

Parents confronting with their child's congenital heart disease

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Abstract

Congenital heart defects represent the most prevalent congenital disorder affecting newborn infants. In Slovenia, the annual incidence of infants born with a congenital heart defect is estimated to be between 80 and 100 cases. Notably, half of these infants require surgical intervention within the first month of their life. It is estimated that 50% of all new-borns with a congenital heart defect require immediate surgical treatment, and their parents are in need of prompt access to information and support. The parents' initial reaction to the diagnosis is shock, reflecting the unexpected nature of a congenital heart defect. This is followed by a multifaceted emotional response, encompassing a range of emotions including sadness, anger, despair, shame, guilt, denial, and isolation. Conversely, the parents may also demonstrate a proactive response, seeking information about the diagnosis, further treatment options, and potential courses of action. In emotionally challenging circumstances, some parents exhibit a tendency to disengage mentally from the situation, manifesting behaviours such as crying, turning to faith and prayer, and seeking support from loved ones. It is important to note that each situation is unique and that parents may employ a diverse range of coping strategies. However, a common thread that runs through all of these strategies is the need for parents to be as fully informed as possible about their child's condition and diagnosis. Parents demonstrate a capacity to accept their child in spite of the congenital heart defect, and do not perceive the child as having a medical abnormality. Our research indicates that parents frequently engage in dialogue with their partners and seek information from alternative sources (such as online resources or friends who are employed in the health sector) during challenging periods.

Starševsko soočanje z diagnozo prirojene srčne napake pri otroku

Povzetek

Prirojene srčne napake so najpogostejša prirojena obolenja novorojenčkov. V Sloveniji se letno rodi 80–100 otrok s prirojeno srčno napako, polovica vseh pa potrebuje kirurško zdravljenje v prvem mesecu otrokovega življenja. 50 % vseh novorojenčkov s prirojeno srčno napako potrebuje takojšnje kirurško zdravljenje, njihovi starši pa takojšnje informacije in podporo. S študijo primera smo ugotovili, da starši ob soočanju z diagnozo najprej doživijo šok, saj je prirojena srčna napaka nekaj, česar niso pričakovali. Začetnemu šoku sledi vrtiljak čustev, vse od žalosti, jeze, obupa, sramu, občutka krivde, zanikanja diagnoze, zaprtja vase pa do proaktivnosti – iskanja informacij o diagnozi, nadaljnjem zdravljenju in poteku. Nekateri starši se v težkih trenutkih mentalno umikajo iz situacije, jočejo, obračajo k veri in molijo ter pogovarjajo z bližnjimi. Vsaka situacija je drugačna in vsak starš potrebuje različne strategije spopadanja z diagnozo, vsem pa je skupno, da morajo biti čim bolj celovito informirani o otrokovem stanju in diagnozi. Starši otroka kljub prirojeni srčni napaki v popolnosti sprejemajo in nanj ne gledajo kot na otroka, ki ima zdravstvene posebnosti. Z raziskavo smo ugotovili, da se starši v težkih trenutkih največkrat poslužujejo pogovorov s svojimi partnerji in iskanja informacij drugje (na spletnih straneh ali pri prijateljih, ki so zaposleni v zdravstvu).

INTRODUCTION

Congenital heart defects (CHD) represent the most prevalent congenital disorder, occurring in 1% of all newborn infants in Slovenia (Narancsik et al., 2017). As a result of advances in modern neonatal intensive care and cardiothoracic surgery, it is estimated that up to 85% of children with CHD¹ live to reach adulthood (Štumpfl et al., 2018). The unfortunate reality is that not all congenital heart defects are compatible with life. In fact, according to some authors (Khalil et al., 2019), heart disease is still the cause of 25% of infant deaths in the first year of life. It is therefore imperative that children with CHD are provided with prompt treatment and an interventional response from the healthcare team (ibid., 2019). There are numerous types of heart defects, but the most commonly observed are ventricular septal defect (VSD) and atrial septal defect (ASD). VSD occurs in approximately 30% of infants with CHD, while ASD occurs in approximately 10% (Felc, 2011). Congenital heart defects can be diagnosed in various ways, some can be detected already during pregnancy. This is achieved using a test called fetal cardiac ultrasound, which allows for the suspicion of a fetal heart defect to be formed (Vesel, 2014 in Kržišnik et al., 2014). Following birth, pulse oximetry represents the most typical diagnostic methodology (Fister et al., 2017). Additionally, the utilisation of echocardiography, electrocardiography (ECG), computed tomography (CT) of the heart, and magnetic resonance imaging (MRI) is becoming increasingly prevalent. Three-dimensional imaging of the heart is another increasingly popular diagnostic method, as it allows for the visualisation of the contractility and size of the two ventricles (Vesel, 2014 in Kržišnik et al., 2014).

Upon learning of their child's CHD, parents typically experience a multifaceted emotional response that is often unexpected and overwhelming (Cunningham, 2016). It is notable that each parent responds differently to this diagnosis, and that the emotional experiences associated with it vary considerably between individuals. The initial phase of coping with the diagnosis is characterised by shock, given the unexpected nature of the news (Cunningham, 2016). The most common emotions that parents experience when they learn of their child's CHD are sadness, anger, fear, denial of the diagnosis, guilt, shame, substance abuse, or, in more extreme cases, rejection of the child or excessive concern for the child with a concomitant need to protect the child from harm (Woolf-King et al., 2018; Kübler-Ross and Kessler, 2004; David, 2015; Demianczyk et al., 2021; Davey et al., 2023). This type of situation has been found to have consequences for parents' mental health, regardless of the severity of the child's condition and the complexity of the child's CHD (Woolf-King et al., 2018). It is therefore essential that parents receive support from those closest to them during this period (Restoux, 2010).

The care of newborns and infants with clinically significant CHD is a challenging and time-consuming endeavour that demands a high level of commitment from the entire care team (Fister et al., 2017). It is of the utmost importance that a collaborative relationship is established between parents and professionals during the child's time in hospital. Parents ought to be informed of all aspects of their child's care, including feeding the infant via nasogastric tube and subsequently via bottle, monitoring for indications of deterioration, weighing feedings, monitoring fluid intake and output, dosing and administering medications, and caring for the post-operative wound, among other topics. It is incumbent upon the professional team caring for the child with CHD to provide parents with sufficient quality information, as they are the primary source of guidance for the family. The expert team also includes a neurophysiotherapist who advises parents on the optimal handling (therapeutic) positions for their child with CHD.

¹ Congenital heart defect - hereafter CHD.

OBJECTIVE

The aim of this study was to find out what stages parents go through in coping with their child's CHD, and which of these stages is the longest and most persistent. Furthermore, we wanted to find out where parents get the majority of information about the effects of CHD on their child's development, about further treatment, and how it progresses. Additionally, we sought to find out whether the diagnosis of CHD prevents parents from fully accepting their child, whether parents reject their child following the diagnosis, whether they are over/underprotective of their child, and whether they have ever thought that it would have been better if the child had died.

METHODOLOGY

A causal, non-experimental and descriptive method of educational research was used. A qualitative research method - a case study - was used to explore how parents cope with their child's diagnosis of CHD. The intention was to present the parents' experiences as objectively as possible and to present the findings alongside the scientific profession. The sample was purposive and non-randomised and included 10 parents of children with CHD who underwent surgery in the first year of life. A structured interview consisting of open-ended questions was prepared to cover several areas (coping with the diagnosis, acceptance of the child with CHD, effects on mental health and parents' information about CHD).

R1: How do parents come to terms with the reality of having a child with CHD?

R2: At which stage of the coping process do parents of children with CHD remain for the longest period of time?

R3: In which sources of information do parents of children with CHD seek the majority of their knowledge about their child's condition, the course of treatment, and its impact on the child's development?

R4: To what extent does a parent's experience of a child with CHD impact the mental health of the parent?

RESULTS

The findings indicate that parents of children with CHD fully accept their child, do not perceive them differently, and do not treat them as a child with a clinically significant heart defect. They demonstrate a tendency to ignore the heart defect but are acutely aware of it each time they attend medical examinations and check-ups with various specialists. Children with CHD are managed in different outpatient clinics according to their specific needs, and cardiological follow-ups are quite frequent.

The manner in which parents of children with CHD respond to their diagnosis varies considerably. All parents exhibited a primary phase of shock that was unanticipated (Cunningham, 2016). Each parent's experience is unique, and the process of coming to terms with a diagnosis is therefore highly individualised (Woolf-King et al., 2021). The emotional responses to receiving a diagnosis vary considerably between individuals and can persist for different lengths of time, manifesting in diverse ways. The experience of denial was observed in only one mother in the study. The subsequent emotion is sadness, which is also prevalent, accompanied by concern and fear for the infant's wellbeing and the potential outcome of the child's demise. Furthermore, parents may experience a sense of injustice, perceiving the child as blameless and questioning why this has occurred to a child of such a young age. Moreover, feelings of guilt are frequently reported, indicating that parents tend to attribute responsibility for the child's difficulties to themselves. Such sentiments are particularly likely

to manifest among mothers who question whether they may have done something wrong during the prenatal period, a time when the fetal heart is developing (Dodič, 2016). In our study, feelings of guilt were observed in six parents, specifically four mothers and two fathers.

Furthermore, the research findings indicated that none of the participating parents expressed feelings of shame regarding their child. The uncertainty inherent to the complexity of CHD represents a significant emotional challenge for parents in their efforts to cope with the diagnosis. Parents are prepared for a range of eventualities both prior to and during their child's surgical procedure and subsequent treatment. The period spent awaiting surgery is a particularly stressful time for parents, who are in a constant state of anticipation for positive developments and are cognizant of the possibility of unforeseen complications. The uncertainty phase was identified as the longest and most enduring phase in the survey.

The coping mechanisms utilised by parents in response to the diagnosis are diverse, and parents exhibit individual differences. Consequently, each parent requires a unique approach to facilitate their own coping process. The most common coping mechanisms employed by parents are turning to faith and prayer, which have been found to be particularly helpful in difficult times (Cunningham, 2016). The parents in the study demonstrated effective use of the coping strategy of positivism. Parents are compelled to maintain a positive outlook during their child's surgical procedure, placing their trust in the medical professionals' ability to provide optimal care and ensure the child's safety (Davey et al., 2023). Discussing the situation with partners and close relatives was identified as an important coping strategy for supporting parents. Two parents also described disengaging mentally from the situation (for example, by walking the puppies or focusing on academic work) as a coping strategy. Proactively seeking information and being informed about the diagnosis were also identified as factors that helped parents cope.

The findings of our research indicated that none of the parents held the view that it would have been preferable for their child to have died. All parents expressed a desire for their child to survive and articulated expectations that their child would do so. Some parents may exhibit overprotectiveness, which can manifest as excessive care and supervision (Dodič, 2016). In our case, this proved to be a valid assumption, as evidenced by the experiences of one mother who was aware of this phenomenon.

The findings on the impact of coping with a diagnosis on parents' mental health are largely consistent with those of previous research in this area. Eight out of ten parents stated that the situation had had an impact on their mental health. Parents recall all challenging moments, experience elevated stress levels prior to each examination, and frequently recall events from the most distressing periods (Jackson et al., 2015). The responses provided by parents indicated that the situation had a notable impact on their mental health.

The majority of parents reported that they had received most of their information from the medical staff and sought further information from them. This included establishing contact with the child's neurophysiotherapist, a specialist who can commence treatment immediately after birth. However, parents in the study also sought information from alternative sources, including online sources, friends and relatives working in healthcare, and other informal sources of information (David, 2015). At the time of diagnosis, only one mother had contacted the "*S Srcem za srčke*" association, whereas four were unaware of the association. Of these, three stated that establishing a connection with the association and other parents of children with CHD would be beneficial for them and something they would prefer to do.

The parents would have responded to the situation in a broadly similar manner. Two mothers would have sought professional assistance sooner. The parents surveyed advocated that parents of children with CHD should strive to obtain as much information as possible about their child's diagnosis and the course of treatment from their child's cardiologist, who is intimately acquainted with the condition of the child's heart.

DISCUSSION

Research has demonstrated that the experience of having a child with CHD has a significant impact on the mental health of parents. This is consistent with the findings of Woolf-King et al. (2018), who have noted that parents often retain a vivid memory of the moments when their child was connected to medical equipment. As stated by Davey et al. (2023), post-traumatic stress is more prevalent among parents whose children have undergone surgical procedures or cardiac catheterisation. All the children of the parents included in the study had undergone one (or both) of the selected procedures. The parents participating in the study displayed certain characteristics suggestive of post-traumatic stress disorder (PTSD), a condition that, according to Woolf-King et al. (2018), is commonly observed in this context. The emotional responses and coping mechanisms of parents in response to their child's diagnosis vary considerably, as evidenced by the findings of numerous authors (Cunningham, 2016; Lumsden et al., 2019; Woolf-King et al., 2018; et al.). Each case is unique, and the way parents cope with their child's diagnosis may differ from one parent to another. A common theme among these parents was grief and concern for their child. Cunningham (2016) posits that these reactions are typical and genuinely reflective of one's emotional state. It is not uncommon for parents to become overprotective of their child at certain moments, defending them from any potential negative outcomes. Cunningham (2016) suggests that this phenomenon is almost universal, driven by the mother's inherent need to safeguard her sick child. It is also evident that other parents seek to shield their children from potential infections, illnesses and injuries, a response that Cunningham (2016) deems to be a typical parental reaction.

As parents' experiences and acceptance of this ordeal vary, so too do their strategies of accepting the diagnosis. The most common approaches were those that were positive, faith-based, and included prayer. Lumsden et al. (2019) argue that by engaging in this practice, parents are effectively relinquishing control to a higher power and placing their trust in the belief that this entity will ensure positive outcomes. Other strategies included mentally disengaging from the situation, which aligns with the findings of Lumsden et al. (2019). The latter study suggests that parents may benefit from disengaging from the situation for at least an hour a day, as this can provide a new source of motivation to move forward. Additionally, engaging in discussions with loved ones and partners was identified as a helpful coping mechanism. Cunningham (2016) asserts that a state of calmness and positivity is indicative of an individual's acceptance of the diagnosis, a viewpoint that is also espoused by Demianczyk et al. (2021). Two mothers reported feelings of loneliness, which was alleviated by their partners. This finding aligns with the assertion by Restoux (2010) that support from loved ones is crucial in coping with feelings of loneliness. Through discourse, the parents gradually processed the situation and became aware of their feelings, which corroborates the findings of Lumsden et al. (2019). These authors state that connecting with loved ones provides the incentive to confront new challenges. It is therefore evident that parents require a diverse range of coping strategies to assist them in coping with such a diagnosis (Jackson et al., 2015). Parents found it beneficial to be proactive, to seek information and remain informed about their child's condition, the course of treatment and

the child's future development, engaging in dialogue with medical professionals, which has been demonstrated to reduce stress levels (Demianczyk et al., 2021).

The research findings affirm that all parents wish for their child to survive, and that no parent would consider it preferable for the child to die. Our findings are therefore at odds with those of Dodič (2016), who posits that in certain cases, there may occur a rejection of the child. Parents frequently seek information from medical professionals, including therapists. As Rančigaj Gajšek (2018) asserts, this is the responsibility of healthcare providers. The connection between parents and healthcare professionals is crucial already upon the diagnosis of CHD, nevertheless parents often seek further information from other sources, a phenomenon that is also observed by Odžić (2022). This latter author notes that parents frequently seek information online, from friends and acquaintances working in the health sector, and from other sources.

CONCLUSION

The experience of parenting a child with a critical case of CHD who requires an intervention on a walnut-sized heart in the first year of life is a profoundly challenging ordeal for parents. The situation gives rise to a plethora of emotions that parents must navigate, while acknowledging the possibility that, even with surgical intervention, the child may not survive. Parents encounter a range of challenges when processing the diagnosis. They experience concern for their child's wellbeing, a desire for their child to survive, and hope for a positive outcome. It is evident that each parent employs a unique set of coping strategies, which are adapted according to their individual character traits. In most cases, parents seek solace and support from their loved ones, partners, and through positive thinking and prayer by returning to their religious beliefs. Parents accept their child with CHD unreservedly and desire nothing less than a full recovery and survival.

It is imperative that parents obtain comprehensive information regarding their child's CHD and the associated course of treatment throughout the treatment process. It is recommended that parents seek information from the child's cardiologist, who is the only medical professional with the requisite knowledge of the structural and functional capabilities of the child's heart. The parents should strive to obtain all the aforementioned information from the relevant medical personnel, therapists, or other parents of children with the same CHD, who can provide them with valuable advice and insights. A humanitarian association, designated as "*S srcem za srčke*," is available to assist parents in navigating the diagnostic process and acquiring pertinent information.

The experience of having a child with a CHD has a significant impact on the mental health of the parents. It is not uncommon for parents to exhibit symptoms of post-traumatic stress disorder (PTSD) as a result of their experiences in the hospital. It is therefore vital that parents receive professional assistance to help them process the situation and the distressing experience that will inevitably remain with them.

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