Original Article

Journal of Child Health Care
2025, Vol. 0(0) 1–14

DOI: 10.1177/13674935251321531
journals.sagepub.com/home/chc
Sage

Having a heart-to-heart: Parents' experiences preparing their child for a cardiac procedure

Sage Hay[1] and **Jenny O'Neill**[1,2]

Abstract

Cardiac procedures can be overwhelming for children and parents, with a lack of literature surrounding how healthcare professionals can assist parents in preparing young children for such procedures. This exploratory descriptive qualitative study sought to understand experiences of parents preparing and supporting their child with congenital heart disease, for an upcoming cardiac procedure. Parents of children, aged between three and eight years old, who had undergone a cardiac procedure at a tertiary paediatric hospital in Australia were invited to participate in an interview. Seven parents were interviewed, with recordings transcribed and analysed using reflexive thematic analysis. Four major themes identified were (1) evolving information needs; (2) anticipating anxiety; (3) honesty when delivering information; and (4) equipping parents with resources. Findings from this study emphasised that support for children prior to cardiac procedures must include empowering parents, as they know their child best. A key component of procedural preparation is helping parents navigate how to translate procedural information into explanations which are relatable and appropriate for their child. The development of interactive, relatable resources would allow parents to continue their child's preparation beyond the preadmission visit.

Keywords

Cardiac surgery, child, parents, preoperative care, qualitative research

Background

Congenital heart disease refers to any abnormality of the heart present at birth (Strange et al., 2020). Each year, it is estimated 2400 babies are born in Australia with congenital heart disease, half of

---

[1] The Royal Children's Hospital, Melbourne, VIC, Australia
[2] The University of Melbourne, Melbourne, VIC, Australia

Corresponding author:
Sage Hay, The Royal Children's Hospital, 50 Flemington Road, Parkville, VIC 3052, Australia.
Email: sage.hay@rch.org.au

whom will require invasive procedures, such as cardiac surgery or catheterisation (Celermajer et al., 2016). Children with complex congenital heart disease may also require multiple cardiac procedures (Blue et al., 2012).

Invasive procedures can be anxiety provoking experiences (Lööf et al., 2019), for both children and their parents (Chang et al., 2020), often driven by an unfamiliar situation (Clift et al., 2007) and lack of procedural information (Bray et al., 2022). Consequently, children can have a limited understanding of what will happen (Bray et al., 2019a), fear of healthcare professionals (Mahoney et al., 2010), or avoidance of future healthcare encounters (Duff et al., 2012). This can become challenging as continual healthcare interactions and lifelong cardiac surveillance is often necessary, even after successful treatment (Goossens et al., 2011).

Following cardiac surgery, children will often be admitted to a paediatric intensive care unit before being transferred to a cardiac unit for the remainder of their recovery. They may have a surgical incision via a sternotomy (front of the chest) or thoracotomy (side of the chest), in addition to chest drains, a peripheral intravenous cannula, central venous line, urinary catheter, and pacing wires (Ofori-Amanfo and Cheifetz, 2013). In contrast, children who have cardiac catheterisation will have a pressure dressing over the catheter site and peripheral intravenous cannula in their arm (Brown et al., 2019), and often require an overnight hospital stay.

Regardless of the procedure, there is evidence to suggest children and parents have an improved experience when they are informed and well prepared about what will happen (Bray et al., 2022). Therefore, it is important to offer age-appropriate information about upcoming hospitalisation (Kennedy and Howlin, 2022). Different services used to deliver information and preparation include preadmission clinics, hospital orientations (Månsson et al., 2023), and preparation programs (Shaheen et al., 2018). Preoperative preparation programs are generally supported as an effective way to provide education about various aspects of an upcoming procedure and hospital admission (Shaheen et al., 2018).

During such visits there is usually a structured approach to physical preparation, including collection of vital signs, diagnostic images, and blood tests. It is important to highlight that most children only visit a preadmission clinic once prior to their cardiac procedure. An assumption is that translation and reinforcement of preoperative information to young children is part of the parent role (Ben Ari et al., 2019; Sadegh Tabrizi et al., 2015). As such, there is a need for effective resources and support for parents to prepare their child beyond the preadmission visit.

Currently there is a lack of literature surrounding how healthcare professionals can assist parents preparing young children, specifically for cardiac procedures. For this reason, it is important that healthcare professionals delivering preoperative information increase their understanding of how parents deliver information to their child. This will help better tailor resources and education to meet information needs of children and parents. Throughout this study researchers sought to understand the preoperative information needs of parents (person with parental responsibility or primary caregiver) whose child was undergoing cardiac surgery or cardiac catheterisation.

Aim

To understand experiences of parents preparing and supporting their child with congenital heart disease for an upcoming cardiac procedure.

Method

An exploratory descriptive qualitative approach was used to understand parents' experiences of preparing their child for a cardiac procedure. The exploratory descriptive design was most appropriate to address the aim of the study, allowing both the exploration and description of individuals' perspectives, emotions, and actions (Hunter et al., 2019). As outlined by Hunter et al. (2019) the exploratory descriptive design also serves as an appropriate framework for studying areas within healthcare practice that have received minimal prior attention, such as experiences of parents preparing their child for cardiac procedures.

Population and setting

The population included individuals from a single-centre tertiary paediatric hospital in Melbourne, which is the largest paediatric cardiac centre in Australia. The centre completes cardiac procedures on children from metropolitan, regional, and remote areas across the country, including those from Victoria, Tasmania, South Australia, and the Northern Territory. Approximately 700 cardiac surgery and 500 cardiac catheterisation procedures are performed at the centre each year. The average number of interventions may vary for each child, dependent on their specific cardiac diagnosis.

Most children will visit the preadmission clinic once prior to their cardiac procedure, to receive education and preparation about their upcoming admission. Preadmission visits for cardiac catheterisation typically occur the week of the procedure. For cardiac surgery, preadmission visits can range from the week of surgery to a month prior, depending on surgery scheduling. Children will have tests completed that include an echocardiogram, electrocardiography, X-ray, and blood test. The preadmission clinic is primarily staffed by registered nurses, with cardiology doctors and cardiac physiologists also engaging with children during their visit to conduct necessary tests and assessments.

Recruitment

A cardiac procedure scheduling list was used to identify eligible parents. The principal investigator (SH) approached eligible parents, who were informed of the study during their preadmission visit or their child's ward admission following a cardiac procedure. Those interested in participating were provided with a participant information sheet detailing the study purpose, benefits, and risks.

Inclusion and exclusion criteria

As the focus of this study was young children in the pre-operational and early formal operational stage of development, parents were eligible if they had a child aged three to eight years old undergoing a planned cardiac procedure, including either surgery or catheterisation, during a three-month period in late 2021. Parents must have also visited the preadmission clinic prior to their child's cardiac procedure. Parents whose child experienced significant procedural or surgical complications requiring a paediatric intensive care unit admission greater than seven days, were excluded.

Data collection

The data were collected from parents following their child's cardiac procedure. Semi-structured interviews were completed face-to-face during the child's hospital stay or within five weeks following discharge via telephone. Telephone interviews allowed for inclusion of parents whose child had a short hospital admission. Interviews were arranged at a time convenient for parents, with face-to-face interviews conducted in a private room on the ward and phone interviews completed from home. The data were recorded using an audio recording device and verbatim transcribed by the principal investigator (SH). Interview responses were anonymised during transcription of data, and pseudonym names were allocated to parents and their child.

Qualitative interview

Semi-structured interviews allowed the investigator to collect similar types of data from all participants and ensured the research aim was directly covered (Whitehead and Whitehead, 2020). Interviews sought to explore experiences and needs of parents who were preparing and supporting their child for an upcoming cardiac procedure. Discussion included what parents' thought had worked well during their child's preparation and what could have been improved. Other questions explored level of preoperative preparedness, types of questions children asked during their hospital stay, and preparation strategies parents recommended as useful. Semi-structured questions guided the interview, whilst allowing flexibility to provide an opportunity for greater understanding of parents' experiences, without fixed ordering or specific limitations on what was asked (Liamputtong, 2020). An outline of interview questions is available in the Supplemental Material 1. Data collection continued until patterns, meanings, and themes were thoroughly represented, reflecting experiences of parents.

Data analysis

Data were analysed using six phases of reflexive thematic analysis, as detailed by Braun and Clarke (2022). Analysis included all original data obtained from interviews to ensure comprehensive coverage. The data from interview recordings were thoroughly checked and reviewed through close reading and discussion between the principal and associate investigator (SH and JO). Anonymised transcripts were inductively coded independently by investigators and subsequently reviewed and discussed, leading to the development of initial codes into themes (Braun and Clarke, 2022). Themes were defined and named through consensus-making processes, with no disagreement arising between investigators who both agreed on the four themes.

Rigour

To ensure rigour and trustworthiness the Lincoln and Guba (1986) framework was applied, adhering to principles of dependability, confirmability, credibility, and transferability. Dependability and confirmability were achieved by audio recording interviews to capture participant quotes (Ahmed, 2024). Credibility and transferability were maintained through detailed descriptions of findings and data analysis, enabling readers to measure the applicability of findings within their own context (Ahmed, 2024).

Reflexivity

As a practicing paediatric clinical nurse specialist working in the cardiology preadmission clinic, it is important for the principal investigator (SH) to acknowledge this study was close-to-practice, meaning at times they completed both the preadmission clinic and parent interviews. To ensure all participants were comfortable to provide honest dialogue of their experience, interview questions were not directly related to patient care delivered, but rather availability and content of resources, education received, and general preparedness of their child prior to the procedure. A strength of close-to-practice was the opportunity to develop rapport with participants, with a greater understanding and appreciation of the clinical context. The principal investigator was supported by associate investigator (JO) who is also a paediatric nurse, practicing outside of cardiology, and not known to participating parents or those involved in clinical care.

Ethical considerations

Ethical approval was gained from the Human Research and Ethics Committee (HREC 80897) of the study institution. Written informed consent was obtained from all participating parents. It is recognised that there was a potential for imbalance of power and parents may have felt compelled to participate in the study having had preadmission completed by the principal investigator. To address potential concerns about the principal investigator's influence, the participant information sheet clearly communicated that discussions during interviews or the decision to participate in the study would not impact care delivered. Additionally, to reduce a risk of therapeutic misconception, parents who were introduced to the study by the principal investigator, during their preadmission, were not consented during the same visit. If parents felt distressed during the interview, they could cease the interview or withdraw from the study without consequences. No parents withdrew from the study or became distressed by interview questions.

Findings

Ten participants expressed interest in participating in the study and were contacted by the principal investigator to gain informed consent and arrange an interview time. Of these, three subsequently chose not to proceed with the interview due to delayed cardiac procedure and family commitments. Seven parent interviews were conducted with the duration of each interview ranging from 9–29 min (mean duration 16 min). All participants identified as the child's mother, except for one participant who was a long-term female carer of the child. The type of cardiac procedure each child underwent ranged in complexity. For most participants (71%) this was not their child's first cardiac procedure. Additionally, the duration of hospital stay ranged from one night for three children (43%), five

Table 1. Characteristics of parents and their child.

Parent's name	Child's name	Child's age (years)	Number of cardiac procedures in lifetime	Procedure performed	Type of cardiac procedure
Hannah	Toby	4	10	Fontan procedure	Open heart surgery
Joy	Sophie	4	4	Fontan procedure	Open heart surgery
Laura	Isla	4	2	Pacemaker box change	Closed heart surgery
Tracy	Lachlan	5	5	Pacemaker box change	Closed heart surgery
Gracie	Adam	6	5	Mitral valve repair	Open heart surgery
Kim	Harvey	7	1	Electrophysiology study	Cardiac catheterisation
Amanda	Matilda	8	1	Mitral valve repair	Open heart surgery

Note. Open heart surgery – heart is opened in order to perform surgery, almost always requires cardiopulmonary bypass. Closed heart surgery – surgery is performed around the outside of the heart, does not require cardiopulmonary bypass. Cardiac catheterisation – involves introducing a catheter tube into the child's heart, through an artery or vein.

nights for one child (14%), and greater than two weeks for three children (43%). Characteristics of parents, their child, and type of cardiac procedure are presented in Table 1.

Themes

Four themes were generated, detailing experiences and needs of parents preparing and supporting their child for an upcoming cardiac procedure (see Figure 1) with the starting point being (1) the child's evolving information needs, which necessitates (2) anticipating anxiety, balanced with (3) honesty when sharing information and (4) equipping parents with resources.

Evolving information needs

One of the key themes identified across this study was children's evolving information needs over time. Parents described that their child's level of understanding and preparation requirements, changed and developed.

> *It has certainly evolved as he has gotten older, because when he first had major surgery, he was only 18 months old. He didn't really understand at all and wasn't aware that he was different or that he had a pacemaker. As he's gotten older, I think we haven't gone into too much detail, but we do certainly talk about that he's got a computer* [pacemaker]*, and you know he thinks it's pretty cool.* Tracy, mother of Lachlan, age 5.

The theme of changing information needs was highlighted by multiple parents and was often noticed through the questions raised by their child.

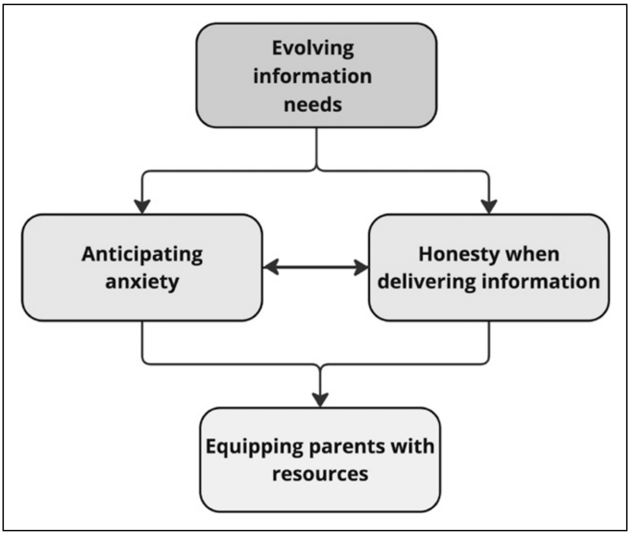

Figure 1. Aspects parents considered important when preparing and supporting their child for an upcoming cardiac procedure.

> *Probably a few months ago* [Sophie] *started asking me 'oh what is this thing I have on my chest?' The cut. So, I explained to her this was when they fixed your heart, and you have another* [procedure] *that you will need to go for probably soon.* Joy, mother of Sophie, age 4.

For parents there was a notable change from when their child was very young and tended to be less aware of their environment, to when they became older and were more capable of processing what was happening around them.

> *When he was younger, he was less aware of what was happening, so we were able to keep him calmer, it was manageable. But now that he is older and can think about and process things, its more challenging.* Gracie, mother of Adam, age 6.

Examples parents gave of age-appropriate language and simple medical explanations they used, can be found in Supplemental Material 2.

Anticipating anxiety

Alongside children's changing information needs, a key concern for parents was the potential for the information given in the preadmission visit to affect their child's level of anxiety. In some cases, preparation was seen as a strategy to decrease anxiety.

> *It would definitely be helpful for there to be a solid* [strong] *approach… to help them* [the child] *adapt and cope with anxiety they are experiencing.* Hannah, mother of Toby, age 4.

For children who had experienced previous surgeries, anxiety was commonly identified as a notable issue. Parents often described their child as having built up fear, anxiety, apprehension, and a fixation around medical procedures. One parent expressed their child would likely struggle to deal with their hospital admission due to trauma experienced from previous visits.

> *Over time* [Isla] *has periods where she's really good about visiting the hospital, then other times when she has gotten pretty upset about it. I don't know if it's just her or what she's gone through, but she's really fixated on anything medical, like needles and injections, which she gets really upset about.* Laura, mother of Isla, age 4.

Parents described the importance of familiarity with the hospital environment as a necessary aspect of procedural preparation, helping them and their child feel comfortable and confident about their upcoming visit.

> *I think it's more about making things familiar, so that they are more comfortable with what's going on.* Hannah, mother of Toby, age 4.

Honesty when delivering information

All parents described the importance of being honest when delivering information and that their child was informed about the upcoming procedure prior to arriving at the hospital.

> *We are honest, he hates being lied to, he absolutely hates it.* Kim, mother of Harvey, age 7.

Parents also explained the value of honesty when having conversations with their child.

> *Leading up to this surgery* [Isla] *started to notice her pacemaker and her scars. We were pretty honest with her about the scars, you know they are not 'magic fairy kisses' or anything, they are just her scars. We have kind of just tried to explain that, because at one point I think she was thinking 'what's wrong with my heart'...* Laura, mother of Isla, age 4.

Parents identified that honest information allowed their child to develop expectations that matched reality. These realistic expectations, based on honest communication, helped to reduce the shock associated with any new experiences.

> *Having his expectations align with what's going to happen as much as possible, so there's a sense for him that he's going to be alright.* Hannah, mother of Toby, age 4.

However, despite this agreement about the importance of honesty, parents balanced presenting the truth with an element of caution. Parents were often worried about adding to underlying anxiety that their child was experiencing, and therefore thought it was important to delicately balance the amount of information they provided.

> *We need to be careful about what we say. We were happy to answer any questions that he had, but again we will always be very cautious about not giving too many details and explaining it in language that he understands.* Gracie, mother of Adam, age 6.

Balance between giving correct and truthful information with containing anxiety was managed by using age-appropriate language.

> *Lachlan asked me, how are they going to get it out, how are they going to get the battery* [pacemaker box] *out and change it? ...are they going to use scissors on me?* Tracy, mother of Lachlan, age 6.

Tracy went on to explain:

> *I think as they get older its more around the language you use and how to delicately explain procedures. When he is starting to ask me how they get in there and then he is starting to talk about scissors and cutting him open and everything, that sounds so traumatic. So, language is important.*

Equipping parents with resources

Sharing of developmentally appropriate and honest information about cardiac procedures with children, while managing their own anxiety can be challenging for parents.

> *I wish someone told me you're probably going to find that you have anxiety, as well as your child about how this is going to go, but here are some of the things that may help…* Gracie, mother of Adam, age 6.

Four parents in this study described seeking out information prior to their child's pre-admission visit, including the hospital website or online parent cardiac surgery resources. However, the remaining three parents stated they did not review any information prior to attending the preadmission visit, and one mother whose child had undergone multiple cardiac surgeries explained:

> *I can't think of a specific time when I have sought some information and thought, right, that's how I'm going to approach something… Rather I have picked things up along the way.* Tracy, mother of Lachlan, age 5.

One parent expressed they lacked confidence to approach a procedural conversation with their child. Resources and practices parents found helpful following their preadmission visit included '*reading a social story*' Gracie; touching monitoring stickers, '*so they know what it feels like going on and off*' Hannah; and '*watching the* [hospital procedural] *videos*' Kim.

Interestingly, all parents interviewed found the cardiac surgery doll (Elsa doll), which was used to help deliver education to children during their preadmission visit, 'incredibly useful.'

> *For me at that moment I didn't know how to explain to* [Sophie] *what she was going to go through in a way she would understand. The nurse was very helpful, and showed her a doll, and the doll was realistic and had all the tubes and everything on her... So that actually helped me a lot when I came back home too.* Joy, mother of Sophie, age 4.

The cardiac surgery doll was identified as not only benefitting children, but also their parents. For many, accessing these resources came as a powerful relief to themselves and their child.

> [I was] *quite surprised at how engaged* [Matilda] *was and interested in looking through those pictures… Literally the first day when she was extubated in PICU* [paediatric intensive care unit]*, she just started feeling around everything. Everything she said was 'that one's like Elsa, and what's this one for?' In a way thinking that someone else, Elsa, had all of this* [surgery] *done as well.* Amanda, carer of Matilda, age 8.

Discussion

This qualitative study interviewed seven parents to explore their experiences of preparing and supporting their child for an upcoming cardiac procedure. Findings revealed parents considered evolving information needs, anticipating anxiety, honesty when delivering information, and being equipped with resources, as important features of preparing and supporting their child. Arguably, it is beyond 'usual' parenting expectations to prepare a child for complex medical procedures, such as cardiac surgery or catheterisation. However, also consistent with previous literature by Gordon et al. (2010) and Kennedy and Howlin (2022) parents in this study were typically the primary support and key information providers.

Throughout this study, parents noticed their child's information needs changed and evolved over time, aligning with the idea that children's understanding of illness, changes with age and experience (Koopman et al., 2004). As such, there is a need for parents to adapt their preparation to be consistent with the child's level of development (Rasnake and Linscheid, 1989), placing an importance on using language that is clear and age-appropriate (Jaaniste et al., 2007).

Concurrently, parents are also grappling with their own understanding of congenital heart disease, procedures, and disruption to their own lives, which is further compounded by the emotional impact of caring for a child with a cardiac condition (Wei et al., 2016). Given these factors, we have a responsibility to critically appraise whether enough is being done to ensure parents have the skills and support needed to undertake the role of preparing and supporting their child for a cardiac procedure.

Challenges often arise when parents are unfamiliar with aspects of their child's procedure and the hospital environment (Gordon et al., 2010), or do not know what to say to their child (Bray et al., 2019a). While the provision of information is a primary component of preadmission or preoperative preparation programs (Shaheen et al., 2018), this study highlights there must also be a focus on supporting parents to appropriately translate provided information to their child. Additionally, individualised preparation approaches are needed for children of different ages and those who have various levels of experience with medical procedures (Jaaniste et al., 2007). A vital component of the preadmission clinic included equipping parents with resources and strategies, as well as the confidence to continue their child's preparation at home.

In this study, translation of complex information to children was reported to be achieved not only with written materials, but through role modelling and interactive demonstrations of conversations parents could have with their child. Quotes from parents in this study illustrated how the preadmission session supported them to continue preparation with their child, noting that their own understanding of the procedure was enhanced through the use of the demonstration doll. Previous authors also suggest that parents have benefitted from watching therapeutic play activities and explanations given to their child when preparing for surgery (Yahya Al-Sagarat et al., 2017). These findings further align with a review by Jaaniste et al. (2007) who reported that providing parents with accurate information about upcoming procedures can ease their burden of knowing what to tell their child.

Parents described how they balanced the delicate task of being honest whilst minimising their child's anxiety when providing procedural information. An example of this included using familiar dialogue. One child in the current study referred to a pacemaker as his 'computer', as this was a term he was familiar with. Most parents appreciated an importance of honest and truthful explanations in preserving a trusting relationship with their child, with strong ethical reasons to tell the truth about medical interventions even with very young children (Hudson et al., 2019). This is further reflected in literature, which highlight children desire information that is realistic (Dai and Livesley, 2018), honest (Bray et al., 2019a), and clear (Jaaniste et al., 2007), to reduce uncertainty about what will happen (Bray et al., 2019a).

Parents were concerned about raising their child's anxiety when considering how much honest information to give. This can be particularly challenging for children with past hospitalisations, as Gordon et al. (2010) found that children with previous distressing hospital experiences were more likely to have anxiety on future admissions. Parents in the current study were understandably cautious when delivering procedural information to their child, which was consistent with work by Kennedy and Howlin (2022) and Bray et al. (2019a). These authors also found parents were concerned that procedural information may increase their child's anxiety and were therefore hesitant to talk to their child about a planned procedure. Previous research also detailed how parents shaped or withheld procedural information to prevent upsetting their children (Bray et al., 2016). Balancing honesty with anxiety therefore increases complexity of information translation and may increase the burden on parents, potentially resulting in inadequate or inappropriate preparation of children.

Although it is not disputed that parents know their child best (Kerimaa et al., 2023), it is clear procedural preparation is not straightforward. It is proposed that traditionally, adequate resources and support have not been offered to parents to undertake this task; putting them in the position where they need to seek out information or ask questions to clarify their understanding (Bray et al., 2019a), both of which can be difficult to do.

The current study highlighted parents, when given the opportunity, identified a range of tools including written, audiovisual, and tactile resources to help proactively improve their child's preparation. This is consistent with previous findings that suggest preparatory interventions found to be most beneficial for children combine numerous methods of information including spoken, written, and digital media (Kerimaa et al., 2023).

Understanding the needs of parents to prepare their child for a cardiac procedure beyond a preadmission visit, has the potential to lead to changes in standardised education provided during a preadmission visit. This could include development of more appropriate and accessible resources that provide honest information, that can be proactively utilised, and interactive; as each child's circumstances and information needs differ (Bray et al., 2019b). The anticipated benefits include enhanced procedural preparation and empowering parents to support their child (Jaaniste et al., 2007), which is likely to improve the overall hospital experience.

Limitations

The small sample size, while reflective of the specific population of those requiring cardiac surgery in early childhood, is a limitation for consideration. Primarily, participating parents identified as female or the child's mother, leading to an absence of representation from other primary caregivers, specifically those identifying as fathers. Due to the scope of the project, this study lacked public involvement during design and development. Additionally, only parents who were able to communicate in English were included, reflecting a limitation in the capacity to include parents from diverse backgrounds. This study was also completed at a single-centre, focusing solely on parents of children aged three to eight years old. This age range may have influenced perspectives and information priorities that parents considered important when preparing their child for a cardiac procedure. It is therefore necessary to acknowledge experiences could vary for parents of different genders, those of children outside the age range, or those from different cultural backgrounds. Future studies should consider exploring a more diverse sample, including children from different cultural backgrounds and with neurodevelopmental conditions or learning difficulties.

Implications for practice

This study highlights that preadmission visits are essential and valuable to prepare both children and parents for upcoming cardiac procedures. When assisting parents prepare their child for cardiac procedures, we recommend healthcare professionals provide individualised, age-appropriate strategies, such as child-centred explanations; empowering parents to continue their child's preparation beyond the preadmission visit. Additionally, to further support preparation, there is a need for the development of interactive and relatable resources that can be taken home. While the primary focus of this study surrounds children with congenital heart disease, the findings have broader implications and can be useful for preparing children with complex conditions who are undergoing various surgical procedures.

Conclusion

The findings from this study emphasise the challenging task parents have of preparing their child for cardiac procedures, because of the need to deliver information in a developmentally appropriate way, while balancing the need for honesty with containing anxiety. There is no doubt that support for children prior to cardiac procedures must include empowering parents who know their child best, but it must also be recognised that parents may need resources beyond information traditionally given in a preadmission clinic. This includes individualised, age-appropriate strategies that assist parents in explaining cardiac procedures to their child, and interactive, relatable resources that allow parents to continue preparation beyond the preadmission visit.

Acknowledgements

Authors would like to thank parents who participated in this study for generously giving up their time to share their experiences with such honesty. This research was completed through the BEST Practice Program at The Royal Children's Hospital, which is supported by The Royal Children's Hospital Foundation.

Author contributions

Ms. Sage Hay designed study, undertook parent interviews, performed data analysis, original draft, and writing – review and editing of manuscript. Dr. Jenny O'Neill contributed to study design, assisted with data analysis, interpretation of results, and writing - review and editing of manuscript.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

ORCID iDs

Sage Hay https://orcid.org/0009-0005-2221-4530
Jenny O'Neill https://orcid.org/0000-0002-2137-3776

Supplemental Material

Supplemental material for this article is available online.

References

Ahmed SK (2024) The pillars of trustworthiness in qualitative research. *Journal of Medicine, Surgery, and Public Health* 2: 100051. DOI: 10.1016/j.glmedi.2024.100051.

Ben Ari A, Margalit D, Roth Y, et al. (2019) Should parents share medical information with their young children? A prospective study. *Comprehensive Psychiatry* 88: 52–56. DOI: 10.1016/j.comppsych.2018.11.012.

Blue GM, Kirk EP, Sholler GF, et al. (2012) Congenital heart disease: current knowledge about causes and inheritance. *Medical Journal of Australia* 197(3): 155–159. DOI: 10.5694/mja12.10811.

Braun V and Clarke V (2022) *Thematic Analysis: A Practical Guide*. Thousand Oaks, CA: Sage.

Bray L, Carter B and Snodin J (2016) Holding children for clinical procedures: perseverance in spite of or persevering to be child-centered. *Research in Nursing & Health* 39(1): 30–41. DOI: 10.1002/nur.21700.

Bray L, Appleton V and Sharpe A (2019a) 'If I knew what was going to happen, it wouldn't worry me so much': children's, parents' and health professionals' perspectives on information for children undergoing a procedure. *Journal of Child Health Care* 23(4): 626–638. DOI: 10.1177/1367493519870654.

Bray L, Appleton V and Sharpe A (2019b) The information needs of children having clinical procedures in hospital: will it hurt? Will I feel scared? What can I do to stay calm? *Child: Care, Health and Development* 45(5): 737–743. DOI: 10.1111/cch.12692.

Bray L, Appleton V and Sharpe A (2022) 'We should have been told what would happen': children's and parents' procedural knowledge levels and information-seeking behaviours when coming to hospital for a planned procedure. *Journal of Child Health Care* 26(1): 96–109. DOI: 10.1177/13674935211000929.

Brown L, Hinsley K, Hurtig M, et al. (2019) The current practice and care of paediatric patients post cardiac catheterisation. *Cardiology in the Young* 29(2): 146–151. DOI: 10.1017/S104795111800197X.

Celermajer D, Strange G, Cordina R, et al. (2016) Congenital heart disease requires a lifetime continuum of care: a call for a regional registry. *Heart Lung & Circulation* 25(8): 750–754. DOI: 10.1016/j.hlc.2016.03.018.

Chang C, Li Y, Or LL, et al. (2020) A qualitative study exploring Singaporean parents' perceptions on preparing their child for surgery. *Journal of Pediatric Nursing* 54: e69–e77. DOI: 10.1016/j.pedn.2020.05.004.

Clift L, Dampier S and Timmons S (2007) Adolescents' experiences of emergency admission to children's wards. *Journal of Child Health Care* 11(3): 195–207. DOI: 10.1177/1367493507079561.

Dai Y and Livesley J (2018) A mixed-method systematic review of the effectiveness and acceptability of preoperative psychological preparation programmes to reduce paediatric preoperative anxiety in elective surgery. *Journal of Advanced Nursing* 74(9): 2022–2037. DOI: 10.1111/jan.13713.

Duff AJ, Gaskell SL, Jacobs K, et al. (2012) Management of distressing procedures in children and young people: time to adhere to the guidelines. *Archives of Disease in Childhood* 97(1): 1–4. DOI: 10.1136/archdischild-2011-300762.

Goossens E, Stephani I, Hilderson D, et al. (2011) Transfer of adolescents with congenital heart disease from pediatric cardiology to adult health care: an analysis of transfer destinations. *Journal of the American College of Cardiology* 57(23): 2368–2374. DOI: 10.1016/j.jacc.2010.11.068.

Gordon BK, Jaaniste T, Bartlett K, et al. (2010) Child and parental surveys about pre-hospitalization information provision. *Child: Care, Health and Development* 37(5): 727–733. DOI: 10.1111/j.1365-2214.2010.01190.x.

Hudson N, Spriggs M and Gillam L (2019) Telling the truth to young children: ethical reasons for information disclosure in paediatrics. *Journal of Paediatrics and Child Health* 55(1): 13–17. DOI: 10.1111/jpc.14209.

Hunter D, McCallum J and Howes D (2019) Defining exploratory- descriptive qualitative (EDQ) research and considering its application to healthcare. *Journal of Nursing & Health Care* 4(1): 202.

Jaaniste T, Hayes B and Von Baeyer CL (2007) Providing children with information about forthcoming medical procedures: a review and synthesis. *Clinical Psychology: Science and Practice* 14(2): 124–143. DOI: 10.1111/j.1468-2850.2007.00072.x.

Kennedy M and Howlin F (2022) Preparation of children for elective surgery and hospitalisation: a parental perspective. *Journal of Child Health Care* 26(4): 568–580. DOI: 10.1177/13674935211032804.

Kerimaa H, Ruotsalainen H, Kyngäs H, et al. (2023) Effectiveness of interventions used to prepare preschool children and their parents for day surgery: a systematic review and meta-analysis of randomised controlled trials. *Journal of Clinical Nursing* 32(9–10): 1705–1722. DOI: 10.1111/jocn.16156.

Koopman H, Baars R, Chaplin J, et al. (2004) Illness through the eyes of the child: the development of children's understanding of the causes of illness. *Patient Education and Counseling* 55(3): 363–370. DOI: 10.1016/j.pec.2004.02.020.

Liamputtong P (2020) *Qualitative Research Methods*. 5th edition. Docklands, Victoria: Oxford University Press.

Lincoln YS and Guba EG (1986) But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New Directions for Program Evaluation* 1986(30): 73–84. DOI: 10.1002/ev.1427.

Lööf G, Andersson-Papadogiannakis N and Silen C (2019) Children's own perspectives demonstrate the need to improve paediatric perioperative care. *Nursing open* 6(4): 1363–1371. DOI: 10.1002/nop2.332.

Mahoney L, Ayers S and Seddon P (2010) The association between parent's and healthcare professional's behavior and children's coping and distress during venepuncture. *Journal of Pediatric Psychology* 35(9): 985–995. DOI: 10.1093/jpepsy/jsq009.

Månsson ME, Forsner M and Hedén L (2023) Children need to know: a follow-up study two decades later on informing and preparing children for clinical examinations and procedures. *Pediatric Nursing* 49(1): 32.

Ofori-Amanfo G and Cheifetz IM (2013) Pediatric postoperative cardiac care. *Critical Care Clinics* 29(2): 185–202. DOI: 10.1016/j.ccc.2013.01.003.

Rasnake L and Linscheid TR (1989) Anxiety reduction in children receiving medical care: developmental considerations. *Journal of Developmental and Behavioral Pediatrics* 10(4): 169–175.

Sadegh Tabrizi J, Seyedhejazi M, Fakhari A, et al. (2015) Preoperative education and decreasing preoperative anxiety among children aged 8–10 years old and their mothers. *Anesthesiology and Pain Medicine* 5(4): e25036. DOI: 10.5812/aapm.25036.

Shaheen A, Nassar O, Khalaf I, et al. (2018) The effectiveness of age-appropriate pre-operative information session on the anxiety level of school-age children undergoing elective surgery in Jordan. *International Journal of Nursing Practice* 24(3): e12634. DOI: 10.1111/ijn.12634.

Strange G, Stewart S, Farthing M, et al. (2020) Living with, and caring for, congenital heart disease in Australia: insights from the congenital heart alliance of Australia and New Zealand online survey. *Heart Lung & Circulation* 29(2): 216–223. DOI: 10.1016/j.hlc.2018.12.009.

Wei H, Roscigno CI, Swanson KM, et al. (2016) Parents' experiences of having a child undergoing congenital heart surgery: an emotional rollercoaster from shocking to blessing. *Heart & Lung: The Journal of Acute and Critical Care* 45(2): 154–160. DOI: 10.1016/j.hrtlng.2015.12.007.

Whitehead D and Whitehead L (2020) Data collection and sampling in qualitative research. In: Whitehead D, Ferguson C, LoBiondo-Wood G, et al. (eds) *Nursing and Midwifery Research: Methods and Appraisal for Evidence-Based Practice*. 6th edition. Chatswood, NSW: Elsevier, 118–135.

Yahya Al-Sagarat A, Al-Oran HM, Obeidat H, et al. (2017) Preparing the family and children for surgery. *Critical Care Nursing Quarterly* 40(2): 99–107. DOI: 10.1097/CNQ.0000000000000146.