


REVIEW ARTICLE

Parental experiences of their infant's hospital admission undergoing cardiac surgery: A systematic review

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Abstract

Aim: To explore parents' experiences of parenting a child hospitalised with congenital heart disease (CHD) and undergoing surgery.

Methods: Five electronic databases were systematically searched for articles describing the experiences of parents with a child with a CHD. A thematic analysis approach was used to identify the most common themes.

Results: A total of 188 articles were identified. Eight studies were included in the review. Four themes emerged, including balancing the parental role, experiencing anticipatory grief, decreasing parental stress using coping strategies and professional support.

Conclusion: Having a child with CHD undergoing heart surgery is a stressful experience due to, among other things, the different situation-related parenting role during the hospital stay and feelings of anticipatory grief. Healthcare professionals in the PICU have an essential role in supporting parents and understanding the needs that are crucial for the parents in order to provide better support and reduce stress and anxiety. More qualitative research regarding the pathway from the prenatal diagnosis through the early childhood period is warranted.

KEYWORDS

congenital heart disease, parental experiences, paediatrics, systematic review

1 | INTRODUCTION

Congenital heart disease (CHD) is the most common birth defect worldwide, affecting 9 of every 1000 newborns.¹ Of these newborns, 25% have critical CHD, such as tetralogy of Fallot (TOF), transposition of the great arteries (TGA) and hypoplastic left heart syndrome (HLHS), requiring one or more cardiac surgeries in the first year of life.² CHD leads to the longer hospital stays and higher mortality rates compared to other chronic diseases.³⁻⁵

Having a child diagnosed with CHD and hospitalised for cardiac surgery is a stressful experience for parents.² The experience of getting the diagnosis, the period before and after cardiac surgery and the following years may severely impact the parents' quality of life.⁶ Parents of infants with a CHD under 1 year old showed higher levels of stress compared to parents of healthy children.⁷ Differences in the severity of cardiac diagnoses lead to differences in parental psychological distress.^{2,8} More severe diagnoses may lead to more surgical interventions, poorer

Abbreviations: CHD, Congenital heart disease; HLHS, hypoplastic left heart syndrome; MeSH, medical subject headings; NICU, neonatal intensive care unit; TGA, transposition of the great arteries; TOF, tetralogy of Fallot.

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prognosis, more time spent in a hospital and, as a consequence, more psychological distress.² Research has shown that these parents are at high risk for psychological problems, particularly in the first weeks and months after their child's cardiac surgery.² Approximately 30% of these parents showed symptoms of post-traumatic stress disorder. In addition, 30%–80% reported to experience psychological distress, and another 25%–50% these parents have reported clinically elevated symptoms of anxiety and/or depression.²

There has been an increase in quantitative research about the psychological well-being of parents with a child with CHD, particularly regarding the presence of anxiety and depression.

To our best knowledge, there is no published review about the qualitative experiences of parents during the surgical period. A few qualitative studies have reported parents' experiences during their infant's hospitalisation, but data whether these experiences may lead to an inferior quality of life are scarce.^{9,10} In view of the limitations of the existing literature, we conducted a systematic review with a thematic analysis to document parents' experiences of parenting a child hospitalised with CHD and undergoing surgery in the first months of life.

The results of this review can be used in school programmes for professionals working at the Pediatric Intensive Care Unit to provide better support and coaching to parents. This may reduce anxiety and stress during the hospitalisation period.

Keynotes

- Having a child with congenital heart disease, hospitalised and undergoing heart surgery is a stressful experience for parents.
- A systematic review and thematic analysis approach were used, and four themes emerged: balancing the parental role, experiencing anticipatory grief, decreasing parents' stress using coping strategies and professional support.

2 | METHODS

2.1 | Study selection criteria

Inclusion criteria were qualitative studies that reported on experiences of parents with infants diagnosed with CHD who were hospitalised for cardiac surgery in the first months of life. All types of CHD were included. The language was restricted to English and Dutch. Exclusion criteria were heart transplantation surgery and studies where parents were already at home at the time of interviewing. If possible, the qualitative data of mixed-methods studies were extracted and included in the analyses.

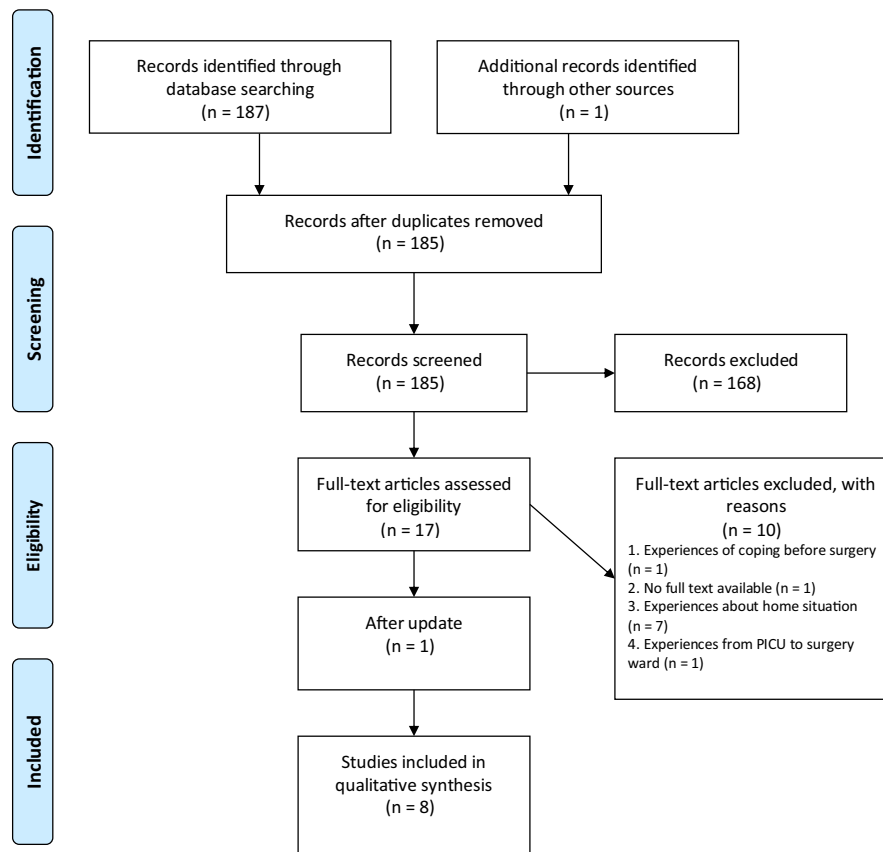


FIGURE 1 PRISMA flow diagram

2.2 | Search strategy

Using a combination of medical subject headings (MeSH) terms and keywords [congenital heart disease], [infant], [thoracic surgery], and [parents], we searched four electronic databases (PubMed, Cochrane, Psych-Info and CINAHL) from inception to June 2020. Complete details of the search strategy are provided in Appendix 1. The reference lists of the selected studies were hand-searched by the first author and the research team to identify additional references. In addition, the research team reviewed titles and abstracts to select articles for inclusion. Duplicates were removed. For the remaining articles, we obtained full-text copies. If an article was not available in full text, the author of the article was contacted to obtain a full-text copy. Full-text articles were read and included if they met the inclusion criteria. Systematic reviews were excluded. If there was any doubt about the eligibility of an article, the research team discussed it until consensus was reached. Reasons for exclusion were reported.

2.3 | Appraisal of quality

Two researchers reviewed the included studies in terms of methodological quality according to the Critical Appraisal Skills Program (CASP) for qualitative studies.¹¹ CASP has 10 items, a user guide and the possibility to add notes. It consists at three section topics.

Section one: are the results valid? Section two: What are the results? Section three: Will the results help locally?

Consensus on the interpretation of the CASP scores was reached by the research team to classify the quality of the articles as good (8-10), moderate (5-7) and low (1-4). Papers of low quality were excluded from the thematic syntheses.

2.4 | Data analysis and synthesis

To analyse the data, we used a method for systematic synthesis or thematic analysis of qualitative research according to Thomas and Harden.¹² Thematic analyses are 'a qualitative analytic method which has been described as identifying and reporting recurrent themes'.¹³ To develop themes, we used a thematic synthesis approach to combine data from primary qualitative studies. First, we collected all the experiences from the parents from all the included primary qualitative articles. In the second stages, the experiences were discussed within the research group and categorised into broader themes. In the third stage, we developed new analytic themes.

To ensure the trustworthiness of the study, each article was read and coded separately by two independent researchers from the research team. Consensus was reached after each step. In case of no consensus, a third researcher (AH) was consulted.

TABLE 1 Methodological quality of included studies

Section A: Are the results valid? / Author	Cantwell-Bartl et al, 2013	Gower et al, 2017	Harvey et al, 2013	Wei et al, 2016	Salgado et al, 2011	Simeone et al, 2018	Simeone et al, 2018 (2)	Vainberg et al, 2019
1. Was there a clear statement of the research aim?	+	+	+	+	+	+	+	+
2. Is qualitative methodology appropriate?	+	+	+	+	+	+	+	+
3. Was the research design appropriate to address the research aims?	?	+	+	+	+	+	+	+
4. Was the recruitment strategy appropriate for the research aims?	?	+	?	+	?	±	+	+
5. Was data collected in a way that addressed the research issue?	+	+	+	+	+	+	+	+
6. Has the relationship between researcher and participants been adequately considered?	+	+	?	?	-	+	+	+
Section B: What are the results?								
7. Have ethical issues been taken into consideration?	+	?	+	+	+	?	+	+
8. Was the data analysis sufficiently rigorous?	-	+	+	+	+	+	+	+
9. Is there a clear statement of findings?	+	+	+	+	+	+	+	+
Section C: Will the results help locally?								
10. How valuable is the research?	+	+	+	+	+	+	+	+
CASP Quality Score (maximum 10 points)	8	9.5	9	9.5	8.5	9	10	10

Note: Good (8-10), moderate (5-7) and low (1-4).

Points: +=1, ?=0.5, -=0.

TABLE 2 Characteristics of the included studies

Author [ref]	Country	Design	Sample size	Patient population	Research questions	Conclusions and themes
Simeone et al, 2018 ¹⁵	Italy	Phenomenological study	n = 16; 9 mothers, 7 fathers	Parents of a child who was admitted to a PICU of a cardiac surgery ward.	Tell me about your experience of the time you spent at the PICU? How did you handle the situation when your child was admitted to the PICU?	When a child is hospitalised in a PICU, specifically a cardiac surgery ward, the nursing staff have to take care of the family as well. The themes revealed by the analysis showed that fathers experienced the same fears and anxiety as mothers. A family-centred care program can help to overcome anxiety and fears. Three themes were identified: 1. The fear of the potential loss of their children. 2. The feeling of having lost their roles as parents. 3. The desire to receive more information and be an active part of the treatment process.
Gower et al, 2017 ¹⁶	UK	Phenomenological study	n = 6; 6 fathers	Fathers, having a child who had been diagnosed prenatally, had undergone at least one procedure for correction or palliation of a major heart defect.	Why are the fathers attending the clinic?	Fathers apparently afloat in the PICU but have their own challenges driven by control, self-competence and gender identity. Their child's sickness and hospitalisation has an impact on their personal life and priorities. Two themes were identified: 1. Relinquishing and reclaiming control 2. Living in the shadow of illness
Simeone et al, 2018 ¹⁹	Italy	Phenomenological study	n = 24; 18 mothers, 6 fathers	Parents from two hospitals, where children were given cardiac surgery after one to three months.	Tell me about your experience of the time you spent at the PICU? How did you handle the situation when your child was admitted to the PICU?	When a child is hospitalised in a PICU, specifically a cardiac surgery ward, the nursing staff have to take care of the family as well The themes revealed by the analysis showed that fathers experienced the same fears and anxiety as mothers. A family-centred care program can help to overcome anxiety and fears. Three themes were identified: 1. The fear of the potential loss of their children. 2. The feeling of having lost their roles as parents. 3. The desire to receive more information and be an active part of the treatment process.

(Continues)

Table 2 (Continued)

Author [ref]	Country	Design	Sample size	Patient population	Research questions	Conclusions and themes
Salgado et al, 2011 8	Brazil	Descriptive, exploratory study	n = 5; 5 mothers, 1 father	Parents of children with congenital heart disease undergoing cardiac surgery.	No information about the research questions.	The hospitalisation of a child with CHD is a turning point for families and their way of life. It provokes different feelings – anxiety and fear but also improved quality of life. Anxiety increased when families underwent unknown situations, when they need information on procedures and when the situation of their family changed. Four themes were identified: 1. Feelings and emotions regarding the child's illness 2. Heart disease under the mother's view 3. The mother and the child in the ICU 4. Coping resources
Harvey et al, 2013 17	USA	Qualitative descriptive research design with phenomenological overtones	n = 8; 8 mothers	Mothers of infants with moderate to severe CHD who were having or had complex heart surgery in the last 5 years.	Please share your experience of the events (from that day). Describe in words (or draw) your thoughts and feelings (days before surgery, day of surgery, days after surgery).	Mothers are confronted with significant new challenges when their child must have heart surgery. Looking back at the process, mothers have strong memories of the surgical experience. The study results can be used for interventions in the context of family-centred care. Six themes were identified: 1. Feeling intense fluctuating emotions 2. Navigating the medical world 3. Dealing with the unknown 4. Facing the possibility of my baby dying 5. Finding meaning and spiritual connection 6. Mothering through it all
Cantwell et al, 2013 20	Australia	Mixed-methods (retrospective, narrative interviews and psychometric testing)	n = 29; 16 mothers, 13 fathers	Parents who had a child with a Norwood repair of HLHS after their first admission.	Explored stressors, traumatic stress, losses, adaptation of the parents and their relationship with their infant.	All parents with children with hypoplastic left heart syndrome in the PICU experienced numerous stresses and losses. Professionals have to support parents with interventions to promote communication and parent-child interaction. Six themes were identified: 1. Receiving the diagnosis of HLHS 2. The environment of the PICU 3. Their infant's health status 4. Their infant's appearance after surgery 5. Relationships with staff 6. Family stressors

(Continues)

Table 2 (Continued)

Author [ref]	Country	Design	Sample size	Patient population	Research questions	Conclusions and themes
Wei et al. 2016 ¹⁸	USA	Descriptive, phenomenological study	n = 13; 10 mothers, 3 fathers	Parents who had a child hospitalised for open heart surgery.	Questions on parents' experiences: the heart disease, heart surgery, waiting for surgery, PICU, cardiac unit. Interview 4-6 weeks after surgery: Questions on parents' experiences: typical day in the hospital, at home, looking back at the time of your child's diagnosis, child's diagnosis, discharge process	The emotions of parents of children undergoing heart surgery are not linear. They experienced 'a rollercoaster' of mixed emotions. Although parents get information about the operation, the parents need more information and support during the child's hospitalisation. Four themes were identified: 1. Uncertainty of outcomes after surgery 2. The loss of parental control. 3. The physical appearance of their child 4. Fear of the technological atmosphere in the intensive care unit
Vainberg et al. 2019 ¹⁴	Israel	Phenomenological study	n = 12; 9 mothers, 3 fathers	Parents who had a child being treated in a children cardiac ICU.	First phase of interviewing: talking about the experience in chronological order. Second phase: focused on the parents' experience within the medical setting.	The experience of having a child in the PICU and undergoing surgery is stressful, with feelings of confusion and helplessness. Support during the hospitalisation period should be increased by trying to strengthen their inner coping abilities and minimise their negative experiences. Eight themes were identified: 1. Parental emotional distress 2. Disrupted parental experience 3. Parental isolation and loneliness 4. Objectifying and criticising medical staff 5. Parental resources and coping strategies 6. Parental involvement in childcare 7. Support system of family, friends and each other 8. Supportive, informative and sensitive medical staff The categories were grouped into four main themes: inner negative experience, outer negative experience, inner positive experience and outer positive experience.

3 | RESULTS

3.1 | Search results

The search identified a total of 188 studies (Figure 1). After duplicate removal and abstract screening, 18 articles were considered for full-text analysis. Among them, 10 were excluded because they did not turn out to meet inclusion criteria. The remaining seven studies were included in our review (PRISMA flow diagram, Figure 1). An update of the search was performed in August 2020 and resulted in one additional article, which was included.¹⁴

The characteristics of the included studies are summarised in Table 1. Six articles were qualitative studies,^{8,14-18} and two were mixed-methods studies.^{19,20} Two studies were conducted in Italy, one in the UK, two in the USA, one in Australia, one in Brazil and one in Israel.

All studies included parents who had a child hospitalised at a Cardiac Intensive Care Unit. Some studies interviewed the parents at home and in the hospital.^{14-17,19,20} One study only interviewed fathers.¹⁶ One study had only mothers included.¹⁷ In six studies, the main research question was mentioned.¹⁴⁻¹⁹ Only one study described the heart disease.²⁰

3.2 | Methodological quality

Table 2 presents an overview of the selected studies and their methodological quality. All eight studies were assessed as being of good quality. The study from Cantwell-Bartl et al, 2013, scored the lowest points: 8 points. The study from Simeone et al, 2018, and Vainberg et al, 2019, scored the highest point 10 points. The question, was the recruitment strategy appropriate for the research aims, was difficult to score. For articles could not give an answer to that question.^{8,15,17,20}

3.3 | Identified themes

The thematic synthesis approach revealed four overarching themes: balancing the parental role, experiencing anticipatory grief, decreasing parental stress using coping strategies and professional support. Table 3 shows the overarching themes and quotation.

3.3.1 | Theme 1. Balancing the parental role

All parents in the studies struggled with their role as a parent. Some parents described this topic as the loss of parental control.^{15,18} During the hospital stay, mothers and fathers grappled with the concept of not being a good parent. Feelings of mastery decreased, and feelings of helplessness increased.¹⁵ Receiving their child's cardiac diagnosis, sometimes right after birth, was very traumatic, and the trauma was increased by the PICU environment.²⁰ Parents experienced a separation from their child that interfered with bonding with their child. The environment of the ward apparently played a major role in inhibiting

parent-infant bonding.²⁰ Parents described a 'rollercoaster of emotions' as their child underwent heart surgery.¹⁸ Being involved as a parent after the surgery period was very hard. Fathers stated that a child with CHD creates unique challenges underpinned by issues of control, self-competence and gender identity. It had a lasting impact on them and their perspective on life, while also offering opportunities for personal growth and a re-evaluation of priorities.¹⁶

3.3.2 | Theme 2. Experiencing anticipatory grief

Parents have to deal with the unknown when they have a child with CHD. Before the diagnosis, they have many expectations about the future of their child. Receiving the diagnosis is followed by increasing uncertainty and an unknown future.¹⁷ Before the diagnosis, parents had a certain perception of life. After the diagnosis, their view of life changed drastically.¹⁵ Parents could no longer make plans or have specific ideas for their children. Life was going in an unexpected direction, and this cast a shadow over family life.¹⁶ The feelings of uncertainty and the disappearance of the future led to anticipatory grief, as things were now on hold. Parents had expectations about their parental function; in all studies, this changed into the fear of the potential loss of their child.^{8,15,18}

3.3.3 | Theme 3. Decreasing parents' stress using coping strategies

The emotions of parents of children undergoing heart surgery were not linear. Happiness and hope alternated with sadness and despair.¹⁸ The ups and downs of their emotions were based on their child's changing condition and the uncertainties they faced. Parents tried to adapt effectively to this situation by finding positive meaning in the process of coping and adapting to the extra demands in their daily life.²¹ Having a child with CHD undergo surgery can be a crisis for a family. However, the surgery can also be seen from a perspective of healing and improving quality of life.⁸ Various strategies were used to cope with this experience - religion, support from the social network, the care of the health team and sometimes a family's life history.⁸ Some parents found meaning and spiritual connections in their circumstances. They were able to make sense of the situation.¹⁷ Parents felt their strength grew when they talked to other parents who had the same experiences.¹⁸ It helped them create some distance to their own emotions. Some parents used multiple coping strategies to deal with the challenges, which had a positive effect on them and their families. Parents' experiences strengthened family relationships, resulting in the feeling that the condition of the child had brought them a lot closer. Parents appreciated their family lives more than before.¹⁸ Parents described the feeling that it had been hard going through all the emotions, from pregnancy until surgery. At the same time, they would not have wanted to change anything in their lives.

TABLE 3 Summary of the main themes and quotations

Analytical themes	Quotations
1. Balancing the parental role	<p>Every time I tried to close my eyes, my baby's cries filled my head. I just didn't know what to do with myself. I was glad I was breastfeeding; it made me feel as though I was doing something to help my son." (Harvey et al, 2018)</p> <p>I saw my son there, in that bed, motionless, full of wires: I looked for help, and I felt helpless: I did not know how to help him. What is a parent who cannot help his child? (Simeone et al, 2018)</p> <p>I wanted to hold my baby and comfort him. But I can't do it... The beeping sounds of the machine freaked me out. I turned around and brake down. (Wei et al, 2016)</p> <p>The first few days (of my child being) in intensive care, I felt strange: I was not a good mother... (Simone et al, 2018)</p> <p>Not being able to hold [child] for like a month after he was born. I was there day in and day out...I stood there and watched him crash right in front of me. I just had to step away from the bed and let the doctors just rush to him, because there's nothing I can do. (Sood et al, 2018)</p> <p>As a dad, I felt nauseated. I felt weak. I was trying to think and comprehend. I wasn't ok at that moment. I became fragile. I was sad and overwhelmed. (Wei et al, 2016)</p>
2. Experiencing anticipatory grief	<p>It was a shock. Your whole world changed. (Wei et al, 2016)</p> <p>It's the uncertainty and the unknown, not knowing what next year will bring... you can't really move your life on at home, you can't make plan because you ultimately don't know where you're going to be or what you'll be doing. So things are pretty much on hold. (Gower et al, 2017)</p> <p>I don't think he's going to play in the premier League. Gower et al, 2017)</p> <p>The moment we were told about the diagnosis, it seemed that we stepped on to a rollercoaster. (Wei et al, 2016)</p> <p>You want life to be normal and it's having to accept that life isn't going to be normal for us. (Gower et al, 2017)</p> <p>It (the diagnosis) was the most devastating thing I have ever heard in my life. (Wei et al, 2016)</p>
3. Decreasing parental stress using coping strategies	<p>I can do everything through Christ who strengthens me. (Salgado et al, 2011)</p> <p>My faith had been made stronger, not because God allowed us to keep our daughter but because I grew closer to Him through the experience. (Harvey et al, 2013)</p> <p>I don't know if I believe in destiny or if I just have a lot of faith, but when there's nothing else you can do, I had to believe that whatever was supposed to happen, would happen. (Harvey et al, 2013)</p> <p>I found talking to people who were in a significantly worse situation than I was helpful to the extent that they are still there and going through it and believing in the process and working through...sometimes strangers can be more of a resource in that they have already gone through this. (Sood et al, 2018)</p> <p>I felt better after I talked to a couple who were going through an even worse situation. (Wei et al, 2016)</p> <p>We, as a family have learned more than we could ever have imagined possible. We learned what was really important in life. (Harvey et al, 2013)</p>
4. Professional support	<p>I cannot explain. When I saw the nurses and doctors accompanying her I was relieved. (Salgado et al, 2011)</p> <p>The day after the surgery was very hard. I remember calling quite a bit but didn't want to go see him. A nurse finally convinced me that night to come see him and that he needs me. So I went hardly left his side that whole hospital visit (stay). I know having his mom made a huge impact on his life! (Harvey et al, 2013)</p> <p>When the cardiologist came in, he immediately put me at ease with his positive attitude. He told me about my son's heart condition, and laid out the solution. I remember what really lifted my spirit was when he said: "Shaun White, he had Tetralogy of Fallot. He won Olympic gold medals." Thank you for saying that. (Wei, et al 2016).</p> <p>And they also explain, they really explain everything ... it really gives you a sense of control and understanding. (Vainberg et al, 2019)</p> <p>Here, the nurses saw that you wanted to act as the parent: they helped you. And you felt important. (Simone et al, 2018)</p> <p>By having that change to meet his surgeon I was able to feel confident in him. (Harvey et al, 2013)</p>

3.3.4 | Theme 4. Professional support

Most parents reported that during the hospital stay, the professionals who cared for their child had become part of their everyday life. Moreover, they reported feeling strengthened by the support and care of the health team.^{8,19} A child's admission to a PICU, specifically to a cardiac surgery ward, forces the nursing staff to care for the family as well.¹⁵ Parents reported wanting to be involved and active

in the care process.¹⁵ During the hospital stay, families also had a strong need for information about therapeutic procedures, hospital routines and the actual life situation.^{8,16}

Parents indicated that good, accessible and understandable information was enormously helpful during their child's hospital stay. Likewise, being shown around the PICU by professionals was very helpful during their stay.¹⁶ The parents' level of anxiety depends on their coping mechanisms and on their relationships with healthcare

professionals.^{8,15} A positive attitude and engagement with health professionals helped reduce parents' stress.²⁰

4 | DISCUSSION

This systematic review aimed to explore parents' experiences of parenting a child with chronic heart disease undergoing surgery. Four themes emerged from the included studies, which are balancing the parental role, experiencing anticipatory grief, decreasing parental stress using coping strategies and professional support.

Within the first theme balancing the parental role, all parents in the studies struggled with their role as a parent.^{8,14-20} It appeared to be an essential theme. The role of a parent changed during hospitalisation. Previous studies have supported our findings that mothers and fathers grappled with the concept of not being a good parent. A review from Al Maghaireh et al (2016) explored the parental experiences in the neonatal intensive care unit (NICU). One of the common themes across parents experiences was the alteration in the parenting role.²² In our review, parents also experienced being involved as a parent was very hard, and parent-infant bonding was difficult.

The review from Provenzi et al (2015) explored the lived experience of fathers of preterm infants in the NICU, and paternal needs were one of the major themes.²³ From literature, we know that parents who are involved in the care for their infant suffer less from feelings of helplessness (34). Parents, who practise Kangaroo care, one of the most robust interventions in the NICU providing bonding between parent and child, did not experience any changes in their role as a parent.²² In the NICU, Kangaroo care is standard, whereas in the PICU Kangaroo care is not possible after surgery. Parents suffer more in finding the parental role in the PICU than in the NICU (34).

The second theme was experiencing anticipatory grief. Studies showed that our theme 'anticipatory grief' is common and that parental feelings of potential loss lead to anticipatory grief.²⁴ Hong Ni et al (2019) showed similar to our review that parents who had a child with CHD, undergo surgery, experienced that they were 'breaking the good life'.²⁵ In our review, parents also shared that they felt that their view of life changed drastically.

Most parents experienced that feelings of intense grief began at the time of diagnosis and continued for an extended period.^{26,27} That's in line with this review were parents experiences that receiving the CHD diagnosis is followed by increasing uncertainty and an unknown future.

The third theme is decreasing parental stress using coping strategies. During hospitalisation, parents used different coping strategies to adapt to the situation effectively. Coping strategies mainly consist of control and to avoid negative feelings. In our review, we found religion, support from the social network, the care of the health team and family's life history as used coping mechanisms. These findings are in line with the review of Abela et al (2019) about the impact of paediatric critical illness and injury on families. Abela et al showed that the most common coping theme was that family members felt

supported and guided by faith and spirituality.²⁸ In our review, religion is also an essential coping mechanism; in addition, the social network is also a central coping theme.

Gaskin et al (2017) explored the patterns of transition for parents going home from hospital with their infant, after first stage surgery for complex congenital heart disease. One of the coping mechanism parents described was peer support. Peer support helped the parents to create some distance from their own emotions.²⁹ In our review, parents used peer support, not only to create space from their feelings but also to feel strengthened when they talk to other parents who had the same experiences.

The studies from March (2017) and McMahon (2020) described the experiences of parents with a child with a CHD undergoing cardiac surgery. Using coping strategies had positive effects on family life. Parents' experiences strengthened family relationships, with the result feeling that the condition of the child brought them closer.^{30,31} In our review, we found similar with March and McMahon that parents experienced better family relationships.

The review of Provenzi et al (2015) described the experiences of fathers in the NICU. One central theme was the use of two coping strategies described as: "going back to work" and "hiding their feelings" (34). In our review, we did not recognise these themes; in contrast we found that some parents experienced, they would not have wanted to change anything in their lives.

The review of Loewenstein et al (2019) described the experiences of parents in the NICU within the transactional model of Stress and Coping. Regulating emotions and social support and faith and spirituality and managing the NICU were four significant themes.³⁶

The fourth theme emerged was professional support. From research, we know that parents have a desire to collaborate with care providers, especially nurses. Nurse's communication style is an essential factor in the relationship between nurses and parents.³³ Nurses have the potential to assist families on the PICU during the cardiac surgery period. The review from Loewenstein et al (2019) showed that one of the essential needs of parents with a child in the NICU was the positive relationships with the NICU staff.³² This positive relationship is similar to our review, and despite the differences in population, our review showed that parents experience feelings of strength by the support of the healthcare team in particularly nurses.

The review of Cleveland (2008) was conducted to explore the needs and supports of parents who had an infant in the NICU. Six needs were identified. Two recommendations were: "being positively perceived by the nursing staff" and "a therapeutic relationship with the nursing staff".³³ These findings are semi-recognisable with our review, were parents highlighted the vital need for information. An explanation for this conclusion could be that surgery is a very moving process for parents, and their need for information is high. In addition, the care after the surgery is experienced as very intense.

Strength of this review is the use of the systematic methodology. We used thematic analysis and the PRISMA method for reporting results. A protocol was made beforehand and registered in Prospero.

Rigour and trustworthiness were performed using investigator triangulation.^{37,37} Investigator triangulation was attained by debating the data extraction and defining analytical themes among the researchers and within the research group. Disagreements were discussed in the research group until consensus was reached. However, some limitations should be addressed. The included studies used different research questions in interviewing parents. Sometimes, the interview questions were even not mentioned.

Different themes appeared in the included studies. It is shown that family of children with more severe CHD report more negative impact than families of children with milder forms CHD, leading to other themes.³⁵ Unfortunately, not all the included studies described their definition and severity of the heart malformation; therefore, it is impossible to compare between less or more severe heart malformation and the differences in themes.

5 | CONCLUSION

Having a child with CHD undergoing heart surgery is a stressful experience due to, among other things, the different situation-related parenting role during the hospital stay and feelings of anticipatory grief. Most parents try to cope effectively by finding positive meaning in the situation and by trying to deal with and adapt to the added demands in daily life.

Healthcare professionals in the PICU have an essential role in supporting parents and understanding their needs in order to provide better support and reduce stress. More qualitative research regarding the pathway from the prenatal diagnosis through the early childhood period is warranted.

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CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

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APPENDIX 1

SEARCH STRINGS

PubMed: Hospitals AND Infant AND Congenital Heart Dis OR congenital AND Heart AND Disease OR Pediatrics OR AND Thoracic surgery OR Thoracic AND Surgery OR Heart AND surgery OR Heart surgery OR Cardiac AND Surgical AND Procedures OR Cardiac surgical procedures AND experiences.

Psych-Info: Parental experiences of their infant's hospitalization for cardiac surgery AND Cardiac surgery AND hospitalization AND infant AND parental experience AND qualitative method.

CINAHL: Parent experiences AND Infant AND hospital AND Congenital heart disease.

Cochrane: Infant AND Congenital heart defects OR cardiac-surgery AND hospital AND parental experiences.