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Supports for Parents of Infants Diagnosed with a Congenital Heart Defect: A Narrative Synthesis of Qualitative Research

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Abstract

Parents of infants diagnosed with a congenital heart defect (CHD) often experience an overwhelming emotional journey, characterized by anxiety, stress, and role strain. This study examines the informational, emotional, and practical supportive care needs of parents whose infants are diagnosed with a CHD in hospital, at birth. Employing a secondary analysis of qualitative literature in the form of a narrative synthesis, this research categorizes parents' needs into three types: (1) informational, where parents often feel overwhelmed by medical terminology and desire clear guidance; (2) emotional, where parents require empathy and understanding from healthcare providers and benefit from peer support; and (3) practical, highlighting parents' need for assistance with daily responsibilities and self-care. Findings from this synthesis emphasize the role of nurses in meeting these needs through comprehensive education, compassionate care, and practical resources. Thus, nurses can collectively help reduce parental anxiety and foster a supportive environment for families.

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Introduction

Congenital heart defects (CHDs) are the most common type of birth defect, affecting 12.1 per 1,000 births in Ontario each year (Miao et al., 2023). Global estimates of CHDs at birth are as high as 1.8 per 100 live births (GBD 2017 Congenital Heart Disease Collaborators, 2020). Congenital heart defects are structural abnormalities of the heart present at birth, which can affect both the heart muscle and the surrounding vessels, necessitating multiple surgeries, hospital stays, medical interactions, and a lifelong commitment to care management (Buratto & Kostantinov, 2016; Rao, 2024). The etiology of CHDs is multifactorial, involving genetic, environmental, and possibly maternal health factors (Sun et al., 2013). Genetic contributions can include chromosomal abnormalities and single-gene mutations, while environmental factors may involve maternal exposures to certain medications, alcohol, or infections during pregnancy.

Congenital heart defects can be diagnosed prenatally, at birth before discharge (neonatal), and after discharge from hospital, where better outcomes have been reported with prenatal diagnosis (Wren et al., 2008). Severe CHD conditions typically present at birth with cardiorespiratory decompensation evidenced by cyanosis (Pavlicek et al., 2021; Wren et al., 2008; GBD 2017 Congenital Heart Disease Collaborators, 2020). Pavlicek et al. (2021) report that 40% of CHDs are diagnosed prenatally during the 18- to 20-week ultrasound. If not detected prenatally, 95% of cyanotic CHDs, are identified within the first week of life, due to severe symptoms. Additionally, 66% of acyanotic heart defects, such as ventricular septal defects, coarctation of the aorta, and pulmonary stenosis, are diagnosed within the same timeframe when infants fail pulse oximetry screening (Pavlicek et al., 2021; Jain et al., 2022). Thus, diagnosis of CHDs can occur in hospital through pulse oximetry screening (Ewer et al., 2012; Martin et al., 2020; Peterson et al., 2014). This non-invasive test measures blood oxygen saturation (SpO_2) in the right hand and foot, where differences between these readings may indicate abnormal blood flow, such as right-to-left shunting (Ewer et al., 2012). Further diagnostics, such as an echocardiogram, can then be conducted to evaluate the heart's structure and function (Ewer et al., 2012).

Treatment for CHDs varies depending on the type and severity of the defect. Some CHDs may resolve spontaneously or require minimal medical intervention, while others require complex surgical procedures and long-term medical management to improve cardiovascular function (Sun et al., 2013). Effective management and recovery require a multidisciplinary approach, including ongoing monitoring and supportive care from nurses, who play a crucial role in patient education and health promotion (Wilandika et al., 2023; Machado Amazonas et al., 2023).

When parents are informed their infant has been diagnosed with a CHD, they often experience a rollercoaster of emotions, such as shock, fear, and anxiety (Wei et al., 2016). The initial diagnosis often shatters parental expectations of having a healthy baby, leading them to experience grief, guilt, and helplessness (Nayeri et al., 2021; Wei et al., 2016). This emotional distress is intensified by the uncertainty of their child's prognosis and the complexity of the medical information they must process (Tallon et al., 2015; Wei et al., 2016). These heightened levels of anxiety and stress have caused parents to feel their role has altered to a focus on understanding complex medical information, which has been shown to disrupt parent-infant bonding and attachment (Vainberg et al., 2019). The feeling of the need to intensely monitor their infant can also lead to parental role strain and social isolation, further exacerbating their stress and emotional burden (Vainberg et al., 2019).

The birth of a child with a CHD affects the dynamics and relationships among the entire family (Machado Amazonas et al., 2023). Siblings may feel neglected, and marital relationships can be strained due to the emotional and physical demands of caring for the affected child. Furthermore, family routines and dynamics often need to be adjusted to accommodate the child's medical needs, which can include parents leaving employment and having no time for leisure activities (Machado Amazonas et al., 2023). Work interruptions further disrupt family dynamics as 83.4% of mothers in one study reported financial strain, describing a constant struggle to meet expenses and often living paycheck to paycheck (Tallon et al., 2015). Therefore, the impact of lost wages can exacerbate stress within the family, affecting both immediate family dynamics and long-term stability.

Parents frequently report feeling anxious and unsupported while navigating their child's care (Machado Amazonas et al., 2023). Higher levels of anxiety are linked to reduced knowledge and understanding, decreasing parents' confidence in making decisions about their child's care (Tallon et al., 2015). However, too much medical information caused parents to feel overwhelmed and vague information left them with many questions, resulting in feelings of stress and anxiety. In the study by Azhar et al. (2018), the information provided by healthcare professionals was deemed unclear in 30.8% of cases and not helpful for parents to care for their children in 29.2% of cases. Additionally, 56.7% of caregivers declared they had not received education about the long-term management of their child's disease and 69.2% declared they had not received education about the side effects or potential complications of the recommended treatment (Azhar et al., 2018). Thus, support from nurses can have an impact on alleviating negative emotions and improving parental confidence in making care decisions for their children (Tallon et al., 2015; Vainberg et al., 2019).

Since many caregivers report not receiving sufficient education about their infant's diagnosis and treatment, it is crucial to understand their supportive care needs and determine the optimal timing for nurses to provide education (Azhar et al., 2018). The effectiveness of educational interventions in decreasing parental anxiety has been demonstrated in the literature, with lower anxiety levels reported in parents who received structured educational support (Simeone et al., 2017). In a study by Werner et al., 2019, it was evident that the quantity and quality of information provided to parents preoperatively significantly influenced their anxiety levels. Detailed discussions with parents about their child's disease, its etiology, and potential complications of surgical intervention for more than 10 minutes, also reduces anxiety levels in parents (Werner et al., 2019; Azhar et al., 2018). Visual aids, such as photographs from their child's echocardiogram, further enhances understanding and reduces caregiver anxiety (Azhar et al., 2018)..

Objective

Despite existing research on parental experiences when their infant has been diagnosed with a CHD, gaps remain in understanding the informational, emotional, and practical needs of parents during the diagnosis and treatment stages after birth, during the neonatal period prior to hospital discharge. Although existing research highlights the benefits of education and peer support, it does not discuss strategies to inform nursing practice to support parental needs (Machado Amazonas et al., 2023). To bridge this gap, the present study seeks to deepen understanding of parental experiences during the postnatal hospitalization period following a CHD diagnosis. By synthesizing these experiences, the study aims to generate practice-informed insights that can guide nursing interventions and enhance family-centred care.

Methods

Methodology

To address the identified problem, a review of qualitative evidence was conducted in the form of a narrative synthesis (Heaton, 2008). This process involved systematically integrating findings from multiple studies, identifying patterns, themes, and relationships within the data to generate a cohesive summary and suggest the direction for future research (Heaton, 2008). This narrative synthesis aimed to gain insights into the informational, emotional, and practical needs of parents of infants with CHDs, as well as to identify strategies that will inform nursing practice to support these families better. By synthesizing findings from multiple studies, this approach allowed for a comprehensive understanding of parental support needs without the constraints of recruiting participants and conducting interviews (Heaton, 2008).

To ensure methodological rigour of this narrative synthesis, the Scale for the Assessment of Narrative Review Articles (SANRA) reporting guidelines were followed (Baethge et al., 2019). This tool facilitated the appraisal of six domains, including justification of the review's importance, specification of research aims, and critical interpretation of findings, ensuring that the synthesis meets standards of a narrative review (Baethge et al., 2019).

Theoretical Framework

Social support theory is a middle-range theory that emphasizes the importance of informational, emotional, and practical assistance in helping individuals cope with stress (Chouhy et al., 2020; Evans et al., 2022). According to the theory, individuals with high levels of social support are thought to be protected from the negative effects of stress (Langford et al., 1997). Informational support refers to the advice, explanations, and educational resources that can help people make decisions in a time of stress (House, 1981; Langford et al., 1997). Emotional support includes the provision of empathy, love, and trust for reassurance to foster feelings of being valued and understood. Instrumental support, also referred to as practical support, looks at tangible goods and services, such as filling basic physiological needs or accessing care (House, 1981; Langford et al., 1997). Nurses are vital in providing comprehensive support to parents, offering clear information, emotional comfort, and practical help, such as coordinating follow-up care (Fuglsang et al., 2023). Failure to address these needs can result in long-term stress and negative health outcomes for both the parents and their children (Kumar et al., 2019). By recognizing and addressing these supportive care needs, nurses can reduce parental stress, improve family well-being, and promote better health outcomes (Wilandika et al., 2023). Therefore, social support theory was used in this narrative synthesis to conceptualize parental experiences and needs.

Search Strategy

A comprehensive literature search was conducted using the following electronic databases: PubMed, CINAHL, ScienceDirect, and Web of Science. The search terms used for each database frequently included "congenital heart defect", "parents", "experiences" "infants" "surgery" and "qualitative", with a date range of 2014–2024 (Table 1). The search results were imported into Covidence to filter and screen for appropriate studies (Figure 1). The focus was on qualitative studies that explored the experiences of parents with infants diagnosed with CHDs during the neonatal period—while in hospital after birth. Studies containing direct quotes from interview transcripts of parents with infants diagnosed with CHDs in hospital after birth, including those that required treatment in hospital, were selected for analysis. Direct quotations were of particular interest in this synthesis, as they encapsulated the experiences of the interviewees, providing insight into their lived realities through their own words. A hand search was also conducted to ensure relevant pieces of literature were captured. One study conducted in the United Kingdom was identified and included for analysis. A total of 7 studies were included by the following authors: Gaskin et al. (2021), Gramszlo et al. (2020), Nayeri et al. (2021), Ni et al. (2019), Thomi et al. (2019), Vainberg et al. (2019), and Wei et al. (2016). In instances where mixed-methods studies were included, only the qualitative data derived from semi-structured interviews was extracted and analyzed. This data, typically presented as participant quotations, was treated equivalently to those from purely qualitative studies. This approach ensured consistency in the synthesis process, with all qualitative

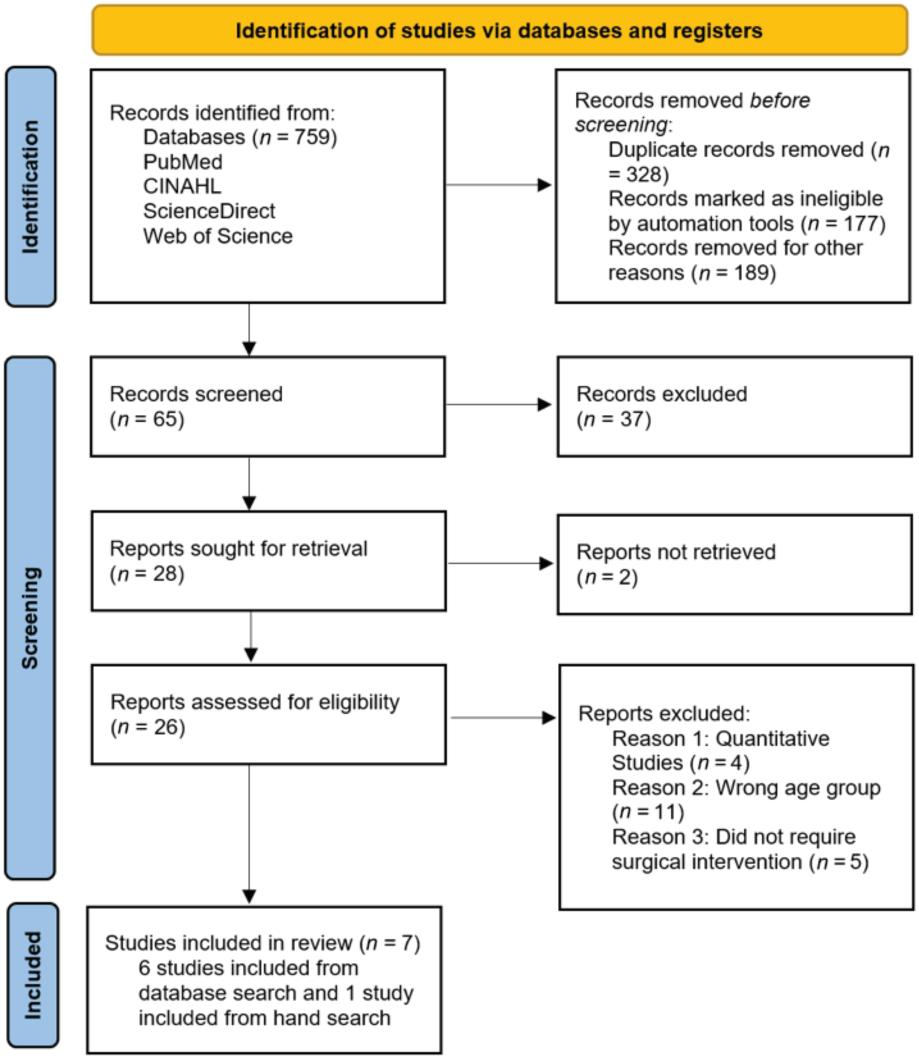
Table 1

Search Strategy

Database	Year	Search Terms	Number of Results	Article(s) Selected
Web of Science	2014–2024	"parent experience", "congenital heart disease", "qualitative"	145	Nayeri et al. (2020)
CINAHL	2014–2024	"parental experience", "congenital heart defect OR disease", "surgery", "qualitative"	17	Thomi et al. (2018)
PubMed	2014–2024	"parents", "experience", "congenital heart", "surgery", "qualitative"	43	Vainberg et al. (2019) Ni et al. (2019)
PubMed	2014–2024	"support", "parents", "infant", "hospital", "congenital heart disease OR defect"	163	Gramszlo et al. (2020)
PubMed	2014–2024	Hand search	-	Gaskin et al. (2021)
ScienceDirect	2014–2024	"parents", "experiences", "infants", "congenital heart defect", "qualitative"	391	Wei et al. (2016)

Figure 1

PRISMA Tool for Identification of Qualitative Studies



findings—regardless of study design—subjected to the same analytic criteria and interpretive rigour.

Data Analysis

Data analysis was conducted using Braun and Clarke's (2019) codebook thematic analysis, guided by social support theory as the coding framework (Braun & Clarke, 2021; Chouhy et al., 2020; Evans et al., 2022). This approach enabled the early identification of themes related to the categories of informational, emotional, and practical support. Articles were read in entirety to become familiarized with themes and findings, which were compiled in a summary table of major findings (Table 2). The methodological quality of included studies was appraised using the 2021 version of the Joanna Briggs Institute (JBI) six-item checklist (Aromataris & Munn, 2020). This version was selected due to its capacity to generate categorical ratings of high, medium, or low quality, thereby facilitating comparative assessment across studies. In contrast, more recent iterations of the JBI tools do not provide such scoring distinctions, making the 2021 checklist more suitable for the purposes of this review.

During the coding process, quotes from interview transcripts in the selected studies were highlighted in different colours based on which category of social support theory they aligned with. Quotes that directly or indirectly conveyed parental needs across the three support categories were included in the analysis. This use of social support theory as a coding framework to understand the supportive care needs of parents of infants diagnosed with a CHD has yet to be done by another study. Therefore, the findings provide a deeper understanding of the supportive care needs of parents, leading to the development of evidence-based recommendations for nursing practice.

Table 2

Summary of Articles in Analysis

Authors, year of publication, origin/country of study	Research Question or Objective (Phenomena and Population)	Qualitative Methodology	Major Findings	Quality Appraisal JBI
(Gaskin et al., 2020) United Kingdom	**Objective** To examine parents' experiences during the transition from hospital to home with their infant following stage 1 cardiac surgery for complex congenital heart disease.	Mixed methods feasibility study including both quantitative and qualitative methods. A 6-phased approach to thematic analysis was used to analyze qualitative data. Sample – 12 mothers and 4 fathers of 12 infants were included Semi-structured interviews were used for qualitative data collection. The interview guide was developed based on the Middle Range Transition Theory.	• Parents experienced heightened anxiety and depression before hospital discharge, influenced by fear, uncertainty, and traumatic experiences. While emotional well-being improved over time, some parents continued to face lingering effects of guilt, self-blame, and vivid memories of the intensive care period. • Parents faced challenges meeting their own physiological needs (e.g., sleep, nutrition) during hospitalization but adapted routines post-discharge to balance their infant's care with household needs. • Hospitalization and caregiving impacted family finances due to lost income, travel expenses, and increased household costs. Support from employers, benefits, and extended family were vital in alleviating financial burdens for some families, while others faced significant financial hardships.	High
(Gramszlo et al., 2020) United States of America	**Objective** To examine parental preference for intervention programs to support psychosocial needs.	Mixed methods study. Qualitative data analyzed using an inductive thematic approach. Sample – 20 mothers and 14 fathers of 21 young children with a congenital heart defect (CHD) Semi-structured interviews used for qualitative data collection. Parents also reviewed and commented on 3 psychosocial programs.	• Program Goals: Focused on empowering parents through education, self-care guidance, and effective communication, preparing them for post-hospital challenges and supporting their child's neurodevelopment while fostering social support. • Program Structure: Delivered through formalized, stage-specific support with brief, personalized interventions in small groups or one-on-one settings, integrating multidisciplinary teams and peer mentorship.	High
(Nayeri et al., 2021) Iran	**Objective** To explore the meaning of parenting a child with CHD	Qualitative explorative study using content analysis approach and constant comparative analysis. Sample – 17 parents Semi-structured interviews were used for data collection.	• Parenting a Child with CHD: Involved emotional breakdowns characterized by denial, guilt, sadness, and isolation, compounded by the catastrophic burden of care, including financial hardship, social restrictions, and distress over medical procedures. • Coping and Challenges: Parents turned to spirituality for comfort and meaning, viewing their child's condition as a divine test, while also navigating significant marital, emotional, and psychological strain due to external pressures like poverty and difficult living conditions.	Moderate
(Ni et al., 2019) China	**Objective** To explore the home care experiences of those taking care of children diagnosed with a CHD.	A qualitative design Sample – 17 mothers, 5 fathers Semi-structured, open-ended interviews were used for data collection. Data on caregiver experiences were collected both prior to and after cardiac surgery.	• 5 main themes were generated from 12 themes: excessive mental burden, under pressure and agony, the impact on personal life, adapting roles constantly, and self-fulfillment in caring activities. • Parents were fearful that they would not provide adequate care to their child and often put blame on themselves for their child's defect. • Healthcare workers can identify the needs of caregivers and help them feel better supported from diagnosis to after surgery. • Health care workers can alleviate some stress, anxiety, guilt, and hopelessness experienced by caregivers by providing education and psychosocial support.	High

Authors, year of publication, origin/country of study	Research Question or Objective (Phenomena and Population)	Qualitative Methodology	Major Findings	Quality Appraisal JBI
(Thomi et al., 2019) Switzerland	**Objective** To explore both mothers' and fathers' experiences from prenatal or postnatal diagnosis of their newborn's congenital heart disease (CHD) to the first discharge after heart surgery.	A qualitative research approach using a constructivist paradigm and Braun and Clarke's thematic analysis was used. Sample – 18 parents Semi-structured interviews containing open-ended questions developed based on literature and the authors' experiences in the field.	• Overarching theme was that parents experienced demanding emotional and hands-on challenges, feeling as though they were on a roller-coaster from diagnosis to hospital discharge. • Key Experiences: Parents faced shock and fear during diagnosis and delivery, stress and mixed emotions in the pediatric intensive care unit and surgery, and initial anxiety followed by gradual adaptation on the pediatric cardiac unit. Discharge evoked both readiness and lingering concerns. • Parent-HCP Interplay: Trust was built through transparency, continuity, and compassionate care. Parents valued clear communication and empathy but were distressed by excessive information or errors. Multidisciplinary support was essential for navigating the journey.	High
(Vainberg et al., 2019) Israel	**Objective** To explore the experiences of parents as primary caregivers for their child in the intensive care unit with a CHD. Establish a greater understanding of personal feelings in relation to experiences with the medical system.	Interpretative phenomenological analysis and grounded theory. Sample – 12 Parents Semi-structured interviews were used for data collection.	• Parent-infant bonding and attachment were disrupted as parents felt their role was altered. • A lack of perceived social support negatively impacted parents as it was associated with feelings of isolation and loneliness. • Parent's emotional distress increased when they felt medical staff were insensitive to their emotions and beliefs. • Parents felt relief and support when the medical staff acknowledged their needs opposed to just viewing them as associated with their child.	High
(Wei et al., 2016) United States of America	**Objective** To describe parents' experiences when their child with CHD underwent heart surgery. Took place in a children's hospital on the east coast in the US. Recruitment was on the cardiac unit between July–Dec. 2014	Descriptive Phenomenology. Authors stated they combined the data analysis methods of Colaizzi, Giorgi, Swanson-Kauffman and Schonwald, Wojnar and Swanson, and Wojnar, Swanson, and Adolfsson. Sample – 13 Parents In-depth interviews conducted for data collection.	• Parents experienced intense emotional responses, including shock, heartbreak, and self-blame, upon learning of their child's heart defect, regardless of timing or type of diagnosis. • Fathers expressed concern for both their child and their wife, while mothers struggled with making surgical decisions. • Parents found relief from their anxiety when connecting with others who shared similar experiences.	High

Results

The analysis of reported interview quotes in qualitative studies allowed for the identification of several experiences that illustrate the informational, emotional, and practical supportive care needs of parents with infants diagnosed with a CHD at birth, including those hospitalized for treatment. Each category reflects a distinct type of support parents required during their hospital experience, which was often unmet or partially fulfilled.

Informational Support Needs

Parents frequently expressed a need for more comprehensive information about their child's diagnosis, treatment, and care processes. Many felt confused or overwhelmed by medical terminology, which led to feelings of disempowerment and frustration. Key quotes demonstrating the informational support needs included: *"We were upset that we didn't understand my son's illness"* (Nayeri et al., 2021), emphasizing that parents lacked a clear understanding of the diagnosis and needed support to process complex information. Informational support related to the causal factors and formation of the defect were also reported, *"I've got time to myself to be constantly thinking about what did I do wrong, what did I do wrong in my pregnancy"* (Gaskin et al., 2021), demonstrating the need for the delivery of accurate information to address parental guilt and misconceptions. "*We would've felt more empowered if we could have known things from the beginning and been physically caring for her more"* (Gramszlo et al., 2020), highlighting that early access to information could have made them feel more involved in their child's care. Similarly, *"I tried to cope by learning everything I could about his diagnosis. I asked endless questions, I read journal articles, I memorized what drugs he was on and what they all did. This helped to at least make me feel like I was a small part of the team keeping this sweet baby alive"* (Gramszlo et al., 2020), illustrating how learning about their infant's condition became a coping mechanism and fostered a sense of involvement. *"We didn't know what these words were, what this defect in the baby even was and where it had come to us from"* (Vainberg et al., 2019), further showing the importance of clear communication in helping parents comprehend their infant's condition. Collectively, these quotes from multiple studies demonstrate the need for clear information regarding their infant's diagnosis and care needs to fulfill their informational support needs.

The Benefits of Informational Support

The positive impact of providing information to parents in a way they understand was demonstrated by one parent who said, *"They really explain everything… it really gives you a sense of control and understanding"* (Vainberg et al., 2019). Thus, healthcare providers thoroughly explaining medical information may fulfill the informational support needs of parents. Additionally, parents valued opportunities to ask questions and observe procedures, over reviewing printed resources, as seen in *"We observed how [and] to what they [the nurses] reacted. We learned to like this, rather than buy any leaflets"* (Thomi et al., 2019). Direct interactions with healthcare professionals, as one parent described, were valuable: *"We were encouraged to ask questions, we were informed very well by different people, by nurses and physicians. We were involved and taken seriously"* (Thomi et al., 2019).

Emotional Support Needs

The emotional journey of having an infant hospitalized with CHD was filled with anxiety, isolation, and a deep need for empathy from healthcare providers and peers. Parents expressed a strong desire for emotional support from people who understood their experience and could provide validation and compassion. Key quotes demonstrating the emotional support needs included: *"I've cried a lot, I've looked at other people... I feel like crying now"* (Gaskin et al., 2021), demonstrating the vulnerability experienced by parents, highlighting their need for empathetic support during the challenging journey of navigating their infant's diagnosis and treatment. *"I'm going to the house of those who have this problem. I ask what you did"* (Nayeri et al., 2021), shows that peer support from others who had been through similar situations was emotionally reassuring. While statements such as, *"There was a lactation specialist who was insisting that I get back to breastfeeding and ignoring my stress over potentially hurting my baby… She was a knowledgeable professional but she wasn't very supportive. Pumping was what worked for us and she could have been more respectful and encouraging of our choice"* (Gramszlo et al., 2020), highlighting the importance of flexibility and respect for parents' decisions. Parents commonly experienced feelings of unpreparedness, uncertainty, and confusion that was heightened by caring for an infant with complex needs related to their CHD. *"I also wish someone would have told me that anxiety and PTSD are common for heart parents and that it is completely normal to feel overwhelmed, worried, scared, helpless, and isolated. I don't think I was prepared for all of those feelings and I certainly didn't know what to do with them"* (Gramszlo et al., 2020), identifying the need for emotional support to normalize parents' experiences of anxiety and trauma. *"During that month when he was hospitalized, there was no one for me to speak to"* (Vainberg et al., 2019), indicating a need for someone, such as a nurse, to be available for emotional support when caring for the infant. Additionally, parental responses of, *"Compassion. I was missing compassion from some [HCPs]"* (Thomi et al., 2019), demonstrating the emotional need for empathy from care providers. Collectively, these quotes from multiple studies demonstrate the need for empathetic support from nurses and other care staff to fulfill their emotional needs when vulnerable.

The Benefits of Emotional Support

One parent expressed appreciation for the emotional support provided in the hospital by saying, *"It was nice to have their guidance but not be forced to do things their way so I could* *learn to parent and bond with my baby in an almost normal way, despite being inpatient"* (Gramszlo et al., 2020). This quote illustrates how guidance and a holistic approach allowed parents to bond with their infants in a way that was natural and gave them some control. Parental presence and compassion from healthcare providers were also significant in terms of emotional support. One parent emphasized the importance of time spent on the unit stating, *"I was able to spend a lot of time here [on the unit]. And that takes away the fear"* (Thomi et al., 2019). Additionally, the value of peer support was also noted as a source of comfort as a parent shared, *"I could not calm down while I was waiting, until I talked to other people who had some similar experiences. That was really helpful"* (Wei et al., 2019). Therefore, these quotes reveal how time, empathy, and peer relations can help parents emotionally.

Practical Support Needs

Parents needed practical support in managing day-to-day responsibilities and self-care during their child's hospitalization. They reported often feeling overwhelmed by the demands of being constantly present in the hospital and maintaining responsibilities outside the hospital. Key quotes demonstrating the practical support needs included: *"When he needed surgery, we were in hospital for over one month with my child alone. I hoped to have one hour to take a rest somewhere"* (Nayeri et al., 2021), demonstrating the need for time to rest and recover while remaining in the hospital. Self-care needs were also apparent, *"I was just really feeling really poorly myself... but in that situation you kind of think, no... forget me, your baby's like... severely poorly"* (Gaskin et al., 2021), emphasizing the need for support that addresses parents' own well-being, as their instinct to prioritize their infant's needs often leads to neglect of their health. *"I wish they had considered how involved we wanted to be, especially in the ICU… They could have asked us what we wanted to do or if there was anything we weren't comfortable doing"* (Gramszlo et al., 2020), pointing to the desire for involvement in care while balancing the need for a "normal" experience. Anticipatory toll of caregiving was also expressed. *"Originally, I planned to pursue postgraduate studies in 2 years and look for new career development opportunities, but the child is not well and I don't have time and energy to learn"* (Ni et al., 2019), illustrating the sacrifices parents made due to the demands of care. *"In order to take care of the sick child, I never participate in my company's dinners and activities, let alone travel"* (Ni et al., 2019), showing how the burden of caregiving responsibilities limited other life activities. *"I have to take care of my child all the time, so I have no time to do housework… I have no work now and our family life depends on my husband. His salary is only US $2000 per month, and I am almost unable to pay the medical fees"* (Ni et al., 2019), reflecting the financial burdens and lack of time for employment, let alone household tasks. *"I wanted to hold my baby and comfort him. But I can't do it…The beeping sounds of the machines freaked me out"* (Wei et al., 2016), highlighting how parents experienced challenges in providing comfort to their infants due to the hospital environment. Collectively, these quotes from multiple studies demonstrate the need for support with caring for their infant, as well as themselves, to fulfill their practical supportive care needs.

The Benefits of Practical Support

Parents appreciated the gentle reminders from healthcare providers to practice self-care while caring for their child. One parent shared, *"They even had recommendations, like go and eat, drink, take care of yourself… I think that's what encouraged me was that they understood that I needed to preserve my strength"* (Vainberg et al., 2019). This encouragement offered support for addressing the practical needs of the parent, such as eating and sleeping, reinforcing the importance of self-care to sustain their strength during challenging times.

Discussion

The findings from this synthesis of literature highlights the diverse and complex supportive care needs of parents with infants hospitalized for CHDs. To our knowledge, this study is unique in its use of social support theory, providing an important perspective to inform nursing practice. The codebook thematic analysis conducted revealed that parents face significant informational, emotional, and practical challenges, aligning with themes identified in previous literature on parental anxiety, when their infant is undergoing surgery for a CHD (Kumar et al., 2019; Simeone et al., 2017). Therefore, it is evident that informational, emotional, and practical support all play a role in empowering parents, reducing distress, and enabling them to participate actively in their child's care.

Informational Support: Empowerment Through Knowledge

The need for clear, comprehensive information about their child's diagnosis, treatment options, and care processes was a recurring theme, demonstrating parents' desire to feel competent and involved (Gaskin et al., 2021; Gramszlo et al., 2020; Nayeri et al., 2019; Vainberg et al., 2019). Previous studies have similarly identified that a lack of knowledge can exacerbate parental anxiety, stress, and a sense of helplessness when dealing with a CHD diagnosis (Azhar et al., 2018; Kumar et al., 2019; Simeone et al., 2017). Information, especially when presented with empathy and in lay terms, can empower parents, enhance their understanding, and enable them to engage in informed decision-making (Azhar et al., 2018; Tallon et al., 2015).

For nursing practice, this reinforces the importance of providing structured, individualized education that is responsive to parental questions and paced according to their emotional readiness (Machado Amazonas et al., 2023; Wilandika et al., 2023). Additionally, practical teaching methods, such as demonstrations and allowing for questions from parents, could help parents retain complex information better than informational leaflets alone (Simeone et al., 2017; Thomi et al., 2019). Future interventions might also incorporate multimedia tools, such as videos or interactive platforms, to make information accessible and adaptable to diverse learning preferences.

Emotional Support: Validating and Normalizing Parental Experiences

The emotional journey of parents in this study revealed intense feelings of anxiety, isolation, and the need for validation, aligning with the emotional support needs documented in other studies on parental experiences of having an infant with a CHD (Simeone et al., 2017; Thomi et al., 2019; Wei et al., 2016). Parents expressed a desire for compassion and understanding from healthcare providers, as well as opportunities for peer support, which could normalize and alleviate their emotional struggles (Thomi et al., 2019). Similar findings of distress, uncertainty, and fear have been reported in a qualitative meta-synthesis of parental experiences when their child is diagnosed with a CHD (Dandy et al., 2024). Having a trusted healthcare provider to confide in, along with accessible peer support, could reduce feelings of isolation and promote positive coping skills.

Nursing practice implications emphasize the importance of incorporating emotional support into routine care for parents of infants with CHDs. One strategy is the integration of compassionate communication and empathy-focused care into nursing training. Nurses should be trained to recognize and respond to the emotional needs of parents, providing reassurance, active listening, and empathy throughout their interactions (Fuglsang et al., 2023). This approach helps alleviate parental anxiety, creating a more supportive environment for both the parents and their child. Additionally, nurses can play a pivotal role in facilitating peer-support programs or group sessions within the hospital setting. These opportunities allow parents to connect with others who are going through similar experiences, providing a sense of shared understanding and emotional relief.

Practical Support: Balancing Hospital and Home Demands

Practical support needs highlighted the struggle of balancing hospital commitments with other life responsibilities, such as employment, finances, and self-care (Gaskin et al., 2021; Ni et al., 2019). Parents often find themselves caught between being present for their child in the hospital and fulfilling other obligations at home or work, creating a sense of guilt (Ni et al., 2019). These challenges extend beyond just the basics of care, as they encompass the emotional burden of not being able to fully attend to all their roles, even when transitioning to caring for their infant at home (Gaskin et al., 2021; Vainberg et al., 2019). These findings demonstrate the need for support in areas such as ways to care for their child and themselves simultaneously.

For nursing practice, this emphasizes the promotion of self-care by proactively assessing and addressing parents' physical and practical needs, emphasizing the importance of rest and nutrition to enhance the parents' overall well-being. Practical measures, such as offering the family a reclining chair for bedside rest and creating relaxing spaces within the hospital, can support parents' well-being and improve their ability to care for their child, because they feel less stressed. Additionally, nurses can empower parents by providing clear guidelines on participation in care and creating opportunities for bonding while navigating the ICU environment. This can include providing step-by-step instructions on how they can provide their child with skin-to-skin contact to facilitate bonding and support their child's recovery.

Limitations

The search of databases was limited to the past 10 years to capture more recent experiences. However, this may have omitted experiences before this time frame. Additionally, interest was specific to diagnosis during the neonatal period, which may have resulted in exclusion of parental experiences captured at other times.

Future Directions for Research

This narrative synthesis provides a foundation for future research aimed at gaining deeper insight into the specific informational, emotional, and practical supportive care needs of parents with infants diagnosed with CHDs at birth in hospital. Given that a lack of information was identified as a theme in the data, future research could explore a co-design approach, collaborating directly with parents to develop informational resources that are specifically tailored to their unique needs. By directly asking parents about their needs, future studies can identify specific gaps and opportunities for improvement in the care provided to these families. Addressing these gaps will allow for future studies to contribute to the design of holistic, evidence-based practices that promote family-centred care.

Conclusion

In conclusion, the effects of CHDs extend beyond the infant, impacting not only the health of the child but also the emotional well-being, family dynamics, and daily lives of their parents. The diagnosis of a CHD presents a unique set of challenges for families, particularly in the form of heightened stress, disrupted family roles, and the overwhelming need for clear, compassionate guidance. This narrative synthesis, generated from a secondary analysis of qualitative literature, highlights that parents require comprehensive informational, emotional, and practical support to navigate these challenges effectively. Recognizing these needs, healthcare providers, especially nurses, play a critical role in delivering support that is both informative and empathetic, facilitating family involvement and alleviating parental anxiety. Therefore, addressing these needs not only improves the immediate hospital experience for parents, but also leads to better health outcomes for the child, ultimately enhancing family well-being.

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