Parents' experiences of receiving their child's diagnosis of congenital heart disease: A systematic review and meta-synthesis of the qualitative literature

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Abstract

Purpose: This systematic review aimed to synthesise qualitative research of parents' psychological experiences following their child's diagnosis of congenital heart disease (CHD).

Methods: A systematic search of six electronic databases (CINAHL, Embase, MEDLINE, PsycINFO, PubMed and Web of Science) was completed, inclusive of all years to May 2022. Any included articles were synthesised using thematic synthesis and appraised using the Critical Appraisal Skills Programme Qualitative Checklist.

Results: Twenty-six articles were included. Four main themes, and 11 subthemes, emerged from the synthesis. Theme 1 (*unpreparedness for the diagnosis*) concerned parents' shock, guilt and anger regarding the diagnosis. Theme 2 (*the overwhelming reality of CHD*) described parental fear about decision-making and the child's prognosis, and the influence of professionals on parents' wellbeing. Theme 3 (*mourning multiple losses*) detailed parents' sadness at losing their envisioned pregnancy, birth and parenthood experiences. Theme 4 (*redefining hopes to reach an acceptance of CHD)* described parents' adjustment to the diagnosis.

Conclusions: Receiving a child's CHD diagnosis was a uniquely challenging situation for parents. The findings provided insight into the emotions parents experienced and how they adjusted to the diagnosis psychologically. As parents' experiences were significantly influenced by their interactions with professionals, clinicians should offer compassion, validation and clear information throughout the diagnosis process.

Keywords: Qualitative; congenital heart disease; diagnosis; adjustment; psychological; emotional wellbeing.

Introduction

Congenital anomalies are structural or functional defects present at birth, affecting 2-3% of babies in Europe (Morris et al., 2018). Systematic reviews suggest that a child's congenital anomaly diagnosis creates additional stressors for parents, including decisions regarding termination (Blakely et al., 2019), and loss of a normal pregnancy, healthy child and envisioned future (Lou et al., 2017). It is, therefore, unsurprising that these parents report shock, guilt, grief and anger following the diagnosis, and are at increased risk of anxiety (Bekkhus et al., 2020), depression (Asplin et al., 2015) and post-traumatic stress (Bevilacqua et al., 2021; Cole et al., 2016).

Johnson et al. (2020) proposed a five-phase-model of parents' responses to their child's diagnosis: expectations of the ultrasound, discovering the abnormality, intense shock, uncertainty and decision-making and adjustment to the diagnosis. There was little detail about what adjustment involved, but Lalor et al. (2009) suggested that mothers coped with fetal anomaly diagnoses by "gaining meaning" through gathering information and making decisions, and "rebuilding" by adapting beliefs about pregnancy and their future.

Congenital heart disease (CHD) is the most common congenital anomaly, with a global incidence of approximately 1% (Liu et al., 2019). In a systematic review of 94 studies, Wei et al. (2015) highlighted the diagnosis as being particularly stressful for parents, due to challenges of understanding the condition, making medical decisions, and the possibility of their child dying. Compared to clinical norms (Bevilacqua et al., 2013) and parents of healthy children (Brosig et al., 2007; Rychik et al., 2013), these parents present with higher stress, post-traumatic stress, anxiety and depression scores.

Thus, important psychological implications, including how professionals support parents' understanding of information (Carlsson et al., 2015; 2016; Reid & Gaskin, 2018) and decision-making (Hoehn et al., 2004), should be considered. For example, the timing of

diagnosis is influential: postnatal diagnosis has been associated with more anxiety and stress compared to prenatal diagnosis (Pinto et al., 2016). However, studies with larger samples report the opposite (Bratt et al., 2019) or no differences at all (Brosig et al., 2007). Crucially, due to their quantitative nature, these studies could not consider experiences in detail, including how parents respond, cope and adjust over time.

Studies have explored parents' experiences of having a child with CHD, and systematic reviews have synthesised qualitative findings related to prenatal counselling practices (Tacy et al., 2022), psychosocial coping (Lumsden et al., 2019), fathers' perspectives (Lin et al., 2021), the wider familial impact (Jackson et al., 2015), and specific events, such as surgery (de Man et al., 2020; McMahon et al., 2020). However, as diagnosis is crucial in the parental experiences of CHD, this meta-synthesis aimed to review and synthesise qualitative studies systematically to answer the following research question: what were parents' psychological experiences when they received their child's CHD diagnosis?

Method

The review followed Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidance (Moher et al., 2009) and was registered on PROSPERO (Ref: CRD42021264117).

Search Strategy

Initial scoping searches of keywords related to the research question informed the final search strategy. A systematic search of six databases (CINAHL, Embase, MEDLINE, PubMed, PsychINFO and Web of Science) was completed, inclusive of all years up to 17/05/2022. The SPIDER search tool (Cooke et al., 2012) was used to select and organise terms (see Table 1), which were combined using Boolean operators 'OR' within each concept and 'AND'

between concepts. The word "diagnosis" was not included in search terms because it excluded articles exploring wider parent experiences, of which diagnosis was only part. Medical Subject Headings (MeSH) and exploded terms were used when possible. Searches were limited to title and abstract. To improve recall of papers, a near field search was included (i.e., heart N5 (disease OR defect)), because qualitative papers may not use fixed terminology (Appendix A contains an example search). Finally, reference lists of included papers were checked and the 'cited by' function on Google Scholar was used to identify any additional papers.

[INSERT TABLE 1]

Eligibility Criteria

To be included in the review, studies had to 1) sample parents of children with CHD, 2) include sufficient findings (see below[1]) related to parents' psychological experiences when receiving their child's CHD diagnosis, 3) utilise qualitative methods for primary data collection (mixed methods studies were considered if a qualitative methodology was described and sufficient data presented), 4) use a recognised, inductive method of qualitative analysis, 5) explore first person accounts, evidenced by original data excerpts, 6) be published in a peer reviewed journal and 7) be available in English or German. Studies were excluded if they focused on other physical health conditions as well as CHD or were a literature review.

[1]Sufficient findings was defined as at least one quote and one author interpretation specifically referencing parents' emotional experiences at the time of, or in relation to, receiving their child's CHD diagnosis.

Selection Process

Search results were collated using EndNote referencing software. The first author screened all titles and abstracts against eligibility criteria and repeated this process with full texts. Due to time and resource constraints, two independent reviewers reviewed 10% of titles and abstracts (n=146) and 25% of full texts (n=6). The agreement between researchers was 98.63% (n=144) and 83.33% (n=5), respectively. Disagreements were resolved through discussion.

Quality Appraisal

The methodological quality/risk of bias of included studies was assessed using the Critical Appraisal Skills Programme Qualitative Checklist (CASP, 2018). Results were presented in words and numbers (No=0, Partially agree=0.5, Yes=1). In line with other meta-syntheses (e.g., Harries et al., 2023; Tuck et al., 2023), quality/risk of bias was then categorised as high (>8-10), moderate (6-8) and low (<5). The methodological quality of all studies was assessed by the first author and an independent researcher; their agreement was 100%. No papers were excluded based on its quality assessment, given ongoing debates regarding what constitutes quality in qualitative research (Garside, 2014).

Data Extraction and Synthesis

Thematic synthesis (Thomas & Harden, 2008) was used to synthesise data, because it allows synthesis of both descriptively 'thin' and 'rich' data, whilst still allowing interpretation (Booth et al., 2016; Flemming & Noyes, 2021). Data were considered to include all text under 'results' headings and were analysed inductively using NVivo software. Firstly, the first author repeatedly read each study and completed line-by-line coding. As the same process was completed for each included study, reciprocal translation was possible at this

stage. Secondly, codes were grouped into descriptive themes that represented similar concepts. Finally, the first author compared and interpreted the descriptive themes to develop analytical themes, which were discussed and finalised by the research team.

Results

Study Characteristics

Figure 1 illustrates the selection process. Twenty-six papers published between 1995 and 2022 were included. Table 1 summarises the key characteristics and themes of each. Two studies used directed content analysis. Although this is a deductive method, the authors stated that their analysis was not limited to predefined categories (McKechnie & Pridham, 2012; McKechnie et al., 2016).

In terms of methodological assessment (Appendix B), 13 studies were rated to be of high quality and 12 of moderate quality. Only one study (Messias et al., 1995) was rated as having low quality and findings of this study should be viewed with some caution. The included studies tended to satisfy most of the CASP criteria (ranging from 69.2% to 100%), with the exception of the reflexivity criterion, which was only met in 9.6% of cases.

[INSERT FIGURE 1 and TABLE 2]

Findings

Four themes, each with subthemes, were identified: 1) *unpreparedness for the diagnosis*, 2) *the overwhelming reality of CHD*, 3) *mourning multiple losses* and 4) *redefining hopes to reach acceptance of CHD*. A narrative summary of each theme is provided below, and Appendix C shows a matrix of each study's contribution.

Figure 2 presents a conceptual model of themes, which represent phases of emotion that evolved over time. Whilst shock and unpreparedness for the diagnosis appeared to occur immediately, parents' experiences of the other phases could continue for weeks, months or years following diagnosis. Furthermore, some parents experienced all of the emotions described, whilst others only experienced some.

[INSERT FIGURE 2]

Theme 1: Unpreparedness for the diagnosis

Most studies detailed parents' unpreparedness for their child's CHD diagnosis, alongside emotions of shock, guilt and anger. One parent encapsulated the experience: "It [the diagnosis] was the most devastating thing I have ever heard in my life" (Wei et al., 2016, p.156). Several studies also reported short-term avoidant coping strategies.

Subtheme 1.1: Shock

Powerful shock and dismay at diagnosis related to parents' assumptions that their child would be healthy: "It's a big shock when it happens because you think you're going to have a perfectly healthy baby, when they tell you it's a serious condition" (Messias et al., 1995, p.370). Consequently, parents described the experience as surreal: "…after only hearing about such things on TV – I, or people like us, thought that a heart transplant would be needed or something like that. I felt as if I was falling off a cliff" (Kim & Cha, 2017, p.441). The unexpected nature of the diagnosis created a sense of powerlessness, leading some to experience visceral symptoms: "The first time I was told about my child's disease I was unconscious for an hour and a half" (Nayeri et al., 2021, p.4). Postnatal diagnosis seemed especially shocking, because a normal pregnancy may have fostered a sense of security and

limited parents' opportunity to process the diagnosis: "Suddenly an entire team of nurses, midwives and physicians were treating their new-born" (Thomi et al., 2019, p.4).

Subtheme 1.2: Blame towards self and others

Parents immediately searched for causes of their child's CHD. Mothers especially experienced intense guilt, because they felt responsible for carrying the child: "I was blaming myself for a lot of things… What did I do wrong for him to be this way?" (Sood et al., 2018, p.637). There were some cultural variations, as Im et al. (2018, p.470) found inability to meet Korean cultural expectations to product a 'perfect' child heightened maternal guilt and created shame: "She [participant's sister] said: 'you'll be able to be pregnant easily next time, so why do you want to deliver an imperfect baby?'".

Despite blaming themselves, mothers felt resentful that they had done everything 'right': "I was annoyed, cos I didn't smoke, I didn't drink. I didn't do anything… I just don't understand why I got it" (Lumsden et al., 2020, p.4). Conversely, fathers expressed more anger towards the world, implying recognition that the diagnosis was out of their control: "For myself, I think I felt a lot of anger. 'Why us?'… 'Why does my wife have to go through this?' I had a lot of anger at God" (Leuthner et al., 2003, p.124). The intensity of their anger appeared to result from feeling their partner's pain, as well as their own.

Interestingly, Cruz et al. (2022, p.162) found that parents in Brazil, where there are fewer resources (e.g., specialist nurses), expressed anger towards healthcare professionals regarding their distress about the diagnosis, rather than CHD itself: "I would not have gone through so much suffering if they had a little more information or training".

Subtheme 1.3: Avoidance

Avoidance was a common coping strategy, and some parents experienced a sense of incredulity: “My husband said baby is healthy and don’t need to seek treatment. The doctors are wrong” (Nayeri et al., 2021, p.36). Avoidance might have protected against the emotional impact of the diagnosis, and some studies suggested parents even withdrew socially to avoid discussions that could cause distress (Leuthner et al., 2003; Nayeri et al., 2021). However, McKechnie and Pridham (2012, p.1699) argued that social withdrawal allowed parents to confront emotions of sadness, fear and confusion: “Parents described their efforts to sort out their emotions by first talking with their significant other and then expanding the talking to family members, other close contacts, and support groups”.

Theme 2: The overwhelming reality of CHD

The second theme described intense emotions once parents realised the severity of CHD, including feeling overwhelmed by information, uncertainty, and fear regarding their child’s prognosis. Parents adopted various coping strategies but seemed universally affected by interactions with professionals.

Subtheme 2.1: Overwhelming information and decision-making

Whilst trying to manage initial shock, parents found it overwhelming to navigate information about CHD and treatment decisions: “It’s such an emotional time. It’s so hard to just read the information and try to process it on your own” (Delaney et al., 2021, p.899). Parents, particularly those receiving a postnatal diagnosis, felt unprepared for this and under pressure to ‘do the right thing’: “You’re in shock… you had a Caesarean, you haven’t got time to wrap your head around stuff, and you’re told all this information and told you need to make decisions quickly” (Cantwell-Bartl & Tibballs, 2015, p.1069). Nonetheless, parents valued

decisions being theirs to make, because this provided them with a sense of control: “It was always left to me to decide what I wanted to do rather than being pushed into anything” (Bertaud et al., 2020, p.1227).

However, those who did not understand CHD expressed self-criticism, shame and fear about decision-making: “The doctor explained everything, but I couldn’t understand a word he was saying because I didn’t understand medical words. I thought I would look stupid if I asked” (Cantwell-Bartl & Tibballs, 2015, p.1067). Similar concerns were expressed across studies from different regions, including the USA and Iran (e.g., “We were upset that we didn’t understand my son’s illness” Nayeri et al., 2021, p.36), suggesting commonalities in experience despite differing cultures and health systems.

Subtheme 2.2: Uncertainty and fear

Although parents learned about CHD, uncertainty regarding the prognosis remained, so anxiety was prevalent: “The [diagnosis] was scary. It was overwhelming, lots of uncertainty, his diagnosis came before he was born so we still had about five months of anticipation” (Neubauer et al., 2020, p.1674). This anxiety created intense fear about their child’s survival: “My stress levels were high, and I was nervous as to how this was all going to play out for [child] when he was born” (Williams et al., 2019, p.930). For parents in Brazil, uncertainty extended to the availability of scarce health resources, creating a sense of no safety: “…sometimes there is no intensive care bed available, and you need an intensive care unit bed to get the surgery” (Cruz et al., 2022, p.163).

Parents felt hopeless at being unable to help their child, although three studies that included both mothers and fathers found this appeared more prominent for mothers (Leuthner et al., 2003; Messias et al., 1995; Sood et al., 2018). One parent recalled: “I had the feeling that this child will not survive. We’ll just lose it” (Thomi et al., 2019, p.4). Pessimism was

mainly reported in relation to severe CHD, when death is more likely, so might have been used to manage expectations or distress. Indeed, Lee and Ahn (2020, p.7135) found that mothers who struggled to manage their hopelessness could become suicidal: “It was too hard for me. At that time, I even thought about dying with my kid who might die anyway”.

Subtheme 2.3: Coping and the role of professionals

Parents coped with fear and uncertainty by hoping that their child would survive: “Hope! Yeah, that’s all we had, really. I think that throughout the whole thing, the only hope that we ever had was basically that they [diagnosing physicians] were wrong” (McKechnie & Pridham, 2012, p.1700). Some also sought control by, for example, gathering information: “That week I just was closed down, I just wanted to search and make sure I was doing the right thing” (Bertaud et al., 2020, p.1227). For fathers, being in control was viewed as important in fulfilling gendered social roles, such as suppressing their emotions to support their partner: “I didn’t want my girlfriend to see me crying, since [I’m supposed] to try to be strong for her” (Clark & Miles, 1999, p.11). Thus, their experiences of the diagnosis might go unrecognised by family or professionals.

Parents’ experiences of the diagnosis were affected by interactions with professionals. Clear information and treatment plans, with opportunities for repetition, were valued because they allowed parents to feel reassured and develop trust in professionals, thereby reducing stress: “They went through it over and over again, they did diagrams, they gave us information for charities… If they hadn’t have done all that I don’t think I would have coped” (Bertaud et al., 2020, p.1227). This approach also created a sense of relief and hopefulness: “Her diagnosis was terrifying but the steps and treatment plan in place did make [me] feel positive about her future” (Williams et al., 2019, p.930). Parents especially valued compassion at a time of extreme vulnerability: “We were encouraged to ask questions, we

were informed very well by different people, by nurses and physicians. We were involved and taken seriously… not only our baby but also we were important" (Thomi et al., 2019, p.6). Parents who found such qualities lacking in their interactions felt angry, dismissed and anxious: "We were kind of squeezed in where, I would say, it felt rushed. We didn't have the time or the knowledge to ask everything we wanted to" (McKechnie et al., 2016, p.84).

Theme 3: Mourning multiple losses

The third theme, regarding multiple losses brought by the CHD diagnosis, reflected how 'normal' experiences of pregnancy and birth were overshadowed by uncertainty and fear. Parents also mourned the loss of a healthy child and their envisioned future; for example, feeling CHD would impede fulfilment of their expectations of parenthood.

Subtheme 3.1: Loss of 'normal' pregnancy experiences

Parents who received a prenatal diagnosis recalled losing a 'normal' pregnancy. Joy about the pregnancy was difficult to reconcile with the seriousness of CHD, so typically exciting pregnancy experiences became tainted by sorrow and concern: "Every kick, every push, every movement, I don't know how I felt. I felt bad for myself, but worse for my wife" (Leuthner et al., 2003, p.125). Consequently, parents despaired at being unable to revel in pregnancy rituals: "The diagnosis left them 'heartbroken' and shifted their attention away from joyful future plans like 'putting a nursery together'" (Harris et al., 2020, p.8).

Throughout the pregnancy, mothers seemed to ruminate on their sadness at being unable to have a 'typical' birth: "They're [nurses] gonna get to know your baby and all of the little idiosyncrasies that the baby's gonna have and I want that to be me" (McKechnie et al., 2016, p.88). Parents receiving a postnatal diagnosis described birth experiences that created

stress and fear: “It was so unrealistic, a horror scenario. Finally, the child is here and one minute later, they [the HCPs] again take her away” (Thomi et al., 2019, p.4).

Subtheme 3.2: Loss of a healthy child and envisioned future

Regardless of timing, the CHD diagnosis was often accompanied by emotions of grief and sorrow, because parents lost their expected healthy child: “It was like mourning the pregnancy that I thought we would have… mourning the overall health of my baby boy” (Espinosa et al., 2021, p.5). Another parent described: “I went through these stages of, I don’t know, it almost felt like stages of grief even though nobody had died but maybe it was my perception of the ideal child did die” (Woolf-King et al., 2018, p.2789). However, gender expectations to be ‘strong’ meant fathers often felt unable to express and process their grief: “I wept a lot while being seated at the back of the bus and walking through our apartment complex. It was hard to endure my sadness” (Hwang & Chae, 2020, p.110). Carlsson and Mattsson (2018, p.30) interviewed parents who terminated the pregnancy following diagnosis, and suggested their loss was more concrete and compounded by guilt: “The pregnancy termination involved considerable emotional stress and the loss of a wanted child, likened by respondents to an execution”.

Losing the health of their child also disrupted parents’ view of themselves: “We became aware that, yes, we actually have a very sick child.” (Thomi et al., 2019, p.4). This created pessimism and anxiety about the future: “I didn’t think I’d be able to do anything, that I’d have to walk on eggshells, and that I wouldn’t enjoy him” (McKechnie & Pridham, 2012, 1701). Parents coped by hoping their child might still have a good quality of life and fulfil some expectations: “That generally her life would be normal, but that she may be limited in the physical activities/exercise she can engage in” (Williams et al., 2019, p.929).

Theme 4: Redefining hopes to reach acceptance of CHD

The final theme considered coping and adjustment to the diagnosis. Some coping strategies applied to specific situations, as above, and others were utilised throughout. Nonetheless, these strategies appeared to support parents to adjust their expectations of pregnancy, their child and future.

Subtheme 4.1: Ongoing coping strategies

Parents' coping depended upon individual responses to the diagnosis. However, most discussed support from others throughout: "Having good family support has been helpful. I'm very emotional in a crisis and my husband's a calm person. That's been helpful" (Espinosa et al., 2021, p.5). Parents often emphasised the value of peer support, which seemed to offer a unique, shared understanding: "I met many mothers and their children who were in the same boat, with the same pain and grief… We all comforted one another" (Lee & Ahn, 2020, p.7138). Many parents also used religion to understand and accept the diagnosis: "We said this child is created by God. If we terminate, it is like interfering with God's will. What God has given us we have to accept" (Cantwell-Bartl & Tibballs, 2015, p.1070). They also used religion to support decision-making: "I just felt like there's a spiritual aspect that came into place, and I just felt like I think my baby's mission is to come and get a breath of air and pass onto the next life" (Delaney et al., 2021, p.899).

Subtheme 4.2: Adjusting expectations of pregnancy

As parents with a prenatal diagnosis processed their emotions, they were able to "reframe the pregnancy as a personable and enjoyable experience" (McKechnie et al., 2016, p.86). This approach promoted engagement in pregnancy rituals (e.g., nursery decoration) that allowed parents to feel content and more adjusted. Although some parents were reluctant to accept

CHD, doing so seemed to create capacity for hope: “There is no way to avoid the given fate. I guess I just have to accept it. If I go to the hospital with the child and go after it hard, I believe it could get better someday” (Lee & Ahn, 2020, p.7139).

There were also narratives of making the most of pregnancy: “You had to enjoy your pregnancy, ‘cause if you didn’t, you were just going to make things worse” (Rempel et al., 2013, p.622). For some, comfort was gained by seeking connection with their child: “…when she told me, I made the decision that every minute I have this child alive inside me is a moment to cherish.” (Leuthner et al., 2003, p.125). Similarly, Im et al. (2018, p.471) found Korean mothers were influenced by *TaeKyo*, a traditional concept that suggests connection with the fetus supports its development. These mothers found interacting with their child facilitated acceptance of CHD: “I felt happy when she was kicking my belly. I felt as if she was sending me a signal that ‘Mommy, I’m here, and I will be OK.”

Subtheme 4.3: Redefining hopes for the child

Parents’ adjustment to the diagnosis was evidenced as they redefined hopes for their child. Some sought to promote fulfilment, despite CHD: “We were already getting ready for what kind of things we could expose him to, piano lessons, or… Whatever we could throw his way to help him live it to the fullest” (Neubauer et al., 2020, p.1674). However, most discussed defining a ‘new normal’ and adapting their life to accommodate CHD: “Participants formed a new family identity incorporating the prenatal diagnosis” (Harris et al., 2020, p.8). A narrative emerged regarding parents’ unconditional love for their child and, consequently, a willingness to reappraise their priorities for parenthood and expectations of their child. For example, fathers discussed adapting interests to share with their child: “[If] having a heart condition definitely limits his ability to participate, he could still just enjoy being a fan or learning about the sports” (Harris et al., 2020, p.8).

Discussion

This systematic literature review was the first to synthesise qualitative findings focussing on parents' psychological experiences when receiving their child's CHD diagnosis. Across four main themes, parents experienced powerful emotions following their child's CHD diagnosis, including shock, guilt, anger, fear and uncertainty, supporting previous findings regarding other congenital anomaly diagnoses (Blakeley et al., 2019; Carlsson et al., 2017; Irani et al., 2019; Marokakis et al., 2017; Nelson Goff et al., 2013). Interestingly, the synthesis revealed a narrative that these emotions, and the seriousness of CHD, were difficult to reconcile with the initial joy parents had felt towards their pregnancy or new-born. Their subsequent distress could be explained by theories of cognitive dissonance (Harmon-Jones & Judson, 2019), which suggest that incompatible thoughts about an experience can create unpleasant psychological states. Furthermore, uncertainty surrounding the CHD prognosis meant that parents were unable to immediately resolve their simultaneous sorrow and happiness.

The diagnosis also represented multiple losses for parents, of a normal pregnancy or birth, healthy child and envisioned future. Experiences highlighted throughout the synthesis, of anger, avoidance, sorrow and eventual acceptance of the diagnosis, are analogous to those described in Kübler-Ross and Kessler's (2005) grief cycle. This model details the natural process of grief (e.g., denial, anger, depression, bargaining and acceptance), suggesting that a child's CHD diagnosis might have similarities with that of concrete loss following death. Lou et al. (2017) similarly found that prenatal diagnosis of a lethal condition represented multiple complex losses for parents. Whilst CHD is a serious condition, severity and prognosis varies. The studies included in the synthesis represented various CHD types, suggesting that concepts of grief and multiple losses also apply to diagnoses that are not lethal.

Although there were consistencies across parents' experiences, the synthesis identified some differences, particularly according to gender and timing of diagnosis. Across studies, fathers were less likely to express their emotions due to gendered expectations to be strong. This finding was consistent across cultures and reflected previous research regarding fathers' wider experiences of their child's CHD (Gower et al., 2017; Lin et al., 2021).

With regards to timing, quantitative research identified differences in distress levels between parents who received a prenatal or postnatal diagnosis (Bratt et al., 2019; Pinto et al., 2016). The current synthesis expands these findings to include qualitative detail about parents' differing experiences. Parents receiving a prenatal diagnosis described more intense rumination and uncertainty throughout pregnancy, creating anxiety and hopelessness. Conversely, parents receiving a postnatal diagnosis experienced more intense shock, because they had to navigate multiple emotions alongside time-pressured medical decisions. Consequently, the synthesis illustrates that the diagnosis of a child's CHD might be universally distressing for parents, but the specific emotions involved and timepoints at which psychological wellbeing is affected varies between individuals.

Parents' experiences of, and preferences for, information following their child's CHD diagnosis have been discussed (Carlsson et al., 2015; Reid & Gaskin, 2018). The synthesis similarly found that parents often feel overwhelmed by information, yet also obliged to learn as much as possible. Positive interactions with professionals appeared to be a facilitator of parents' psychological wellbeing and adjustment to the diagnosis. Parents valued opportunities to ask questions to aid their understanding, and to receive compassion and validation of their emotional responses. Previous reviews have similarly suggested that professionals' personable skills can facilitate parents' coping with their child's congenital anomaly diagnosis (Kratovil & Julion, 2017; Lou et al., 2017). However, the current synthesis additionally found that unhelpful practice, such as professionals lacking

compassion or rushing information sharing, negatively influenced parents' wellbeing and presented a barrier to their understanding of, and coping with, the diagnosis.

This synthesis found that parents employed coping strategies, including avoidance, hope, seeking control, and seeking support from others, similar to those described in a previous systematic review regarding psychosocial coping among parents of children with CHD (Lumsden et al., 2019). Following completion of the current synthesis, a longitudinal study by Harris et al. (2022) found that parents used similar coping strategies of hope, seeking control and gathering information to reach acceptance of the diagnosis. However, the authors also found differences between parents' coping according to the severity of CHD diagnosis, because parents whose child had a lower mortality risk were better able to utilise hope, whilst those whose child had a higher mortality risk preferred to seek control and information. The findings of the synthesis and similar research may be conceptualised using Lazarus and Folkman's (1987) Transactional Model of Stress and Coping, which suggests coping is determined by an individual's appraisal of the threat posed by a stressor and of their available options. The model proposes two types of coping: problem-focused coping seeks to address the problem, whilst emotion-focused coping prioritises managing emotional responses. In the current synthesis, some parents might have used emotion-focused coping strategies, such as hope or avoidance, to appraise CHD as less threatening and protect them from distress. Other parents could have appraised CHD as highly threatening and used problem-focused coping strategies, such as seeking control or information, to address problems (e.g., decision-making). However, there may be wider psychological, social, practical or cultural variables that inform parents' appraisal of the diagnosis and subsequent coping that were not identified by the synthesis.

Lalor et al. (2009) proposed 'recasting hope' as a model to explain adjustment to a congenital anomaly diagnosis, which involved seeking meaning in the diagnosis and

reconstructing hopes for the future. The current review similarly found that adjustment involved parents' adapting their expectations and hopes for their child in the context of CHD. Parents' use of aforementioned coping strategies, alongside other factors such as positive interactions with professionals, opportunities for reflection, and a clear medical plan, appeared to act as facilitators towards such adjustment. The synthesis extended previous research because an overarching concept of unconditional love for the child was identified to be a key factor in parents' adjustment to their child's CHD diagnosis. In contrast, the synthesis also identified that difficulties with understanding CHD, lack of support from professionals, and pessimism about the future could impede parents' adjustment to their child's diagnosis.

Taken together, the themes identified in the current synthesis appear to evolve over time and may map onto Johnson et al.'s (2020) model of parents' responses following prenatal diagnosis of fetal anomalies. The synthesis also reflects similar models proposed by two included studies. Im et al. (2018) suggested that mothers experienced four phases following their child's prenatal CHD diagnosis: 1) shock and pain, 2) worries and concerns, 3) recognition of the child as a living being, and 4) restructuring the pregnancy experience. According to Neubauer et al. (2020), parents experienced six transitions from receiving their child's CHD diagnosis: 1) learning the diagnosis prenatally, 2), learning the diagnosis postnatally, 3) new normal, 4) taking control, 5) learning death is likely, and 6) after death.

By including additional experiences of anger and uncertainty, as well as consideration of parents' coping, the current synthesis expands on these models. Furthermore, the findings include a phase of mourning, because children with CHD require ongoing care and adaptation, which was not represented in other models. Finally, the synthesis included studies conducted across various types of CHD, cultural contexts and populations and found consistencies in experiences that had not been possible in individual studies.

Clinical Implications

Many parents reported powerful distress following their child's CHD diagnosis, but the extent to which they coped varied. Thus, as recommended by Blakeley et al. (2019), a stepped care model of psychological support may be beneficial. All staff could offer validation, normalisation and basic psychoeducation to maximise the identified facilitators of adjustment, such as access to peer support and space to reflect. Individual support from clinical psychologists could be offered to parents who experience greater or continued difficulties, consistent with recommendations for CHD services (NHS England, 2016).

Although many parents reported shared experiences, the synthesis identified variation between individuals; thus, professionals should tailor support to parents' individual needs. For instance, as parents receiving a prenatal diagnosis reported mourning for their expected healthy child, they might benefit from support with prenatal bonding. Conversely, those who received a postnatal diagnosis reported more shock, so may require support to process information. As this synthesis also highlighted differences in fathers' experiences, professionals should, therefore, encourage fathers to discuss their experiences.

Parents used various coping strategies following the diagnosis and should be encouraged to draw upon their existing resources to facilitate adjustment. Peer support was highlighted as particularly valuable, due to the normalisation it provided, and has been found beneficial for parents of children with several conditions (Bray et al., 2017; Lumsden et al., 2019; Shilling et al., 2013). Thus, health services could facilitate peer support groups for parents who receive a diagnosis of CHD for their child, either in person or online. Peer support groups should promote discussions between parents to support the development of shared understandings, and could identify parents who may benefit from additional, individual support. These groups could also offer psychoeducation, normalisation and

validation regarding parents' psychological responses to the diagnosis, because these factors were identified as important facilitators of adjustment in parents' appraisal of professionals, and have been found to promote positive therapeutic outcomes (Wampold, 2015; Yuen et al., 2022).

The potential emotional impact of delivering congenital anomaly diagnoses on healthcare professionals should also be considered. These professionals have been reported to suffer from burnout and compassion fatigue (Cohen et al., 2020; Tacy et al., 2022), which could explain the negative interactions that some parents reported. Thus, professionals may benefit from access to regular supervision or reflective practice to support their own wellbeing and self-awareness. Indeed, similar practice has been positively evaluated throughout health services (Beavis et al., 2021; Davey et al., 2020).

Strengths and Limitations

The synthesis provided an outline of the emotional trajectory parents may experience following their child's CHD diagnosis. Findings were consistent across studies (see Appendix C), illustrating that the synthesis was not predicated on one population (e.g., Western) or on studies of lower quality. However, criteria for studies to be published in peer-reviewed journals could have omitted other findings containing alternative perspectives.

A key limitation of qualitative synthesis is inherent subjectivity, because authors must select, appraise and synthesise studies. Although coding and identification of descriptive themes were completed by the first author, several steps were taken to ensure rigour. For instance, independent researchers supported the selection and quality appraisal processes, and final themes were identified through collaborative discussion with the research team. Nonetheless, due to time and resource constraints, independent reviewers only assessed some

titles and abstracts. Therefore, the selection process relied heavily on the lead researcher's appraisal.

Nineteen of the included studies contained fathers' perspectives, in contrast to the wider research area, which has predominantly focused on mothers (Wei et al., 2015). However, findings revealed that fathers often felt unable to express their emotions following their child's CHD diagnosis, due to gender expectations to be 'strong', so the synthesis may not accurately summarise their experiences.

Future Research

Further longitudinal research would be beneficial, for example, with parents receiving a postnatal diagnosis, to increase understanding of how parents' psychological responses to their child's CHD diagnosis evolve over time. Furthermore, a review of quantitative findings should be completed, because this may represent a greater number of parents, offer comparison with other groups (e.g., parents of health children) and augment our understanding of psychological needs at the time of diagnosis.

Only three papers included perspectives from parents who terminated the pregnancy following CHD diagnosis (Carlsson & Mattsson, 2018; Delaney et al., 2021; Leuthner et al., 2003). As previous research has considered termination decisions among parents receiving a prenatal diagnosis for their child (Blakeley et al., 2019), future research should seek to explore this specifically following a CHD diagnosis to identify similarities or divergences with other accounts.

Conclusion

This synthesis highlighted that parents experienced distress following their child's CHD diagnosis in several phases of emotions, evolving over time and culminating in adjustment to

the diagnosis. Parents' emotional experiences were influenced by various factors, including gender, timing of diagnosis and coping strategies employed. The review underscores the influence of professionals on parental wellbeing and recommendations are made for supervision and further exploration of parents' preferences to improve support following diagnosis.

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