

## Experiences of Parents with Children Affected by Congenital Heart Disease at a Public Hospital Cardiac Unit

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### Abstract

**Background:** About 8 out of every 1000 live births are affected by congenital heart diseases (CHDs). Survival rates have increased thanks to improvements in medical and surgical procedures, turning CHDs into chronic illnesses. This has an effect on the dynamics of the family and how they behave. **Method:** Qualitative study is to better understand parents' experiences of caring for a child with congenital heart disease. A qualitative descriptive and contextual study design using a phenomenological approach was used for this study. In-depth interviews were conducted with five purposeful selected participants from population of parents with children born with congenital heart abnormalities. The study was conducted at a public hospital Cardiac Unit. Data analysis was done using content analysis and was grouped into five themes.

**Results:** The themes emerged from the analysis were emotions, disrupted parental experience, support system, need for intervention and coping strategies. **Conclusion:** Full understanding of the life experience of these parents will allow the implementation of the target health intervention that are planned at addressing the challenges faced by these parents.

**Keywords:** Emotion, Parents, Experience, Children, Congenital Heart Disease

### Key Points

- Congenital heart disease is a type of congenital condition that affects the heart's normal growth and operation and is brought on by structural defects in the heart from birth and can affect how blood flows through the heart and out to the rest of the body.
- There are 300,486 estimated yearly congenital heart defect (CHD) birth prevalence cases across the 54 African nations and because of the inadequate healthcare systems in Africa
- Helping parents navigate their path and give their children with CHD the best care possible requires the engagement of family, friends, and medical experts.

### Introduction

According to the World Health Organization (World Health Organization, 2023). Congenital heart disease is a type of congenital condition that affects the heart's normal growth and operation and is brought on by structural defects in the heart from birth and can affect how blood flows through the heart and out to the rest of the body. Reports on CHD prevalence continues to raise globally in both developed and developing communities even though the lack of access to healthcare and limited diagnostic tools in the developing world has impacted the number of reported cases, cases remains high (Liu et al., 2020). About 28% of congenital abnormalities globally are

caused by congenital heart disease (CHD), which occurs 9.1 times for every 1000 live births. Currently, CHD poses a significant threat to world health, as it accounts for more than 200,000 fatalities annually (Edwin et al., 2017). Meanwhile, in sub-Saharan Africa it is estimated that approximately 500 000 children are born with CHD (Salim et al., 2019).

Twelve million people worldwide were estimated to have congenital cardiac disease in 2017, an increase of 18.7% since 1990. 261 247 fatalities were estimated to have been caused by congenital heart disease in 2017, a decrease of 34.5 percent from the anticipated death toll in 1990 (Rossano, 2020). There are 300,486 estimated yearly congenital heart defect (CHD) birth prevalence cases across the 54 African nations and because of the inadequate healthcare systems in Africa, congenital heart disease continues to be largely a problem for children's health (Edwin et al., 2017).

### Objectives

The objectives of the study were to explore the experiences of parents with children affected by congenital heart disease at public hospital cardiac unit.

### Methods

In this study, the researcher made use of qualitative research because it captured the feelings and attitudes of the targeted

participants. This study population consisted of five parents of children with congenital heart disease that were determined by data saturation using purposeful sampling. The study took place at public Hospital at Cardiac clinic and at Cardiac unit in 2023. Parents that came for follow ups at cardiac clinic and those admitted in cardiac unit were included in the study.

### Data Collection

The researcher designed a semi-structured interview guide to conduct in-depth face-to-face interviews. The researcher collected data soon after ethical clearance was received from the School of Nursing and Public Health Research Ethical Committee and approval was received from the Ministry of Health and Social Services, approval to conduct a research from Public Hospital superintendent and written informed consent is received from participants. Data was collected in a quiet room with a “do not disturb interview in progress” sign displayed on the door outside the room. Participants signed a written consent agreeing to participant in the research. Data collection process took approximately 5-10 minutes per participant. The researcher continuously collected data until 29 August 2023 when no new events emerged and data saturation had been reached with 5 participants.

### Ethical Considerations

The ethics was in line with the Helsinki declaration. The researcher obtained permission to conduct the study from the following institutions Ministry of Health and Social Services, University School of Nursing and Public Health, ethical Clarence number SoNEC 104/2023, Hospital medical superintendent management committee and written informed consent from participants.

### Presentation of the Study Results

#### Characteristics of the Participants

Five parents of children diagnosed with congenital heart disease were included in the study. Age of participants ranged 27-37 years old. Five themes and six subthemes emerged from the study. table 1.

Themes	Sub themes
Theme Parental Emotions	Feeling overwhelmed and distressed Positive emotions
Theme Disrupted parental experiences	Difficulty balancing work and parenting responsibilities
Theme Support System	Family, Friends and Health workers
Theme Need for intervention	Needing access to resources and information
Theme Coping strategies	Spiritual beliefs

#### Feeling Overwhelmed and Distress

The interviews revealed persistent parental emotional strain throughout the interview. One of the most striking characteristics was the sense of uncertainty and helplessness that pervaded the

entire experience, beginning with the child’s initial diagnosis and continuing throughout his or her life. Along with aspects of the events themselves, such as the parents being exposed to vivid, graphic visuals of their child, the pace at which events progressed, and near-death experiences, fear, frustration, shock, and despair were frequently reported.

*“Shuu (pause) I was very, very (pause) scared, I was emotional, I cried that day because I thought my child was going to die, because the heart is (pause) the most important thing in the body, so I thought if there is a problem with the heart, its jut automatic my child is going to die. So I was very very scared and I was emotional”.* (P2)

#### Sub theme: Positive thinking

This theme explored how parents coped with the often honest or blunt prognosis of their child’s condition despite feeling emotionally distress, they maintain a certain level of functioning care for their child who is hospitalized and often look after their other children as well.

*“I have nothing to do about that its God’s choice (pause) yeh, I am grateful that my baby is alive and I have faith he will be well one day”.* (P1)

#### Disrupted parental experiences

##### Sub theme: Difficulty balancing work and parenting responsibility

Parents expressed a significant burden of care including hospital care, medical appointments and ongoing monitoring of their child’s condition. This can be a source of disrupted parental role for the child diagnosed with the condition as well as with the children left at home.

*“I have my other children at home now (pause) and they need me mos.”* (P1)

#### Theme: Support System

##### Family, Friends and health workers

Social support provided by family friends had a positive influence on the parents as they struggle through their child’s health crisis. For parents, the stress of caring for a child with CHD can be overwhelming and detrimental to their physical and mental health. Parents reflected a positive emotional and financial support from family members which helped them cope with the situation.

*“Yes! My family and friends are very supportive (pause) so I get ahh money for transportation because I have to do follow up here and in Windhoek and also for accommodation (pause) and ahh food, really I have support system that is really good”* (P3)

#### Theme: Need for intervention

##### Needing access to resources and information

Interaction with medical staff have an influence on the parent experiences. Parents expressed relieved when the medical personnel were professional, quick to answer questions and was emotionally sensitive.

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*“Hmm I thank God my family is supportive they were supporting from when my son was a baby and my friend she take care of my other children every time I am coming to the hospital and They are encourage me and send small small money”. (P5)*

### **Theme: Parental coping strategies**

One of the coping mechanisms that was successful in ensuring the continuation of caring and lowering stress in families of children with CHD was optimism and hope for the child's recovery and future. (Lumsden et al., 2019). states parents of children with CHD employ a range of coping mechanisms, such as optimism, hope, keeping the family unit together, and looking for social support. Depending on the stage of CHD, several coping mechanisms may be used, including avoidance in the beginning.

### **Spiritual belief**

*“Wooo my dear it is difficult. I just pray to God to give me strength to accept the situation”*

*“I have nothing to do about that its God's choice (pause) yeh, I am grateful that my baby is alive and I have faith he will be well one day”. (P 1)*

### **Discussions**

#### **Theme: Parental Emotions**

##### **Sub theme: Feeling overwhelmed and distressed**

Congenital heart disease (CHD) parents' experiences are characterized by a feeling of being overpowered by stress, pain, financial, emotional issues and worried. The extensive emotional toll brought on by the CHD diagnosis, treatment, and aftercare for children is a result of these factors. After learning of the diagnosis, parents frequently experience shock and a terrible sense of helplessness. They struggle with worries for their child's welfare as a result of the difficulties and uncertainty related to their child's health. In order to assist parents in navigating their sentiments of being overburdened and distressed, the cardiac unit at the public hospital in the Khomas region plays a critical role in resolving these emotional (Shidhika et al., 2020).

(Lumsden et al., 2019). confirms that parents of children affected by (CHD) run the risk of suffering from depressive symptoms and mental health issues and further states, these feelings and issues can appear at various points throughout the child's life and medical course. Furthermore, parents of these children also have a variety of unfavorable feelings, including anxiety especially around the time of the diagnosis .

According to (Nayeri et al., 2021). these feelings could include astonishment, anguish, concern, guilt, and fear for the future of their child. (Simeone et al., 2018). supports that parent's constant worry and emotional tiredness can result from ongoing medical treatments, surgeries, and the uncertainty surrounding their child's health and can therefore, be difficult to strike a balance between hope and the reality of the situation.

##### **Sub theme: Positive emotions**

Parents of children with CHD expressed coping with their child's diagnosis and surgery by suppressing their emotions,

thinking positively, enlisting the help of others, and practicing self-care. A systematic review done by (Lumsden et al., 2019). on coping in parents of children with CHD indicated that a positive attitude and how parents handled the sometimes-unkind prognosis of their child's health. Despite the unfavorable circumstances, some parents were able to keep a cheerful attitude and hold out hope for the best. Another study done on psychological resilience by (McGrath & Kovacs 2019). reveals parents' positive protective qualities, such as self-efficacy, self-esteem, humor, optimism, and good affect, is crucial for parents of children with CHD.

Parenting can be difficult and challenging, but there are also happy moments. They find inspiration and hope in the fortitude and resiliency of their kids. Parents feel pride and joy when they see their child make progress and achieve goals, no matter how modest. A sense of community and shared optimism is fostered by the emotional support offered by medical staff in the cardiac unit as well as the companionship of parents dealing with comparable circumstances. These satisfying feelings are an essential source of inspiration for parents as they continue to provide for their children and fight for their welfare. Overall, even though parents of children with CHD endure considerable emotional obstacles, they can still feel happy and use coping mechanisms to reduce their stress.

##### **Theme: Disrupted parental experiences**

Traditional parental duties are impacted by the caring of a kid with CHD, when it comes to providing care. Moreover, the affected child's siblings may also experience a disruption in family relations and may need extra care and assistance (David Vainberg et al., 2019). Some parents in the study indicated being separated from their other children while in the hospital and asking family member or friends to care for their other children, this in turns disrupt the parental role (Kolaitis et al., 2017).

##### **Sub theme: Difficulty balancing work and parenting responsibilities**

For any parent, juggling work and parenting obligations can be difficult, but it can be more difficult if your child has congenital heart disease (CHD). (Salim & Jivanji 2019). stated that children with CHD may need frequent check-ups, procedures, and hospital stays. It can be time-consuming and emotionally taxing to manage these medical needs and work responsibilities.

For parents of CHD-affected children, juggling employment and family commitments is a huge difficulty. Many parents are compelled to work fewer hours or even quit their careers in order to care for their child's medical requirements (David Vainberg et al., 2019). Parental stress is exacerbated by the financial pressure that frequently comes with these choices. Many parents in the Namibia, where access to a Cardiologist is scarce, they must travel great distances to Windhoek central hospital, which complicates the logistical challenges of juggling employment and caregiving. It is clear that these families require government and social support systems to lessen their challenging experiences.

(Nayeri et al., 2021). CHD may not be what you expect as the condition of your child could unexpectedly deteriorate, necessitating rapid care and time off from work. Moreover, it can be emotionally hard to care for a child who has a major medical condition. Parents could feel stress, anxiety, and a constant urge to keep an eye on their child's wellbeing and not concentrate at work (Lepage et al., 2023).

### **Theme: Support System**

#### **Sub theme: Family, Friends and Health workers**

Parents indicated the importance of family, friends, and medical professionals cannot be overstated. Family and friends give a network of care that aids parents in navigating their obstacles by providing emotional and practical assistance. In terms of childcare, transportation, and emotional support, the assistance of grandparents, siblings, and close friends is frequently crucial. The cardiac unit's medical staff is crucial to this experience since they offer knowledge and emotional support in addition to medical care.

Having a solid support network in place is crucial while dealing with the diagnosis and ongoing difficulties of managing CHD. Parents frequently rely on a strong support network to help them deal with the difficulties of CHD. Family, friends, medical experts, and support organizations can all provide this assistance. Parents mentioned that their family support them, by taking care of their other children while admitted and others by sending money. (Zhang et al., 2023). also acknowledges that support network can be helpful for parents of children with congenital heart disease (CHD) as they negotiate the difficulties of raising their child. Making connections with other parents who have children with CHD can be especially beneficial since they can offer sympathy, comprehension, and useful information (Cruz et al., 2022).

Relationship between parents and health workers is essential as it creates trust and help parents cope with the challenges they are facing. Parents mentioned feeling relieved after the support they got from the Doctors and nurses.

### **Theme: Need for intervention**

#### **Subtheme: Needing access to resources and information**

One of the most important aspects of parenting is having access to resources and knowledge. Parents frequently struggle with ignorance concerning CHD, which causes uncertainty to enable parents to make knowledgeable decisions about their child's healthcare, it is crucial to provide thorough and accessible information to parents (Simeone et al., 2018). Additionally, the availability of resources for monetary and social support, such as public assistance and neighborhood efforts, can greatly lessen the strain on parents. In order to meet these needs, cooperation between the cardiac unit, governmental bodies, and nonprofit groups is essential.

### **Theme: Coping Strategy**

#### **Sub theme: Spiritual beliefs**

Children with CHD frequently need intensive medical care, such as surgeries, prescription drugs, and recurring checkups. Particularly during crucial procedures, parents may suffer with

a sense of feelings of powerlessness and anxiety about their child's health, especially during critical procedures.

The experiences of parents in the Khomas region who have children who have CHD are significantly influenced by their spiritual beliefs. Many parents find comfort and a sense of purpose in their religious and spiritual practices. The cardiac unit of the public hospital should recognize the significance of spirituality in parents' life and include spiritual assistance in the all-encompassing treatment given (Nayeri et al., 2021). stress is critical for parents to learn efficient coping techniques in order to manage the emotional burden, they may involve going to therapy or counseling individually and as a family.

According to (David Vainberg et al., 2019). parents who are aware about CHD are better equipped to advocate for their children's health and make wise choices. Parents can better control their emotions by learning stress-reduction methods like mindfulness or meditation. (Nayeri et al., 2021). further states that parents of children who have congenital heart disease undergo a wide range of complex and emotionally taxing events and it can be difficult to manage the emotional ups and downs, changes in parental responsibilities, and the requirement for considerable medical intervention. Therefore, coping strategies may help in this regard. A study done by (Cruz et al., 2022). indicated that parents go through this journey and give their kid with CHD the greatest care and support possible if they have a strong support system, resources, and coping mechanisms. The CDC acknowledges that there are groups dedicated to advancing knowledge about congenital heart abnormalities and offering supportive materials for families and healthcare professionals and financial assistance is given by organizations such as The Namibia National Children's Heart Trust, which supports families of children with congenital heart disease. (Shidhika et al., 2020). confirms that parents of children with congenital heart disease may find some of their financial difficulties lessened with financial assistance.

### **Conclusion**

Parents with children affected by congenital heart disease at Windhoek central hospital have encounter a wide range of emotions and difficulties. In order to address these experiences, a multifaceted approach is required, one that considers spirituality as well as psychological assistance, informational access, and job flexibility. Helping parents navigate their path and give their children with CHD the best care possible requires the engagement of family, friends, and medical experts. Additionally, providing a supportive environment for these families depends on coordinated efforts at the governmental and community levels.

### **Relevance for Clinical Practice**

It is crucial to prevent mental health issues in parents of children with CHD since parent mental health has a substantial impact on family and child wellbeing. Helping parents navigate their path and give their children with CHD the best care possible requires the engagement of family, friends, and medical experts. Additionally, providing a supportive environment for these families depends on coordinated efforts at the governmental

and community levels.

### Author Contribution

Joseph Galukeni Kadhila was responsible for supervision, data analysis, data curation, editing, formatting and drafting of the manuscript. Susana Shishiveni was responsible for writing original draft, data analysis and data collection, University of Namibia.

### Conflict of Interest

The authors declared no conflict of interest

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No funding was received for this study.

### Data Availability

Data may be available on request from the corresponding author.

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