society of Thoracic Surgeons–European Association for Cardio-Thoracic surgery mortality categories of 1 or 2, and most were primary English speakers with private health insurance. Prior research has demonstrated that low health literacy has been linked to poor health outcomes and use of preventative care services.<sup>16,37</sup> While patients in our study did not demonstrate significant variability of health literacy or resources since this was a convenience sample of caregivers, there is potential concern that caregivers with lower health literacy may not have the knowledge and competency to effectively manage their complex, post-operative cardiac children (although addressing that question is beyond the scope of this dataset). Since health literacy and learning preferences can be a sensitive topic, study patients may not share their opinions. Future work is needed to determine whether discharge readiness is associated with health literacy.

This study has several limitations. This was a single-centre study design that may limit the generalisability of our findings with other institutions. Our results may reflect respondent bias as patients who had either very positive or very negative experiences may have been more likely to participate. Most caregivers interviewed were Caucasian and English speaking, which may also limit generalisability in experiences during the discharge process. In addition, it may not be possible to determine completely if there are knowledge gaps with discharge and education readiness since there may be inconsistencies within the current institutional discharge process (i.e., instructions for post-discharge care can be given either by an advanced practice registered nurses or registered nurse, educational materials may vary, and the discharge teaching may vary depending on what day). Finally, there may be a psychosocial component (i.e., anxiety or stress) that affects discharge readiness that was beyond the scope of this study, but recent literature suggests this may impact the caregiver experience of taking care of his or her child.<sup>38,39</sup> Further studies are needed to address the psychological burden from the diagnosis of CHD and how that impacts the discharge process.

**Supplementary material.** To view supplementary material for this article, please visit <https://doi.org/10.1017/S1047951120002759>

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