Primary caregivers' experiences of caring for their child post cardiac intervention: An exploratory study.

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KEY WORDS

- Primary caregivers
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- Surgical intervention,
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- Challenges
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ABSTRACT

Children in developing countries are now receiving both surgical and catheter-based interventions for the repair of congenital heart defects. Despite the technically advanced treatment options and improved survival rates of children with congenital heart defects, little is known about the experiences and challenges of primary caregivers whilst taking care of their child after a cardiac intervention in South Africa.

This exploratory, descriptive study used a qualitative research approach to describe some of the key experiences of eight primary caregivers as they took care of their child in their home environment following a cardiac interventional procedure. The interventional procedures being referred to are both interventional cardiac catheterisation and cardiac surgery procedures. A purposive sample of eight primary caregivers from the tertiary level hospital in Kwa-Zulu Natal, South Africa was selected. Data was collected telephonically through semi-structured interviews. Thematic analysis was used to analyse the data and basic statistical analysis of sociodemographic data of participants was conducted. Data was presented both quantitatively and qualitatively in the form of tables, concepts maps, word clouds, participants quotes. In terms of ethics, interviewees participated voluntarily and informed consent was sought from each interviewee and they were informed of their rights to not participate or to stop participating at any time, without any negative consequences to them, their child and the services they would receive from the hospital in the future. Verbal informed consent was sought prior to telephonic interviews and all participant information was kept confidential. The study revealed a number of challenges which primary caregivers described as encumbering the quality of the care they could provide for their child at home. These included poor living conditions, multiple roles as the person running the home, lacking adequate finances to meet the basic needs of the child (like food and clothes) as well as their lack of access to clean water, electricity and proper sanitation. The study identified that these multifactorial challenges impacted on the mental and physical well-being of the primary caregivers. Primary caregivers revealed the need for more information about the congenital heart defect that their child had and a need to receive some form of counselling support at the point of diagnosis as well as on an ongoing basis. Stress amongst primary caregivers commenced from the time of diagnosis and continued post discharge in their home environments whilst taking care of their child after a cardiac intervention. Engagement between primary caregivers and healthcare workers at local health facilities revealed significant instances of either a missed or a delayed diagnosis and/or a delayed referral to a higher level of care. These experiences placed further stress on the primary caregivers. Support for the primary caregivers of children living with a congenital heart defect, who are providing care to a child in a low socio-economic context is vital. This study recommends that more attention ought to be given to supporting the psychological well-being of such primary caregivers. It also recommends that a health care system that is more inclusive of the role of primary caregivers in the treatment and management of children with congenital heart defects should also be promoted.

DECLARATION

I declare that the work presented herein: The perceived needs and challenges of primary caregivers whilst taking care of their child post a cardiac intervention is my own work and it is original. It has not been submitted for any degree or examination at any other university or institution for the award of a degree or certificate. All sources of information and data used or quoted have been duly indicated and acknowledged by complete references.

Full Name: Fathima Bibi Rufeek Ennos

Signature: Dated: 24 February 2022

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LIST OF ABBREVIATIONS

ASD	**Atrial Septal Defect**
CHD	**Congenital Heart Defects**
IALCH	**Inkosi Albert Luthuli Central Hospital**
KZN	**Kwa-Zulu Natal**
PDA	**Patent Ductus Arteriosus**
TAPVC	**Total Anomalous Pulmonary Venous Connection**
TGA	**Transposition of the Greater Arteries**
TOF	**Tetralogy of Fallot**
VSD	**Ventricular Septal Defect**
WHO	**World Health Organisation**

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CHAPTER 1: INTRODUCTION

1.1.Background

Congenital Heart Disease or Congenital Heart Defects (CHD) is a broad term that covers a range of heart defects and diseases within the cardiac anatomy (Poudel, 2011). There is an abnormal development of the heart or the major blood vessels of the heart before birth (American Heart Association, 2017). According to Poudel (2011), a CHD abnormality can occur where the blood flow in the heart can slow down, go in the wrong direction or in the wrong place or be blocked completely. This prenatal structural defect maybe of several types such as ventricular septal defect (VSD), atrial septal defect (ASD), patent ductus arteriosus (PDA), and Tetralogy of Fallot (TOF) (Farooqi et al., 2019; Zhi Hong et al., 2019). However, developments in congenital heart surgery, paediatric cardiology, and paediatric intensive care have significantly increased the survival rate of infants with CHD (Marino, 2013).

Despite these advancements, globally, CHD is one of the major causes of infant mortality, especially in developing countries like South Africa (Amakali & Small, 2013; Jivanji et al., 2019; Tankeu et al., 2017). It is noted that there is a global prevalence of 8 cases per 1000 live births (i.e. 1.35 million new-borns each year with CHD) (Simeone et al., 2018; Tankeu et al., 2017; Zühlke, 2013), however these figures tend to vary worldwide.

In Africa, CHD was the second most common cardiovascular disease responsible for mortality and morbidity amongst young Africans (Tankeu et al., 2017). According to Hoosen et al. (2011) it is estimated that 11 000 children are born annually in South Africa with CHD (0.6 - 0.8/1 000 live born children have CHD) and these range from mild to critical conditions that require cardiac interventions.

Common types of congenital heart defects

In an analysis of the global prevalence of CHD in children over a 50 year period (namely, between 1970 – 2017) Liu et al. (2019) noted that there is an ongoing increase of the prevalence of CHD globally. CHD can be classified into two broad categories as either cyanotic or acyanotic (Rohit & Shrivastava, 2018; Saenz et al., 1999). Cyanotic congenital heart disease is a mixed group of abnormalities of cardiac development that result in deoxygenated blood being pumped to the body without first passing through the lungs (Renno & Johns. J.A., 2018). These defects are often referred to critical congenital heart defects. ASDs, VSDs and PDAs are categorised as acyanotic defects. These defects make up for 93.4% of the total increase in CHD (Liu et al., 2019). Together with TOF the table below (Table 1) provides a summary description of these four types of structural defects and their associated consequences. According to the CDC - Centers for Disease Control and Prevention, (2019) TOF is described as a critical congenital heart defect as it requires surgery or other procedures soon after birth. The list below is by no means exhaustive, however, it describes some of the defects pertaining to the children in this study. A detailed classification can be found in Appendix 14.

Table 1: A description of the common CHD conditions and their consequences

Atrial Septal Defect (ASD)	
Description *(Acyanotic)*(Junghare & Desurkar, 2017)*)*	Abnormal communication between the left and right atrium in the heart via a defect in the walls separating the atria. This defect causes a shunt, which can be described as a “hole” or “passage” between the left and right atrium (Thompson, 2013).
Consequence	This results in the abnormal mixing of oxygenated and deoxygenated blood which results in an increased amount of blood flowing to the lungs and heart. This increased blood volume puts pressure on the heart giving rise to right heart failure and high blood pressure in the lungs (Thompson, 2013).
Ventricular Septal Defects (VSD)	
Description *(Acyanotic)*(Junghare & Desurkar, 2017)	A VSD occurs when there is an incomplete development of the wall between the left and right ventricles known as the interventricular septum (Spicer, Hsu, Co-vu, Anderson, and Fricker, 2014), creating a large defect such as a “hole” and shunt between the ventricles.
Consequences	This defect gives rise to congestive heart failure (CHF) due to an overload of blood in the left ventricle and severe high blood pressure in the pulmonary artery (Dakkak and Olive, 2019; Mostefa-kara, Houyel, and Bonnet, 2018).
Patent Ductus Arteriosus (PDA)	
Description *(Acyanotic)*(Junghare & Desurkar, 2017)	Non-closure of the Ductus Arteriosus is termed PDA-upon birth the ductus arteriosus structure should ideally close within 72 hours (Backes et al., 2014and Dice and Bhatia, 2007).
Consequences	When the duct does not close, a large PDA can develop creating an abnormal link between the major vessel in the body known as the aorta and the major vessel of the lungs known as the pulmonary artery. This abnormal link causes excess fluid in the lungs making it difficult for the patient to breathe (Dice and Bhatia, 2007)
Tetralogy of Fallot (TOF)	
Description *(Cyanotic)*(Junghare & Desurkar, 2017)	A TOF consists of predominantly 4 abnormal conditions namely: 1. VSD (explained above) 2. Narrowing of the pulmonary valve and pulmonary artery (related to the lungs) 3. An enlarged Aortic valve- structure for controlling the upward flow of blood to the aorta and the rest of the body 4. Thickening of the wall of the right ventricle (Bailliard & Anderson, 2009; Khan et al., 2019).
Consequences	A combination of the above conditions result in what is known as cyanosis- bluish skin colour because the blood does not carry enough oxygen to the body (Bailliard & Anderson, 2009; Penny & Vick, 2011).

Note sources from: (Backes et al., 2014; Bailliard & Anderson, 2009; Dakkak & Olive, 2019; Dice & Bhatia, 2007; Khan et al., 2019; Mostefa-kara et al., 2018; Penny & Vick, 2011; Spicer et al., 2014; Thompson, 2013)

Interventions for Congenital Heart Defects

There are various intervention options for CHD that include surgical interventions (such as open heart surgery) and non-surgical techniques - such as catheter-based minimally -invasive procedures (Triedman & Newburger, 2016). Surgical interventions are now being replaced with more technologically advanced catheter - based procedures (Farooqi et al., 2019). The latter is the preferred choice of treatment for defects that are receptive to repair using the various interventional devices available (Rao, 2019). For example, in a study by Melekoglu & Baspinar (2019) conducted in Turkey at a single centre amongst 46 neonates, the authors reported that catheter-based interventions applied during the neonatal period were a promising alternative that could be utilised for new-borns that are underweight preoperatively and at the time are unsuitable candidates for surgery. This study also stated that catheter-based interventions were a viable option in developing countries, like Turkey, where surgical outcomes are poor with limited surgical centres for CHD patients (Melekoglu & Baspinar, 2019). In another study also conducted in Turkey, Odemis et al. (2013) found that the catheter-based interventions reduced the hospital stay for the 15 patients that were part of the study and they were also associated with less scarring on the patient thus making them the more desirable choice of intervention. Thus, the technical advancements and the favourability of catheter- based interventions results in increasing survival rates for CHD patients has thus been noted as a viable option of intervention (Almesned, Al-Akhfash, & Al Mesned, 2013). Notwithstanding the above, trans-catheter procedures may be the preferred option for some defects and surgery may remain the better option for other defects (Rao, 2019).

Decisions about an intervention and the process of hospital discharge

Within the provincial South African tertiary hospital setting in which this study has been undertaken, the Paediatric Cardiology Domain, decisions around an intervention are based on a number of medical factors such as the type and size of the congenital heart defect, the availability of appropriate repair devices, the child's weight at the time of the proposed intervention as well as the medical condition of the child. It is common practice within this setting for children to be either offered a catheter-based intervention or surgical interventions, based on the team's assessment (E. Hoosen, personal communication, June 01, 2019). In both these instances, the patient is hospitalised in the hospital's paediatric ward prior to one of these procedures. After the intervention the child is transferred back to the paediatric ward or in some instances to the hospital's paediatric intensive care unit (ICU).

Whilst the child is in ICU, the primary caregiver is permitted to stay near the child but is not tasked with participating in conducting any medical care for the child. Upon good progress and recovery, the child re-enters the paediatric ward and their primary caregiver is now allowed close contact with the child and actively participates in taking care of their child. This would encompass being able to hold their child after the procedure, feeding their child, as well as administering oral medication under the supervision of the paediatric nurse.

Approximately a week after an intervention children are discharged from the hospital. The transition from hospital-based to home-based care, where the primary caregiver(s) is now responsible for closely monitoring the child, is managed by providing the primary caregiver with basic information and medical supplies as they transition to home. A follow-up appointment with the Paediatric Cardiology Clinic is scheduled for approximately 6 weeks post discharge. As the Head of the Paediatric Cardiology Domain and the team have noted, being responsible for providing post-operative care to a young child in the home environment has the potential to create significant stress for the parents and/or primary caregiver of the paediatric patients (E. Hoosen, personal communication, June 01, 2019).

In addition, Schuh et al. (2016), found that whilst a number of parents in their study of children with CHD (mainly VSDs, ASDs and co-arctations) felt ready for discharge, the study also found that parents required more readiness for administering medication, preparing them for anticipated emotions and more importantly guiding them to services that are available to them in the community.

1.2. The research problem: the primary caregivers[a] experience

Although globally accepted that parents are the primary caregivers of children, this may differ within the South African context. According to Mkhwanazi et al. (2018), in resource constrained settings, parents may seek jobs away from their homes leaving the children in the care of the elderly. In addition, the demise and illnesses of the working class adults from HIV AIDS from previous decades, also meant that children are often cared for by their grandparents or other extended family members (Mkhwanazi et al., 2018). However, in this study all primary caregivers were the biological mothers of the children.

The journey of a primary caregiver and their response to the diagnosis at the onset of witnessing the symptoms, accepting the diagnosis as well as post-cardiac intervention, has been described as a roller-coaster of emotions between feeling sad and optimistic about their child with CHD (Smith, 2017).

The varying outward symptoms at the time of diagnosis, understandably, are of great concern to primary caregivers. For example, in a study in the United States amongst 362 parents - 58% of which were mothers - of a child with a CHD, found that from the time that parents observed such symptoms, followed by the diagnosis and even after undergoing an intervention, parents (especially mothers) experienced a variety of mental health challenges which impacted on the care of their child (Kolaitis, Meentken, & Utens, 2017).

Whilst the technical advancements have resulted in increased CHD survival rates, globally it has also meant that an increasing number of parents and/or caregivers are now having to take more responsibility of a child following a cardiac intervention (Almesned, Al-Akhfash, & Al Mesned, 2013). In relation to this, a number of international studies have reported that parents and families experience a range of financial, social and psychological challenges after their child has undergone a cardiac intervention (Lazar & Hylarides, 2017; Uzark & Jones, 2003; Wei et al., 2016). According to Hoosen, Cilliers, Brown & Lawrenson (2011), of the 11 000 children born annually with CHD in South Africa, approximately 3 000 do not survive

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[a] In this study the term **primary caregiver** refers to the parent or person, for example, the grandparent, aunt or older sibling, who has the greatest responsibility for the daily care and support of the child.

and if they survive, they continue to experience disabilities due to CHD. The majority of children born with CHD in this country thus require on-going support – something which understandably is left to their parent(s) and/or guardian to provide.

In South Africa, little has been documented about the experiences of the primary caregivers as they care for their child post a cardiac surgical or catheter-based intervention within the context of their home environment. According to Nousi & Christou (2010) a number of factors affect the quality of life of the child with CHD as they grow in age. These range from the change in their body image, anxiety and depression, lack of social acceptance, impaired school performance, and decreased physical activities to socio-economic and educational status of the family as well as the parents' personalities that guide the parental styles impacting on the health and well-being of the child with CHD.

To date, known to the researcher, there has only been two studies conducted in South Africa regarding parents' experiences with child with CHD. The one study conducted in the country looked at parental stress amongst parents who had a child that underwent a cardiac intervention (Smith et al., 2017). The study – conducted in Bloemfontein, a city in Free State province in South Africa - found that the parents experienced high levels of stress immediately after their child underwent a cardiac intervention with a number of the parents continuing to experience high levels of stress while taking care of their child post cardiac intervention (Smith et al., 2017; Smith, 2017).
The second study conducted in the Western Cape, South Africa, amongst parents from the informal settlements reported on the ability of the medical staff to maintain communication with parents over a 5-year period. Researchers reported that off the 10 families recruited, they were able to maintain contact with 7 families during the 5-year recovery period. The researchers indicated that effective communication was compromised due to children presenting from poor communities thereby rendering them vulnerable during the recovery period (Vivian et al., 2018). Authors indicated that poor roads, presence of violence within the location of the families and poor circumstances in townships made it difficult to maintain contact with parent or parents to make contact with the healthcare provider. A further article that was published, stemming from the same study, described how parents navigated various uncertainties about their understanding of what was wrong with their child and in what way the medical team will attempt to correct their child's heart condition. This was documented

during multiple phases of their child's cardiac journey- at the onset of the diagnosis, after the first diagnosis as well as the time of signing consent for the surgical procedures (Vivian et al., 2021). The study revealed that despite not fully understanding the rationale for the interventions, parents still signed consent largely due to how doctors explained the decision-making process of what was best for their child.

In the midst of these emotions, primary caregivers have to immediately develop appropriate skills in taking care of their child in order to meet with their child's special requirements. Nursing the wound, administering appropriate drugs, offering nutritious meals, providing physical and mental stimulation and paying close attention to any unwanted complications are amongst the many responsibilities of the caregiver looking after a child with a CHD (Poudel & Malla, 2017). Interestingly, in South Africa, where the prevalence of the various types of CHDs is similar to the global prevalence, little is known about a primary caregiver's experiences when taking care of their child post a cardiac intervention.

1.3.The study setting

The setting for this research study is at the Inkosi Albert Luthuli Central Hospital (IALCH), Durban, South Africa. This hospital services the entire KwaZulu-Natal (KZN) area and the OR Tambo district from the Eastern Cape (Hoosen et al., 2010). Kwa-Zulu Natal, the site of this proposed study, is the second most populated province and makes up 19.9 % of the total population in South Africa. In economic terms 64.5% of the population is not economically active and almost half (44.8%) of the province's households are categorized as lower income households (Kwa-Zulu Natal Provincial Government, 2016). Eighty two percent (82%) of the citizens of the province depend on public health care (Statistical South Africa, 2017). At present IALCH is the only public sector referral hospital offering Paediatric cardiology and cardiothoracic services within the province of KZN, Durban and attends to approximately 300 CHD patients per year (Hoosen, Sprenger, Dama, Nzimela & Adhikari, 2016). The CHD patients are managed by a cardiac team within this tertiary level setting (Hoosen et al., 2010). The team members include the following: cardiologists, cardiothoracic surgeons, anesthetists, intensivists, cardiac technologists, perfusionists, nurses, social workers and physiotherapists (Hoosen et al., 2010b).

The researcher was also previously employed at the hospital and performed radiographic tasks at the Paediatric Catheterisation (Cath) Lab. This was for a duration of approximately 5 years between October 2014 and January 2019 and was regularly involved in first hand implementation of paediatric interventions within the Cath Lab. This setting is ideal for the intended research as it is the only public hospital for CHD patients and parents in KZN.

The CHD patients at Inkosi Albert Luthuli Central Hospital (IALCH) are managed by a cardiac team at the tertiary level hospital (Hoosen et al., 2010), however when the child is discharged from IALCH the primary caregiver is left with the responsibility of ensuring the successful recovery of the child post-cardiac intervention – a significant responsibility that they are likely to have to bear alone.

Despite the cardiac team at IALCH having in place a record of the basic socio-economic and family/ household status of each CHD patient, the nature, extent and impact of the logistical and psychosocial challenges experienced by the primary caregiver in taking care of their child post-cardiac intervention is not well understood by the team. There is a concern within the team that their gap in understanding the caregiver's lived experience (once their child is discharged from IALCH and is back in their community) does not allow them to provide the quality of care and support that their patients and their families might realistically require during the recovery period post-cardiac intervention. Whilst they are provided at discharge with medical supplies (such as pain and inflammatory drugs, dressings for surgical wounds) and some basic information on how to support their child medically, the next contact that a primary caregiver has with members of the cardiac team is only 6 weeks later at the patient's routine follow-up visit to the hospital.

In order to make available appropriate multidisciplinary care, it is important to obtain an enhanced understanding of the psychosocial challenges of children and their parents or primary caregivers (Kaugars et al., 2018). As Hoosen et al. (2010b:11) – the Head Paediatric Cardiology Consultant at IALCH, has noted:

> *"…there is difficulty in the ability to quantify the physical and mental suffering of patients and their families as well as the economic burden that frequent hospital visits and absenteeism places on them".*

In a study by Harvey et al. (2018), the journal records of the experiences post 1 year cardiac intervention of eight mothers of children with CHD were studied and it was reported that in-depth understanding of the experiences of mothers can be useful to nurses and physicians in developing appropriate support for families.

Furthermore, in line with the suggestion made by Wei et al. (2016:23), that it is "…only when healthcare providers understand parents' experiences and care needs will they be able to formulate and implement appropriate interventions", this study aims to explore and describe the range of personal, financial and familial experiences of primary caregivers as they look after a child post a cardiac intervention.

1.4. Introduction to the research design and methodology of the study

This descriptive study used a qualitative research methods approach. A descriptive and explorative qualitative approach was suitable as the aim was to try to elicit and understand the experiences of primary caregivers of children post-cardiac intervention. A qualitative approach permitted, the researcher, as proposed in this study, to understand what this experience meant in the financial, social and environmental context of each primary care giver as well as the relationships in the family system, providing a rich contextual description of the experiences (Sofaer, 1999). The methodological aspects of the study have been further detailed in Chapter 3.

1.5. An outline of the report

The report of the study comprises of six chapters as follows:
Chapter 1 introduces the research problem, the study setting and the purpose of the study. Chapter 2 reviews the literature relevant to the aims and objectives of the study and the context in which the study was implemented. Chapter 3 describes the research methodology used and considers the ethical considerations and the limitations of the study. Chapter 4 presents an analysis of the study data. Chapter 5 discusses the results of the study in the context of the study setting and literature. Lastly, Chapter 6 summarises the key findings of the thesis and suggests recommendations based on the findings.

CHAPTER 2: THE LITERATURE REVIEW

2.1. Congenital heart defects: The burden of disease

Globally, CHD is one of the major causes of infant mortality, especially in developing countries like South Africa (Amakali & Small, 2013; Jivanji et al., 2019; Tankeu et al., 2017). It is noted that there is a global prevalence of 8 cases per 1000 live births (i.e. 1.35 million new-borns each year with CHD) (Simeone et al., 2018; Tankeu et al., 2017; Zühlke, 2013), however these figures tend to vary worldwide. According to Jivanji, Qureshi, Reel, & Lubega (2019) of the 1.35 million children born with CHD, a significant percent (90%) of these children are found in Low to Middle Income Countries, more so in sub Saharan Africa. According to Edwin et al. (2017) there is an estimated total annual CHD birth prevalence of 300,486 cases amongst the 54 countries in Africa.

Even with advances in diagnostic and medical interventions, congenital heart diseases account for 3% of all infant deaths and account for 46% of deaths from congenital malformations in developed countries such as the United States of America (Tankeu et al., 2017; Wei et al., 2015). Wei et al. (2015) note that CHD birth defects result in lengthy in-hospital stays, understandably high overall hospital expenditure and a significant mortality in children.

In Africa, CHD was the second most common cardiovascular disease responsible for mortality and morbidity amongst young Africans (Tankeu et al., 2017). According to Hoosen et al., (2011) it is estimated that 11 000 children are born annually in South Africa with CHD (0.6 - 0.8/1 000 live born children have CHD). Furthermore, approximately 4 500 of these require surgical intervention. With appropriate care, the prognosis for most of these 4 500 children is excellent, with at least 85% expected to survive to adulthood (Hoosen et al., 2011).

However, according to Hewitson & Zilla (2018) a number of factors within the South African context contribute to high mortality of children with CHD. These range from children presenting at a late stage to the hospitals- often due to family situations where there is lack of transport to visit the hospitals, a loss of income as a result of missing days of work as well as poor health of caregivers as a result of poverty. Furthermore, service provider challenges within the public hospital context include a health care system that is under-funded and thus prompt referral to tertiary centres are compromised, but more importantly very few tertiary centres are available whilst base hospitals are understaffed and ill prepared to manage children with CHD (Hewitson & Zilla, 2018). In addition, other economic inequalities and a high unemployment rate (27% for people in the age group < 35yrs) are underlying factors that have contributed to high mortality rates in children with CHD.

Nonetheless, with improved surgical and medical interventions, the spotlight in more recent years has increasingly fallen on longer-term outcomes and challenges of a child with CHD, including growth, development, health-related quality of life as well as the psychosocial experiences of both the child and family – rather than focusing purely on the matter of survival (Baker, 2008; Eagleson, Justo, Ware, Johnson, & Boyle, 2013; B. Marino, 2013; B. S. Marino et al., 2012; B. Marino, Uzark, Ittenbach, & Drotar, 2010).

2.2. A description related local research

To date, only two studies were found that relate to the experiences of CHD in children and parents of children with CHD and that have been conducted in South Africa. The first study, a study by Smith et al. (2017), looked at parental stress amongst 22 participants who had a child that underwent a cardiac intervention. The study – conducted in Bloemfontein, a city in Free State province in South Africa - found that the parents experienced high levels of stress immediately after their child underwent a cardiac intervention with a number of the parents continuing to experience high levels of stress while taking care of their child post a cardiac intervention (Smith et al., 2017 & Smith, 2017). Primary caregivers in this study were predominantly mothers (97.5%) and the ethnicity of majority of the participants was Black (75%). The average education level of the mothers ranged from between Grade 9 to Grade 11. The majority (83%)of the mothers were unemployed and the majority of the unemployed mothers stayed at home in order to take care of their child. This study also stated that the burden of care relating to unemployment, low socio-economic status, low levels of education and a lack of social support may contribute to parental stress (Smith et al.,2017).

Another study by Vivian, Comitis, Naidu, Hunter, & Lawrenson (2018), conducted between 2011 – 2016 with 10 children and their parents attending the Red Cross War Memorial Children's Hospital in Cape Town, Western Cape Province. The study specifically focused on their experiences of the cardiac surgery and the subsequent follow up care offered by the hospital. Conducted in two phases, the first phase explored the experiences of the 10 children and their parents at the time of admission for the cardiac surgery procedure, with the second phase focusing on their experiences of the recovery period over the next 5 years. Of the 10 families recruited, the researchers were able to maintain contact with 7 families during the course of the study. A total of 3 interviews were conducted with these families in both in a clinical and their home setting. In addition, focus groups were held with parents and (separately) with key clinical staff from the cardiology and intensive care departments.

The study noted that in 9 of 10 cases the main carer was the biological mother, with one child being cared for by their grandmother. The study also noted that all but two of the participants came from "more socially disadvantaged areas in Cape Town where many continue to suffer the disadvantages brought in by apartheid, relied on public transport, lived in small brick houses, or in one case a wooden shed, and visited government-run hospitals" (Vivian, Comitis, Naidu, Hunter, & Lawrenson, 2018: 325).

A second article from the same study was published during the year 2020 (Vivian et al., 2021). Findings in this article revealed the difficulty that parents had in understanding the medical terminology and scientific knowledge of their child's condition. However, despite this difficulty parents signed consent for their child's cardiac interventional procedures. Furthermore, researchers described the highly emotional state of parents during the time of surgery. In addition, socioeconomic challenges amongst parents in this study-like community disempowerment, poor education, ethnic and communication challenges as well as poverty-increased parental stress during the hospital phase, caring for their sick child as well as the long term follow- up journey.

2.3. The challenges primary caregivers experience with a Child with CHD

The above two local studies, along with related international studies, all highlight how parents of children with CHD experience a variety of challenges in coming to terms with their child's diagnosis as well as caring for their child post-cardiac intervention. These challenges tend to fall into various themes, namely, financial challenges, the relationship challenges that arose within a family as a result of the child's illness, as well as emotional and psychological challenges for the primary caregivers themselves.

2.3.1. The financial challenges of primary caregivers

Thus, whilst the studies by Smith (2017) & Vivian et al., (2018) have highlighted socioeconomic stressors associated with low socioeconomic status (SES), low levels of maternal education and unemployment as challenges for families, little is known about how exactly these financial stressors impact on primary caregivers of young children living with CHD in South Africa (Smith et al., 2017). A study in South African by Botha, F (2010) that explored the relationship between low SES and levels of education found a negative relationship between poor people and education attainment. A lower level of education attained gives rise to more significant poverty.
According to Connor, Kline, Mott, Harris, & Jenkins, (2010) in a study conducted in Massachusetts, USA, parents of children who had undergone heart surgery reported a financial burden immediately after bringing their child home. The study included parents who were described as having a low to middle level of income which was approximated by the Hollingshead Four factor Index Scale[b]. Parents reported that this financial burden included having to pay out of pocket expenses for things like medication and prescribed infant formula milk – items they described as being unplanned for and which they experienced as being stressful to accommodate within their budget. In addition, some families reported a loss of income as a result of a mother quitting her job to take on the care requirements of her child post-cardiac intervention (Connor et al., 2010).

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[b] The Hollingshead Four Factor Index of Socioeconomic Status is a survey designed to measure social status of an individual based on four domains: marital status, retired/employed status, educational attainment, and occupational prestige (Hollingshead, 1975).

In India, in a similar resource-constrained setting like South Africa, Raj et al. (2015) conducted a qualitative study with the parents and family members of 644 children who had undergone surgery related to a CHD. The study aimed, from a family perspective, to describe the direct and indirect costs associated with their experience of a congenital heart surgery intervention and what impact this had had on each household.

The authors, in conducting interviews with family members at the time of the surgical intervention, immediately after the surgical intervention, and then again 6 months later, found that parents of children with CHD faced financial difficulties *during* the surgical period as well as *immediately after* the cardiac intervention period (Raj et al., 2015). At the time of surgery, (n=644 families), only 75 (11.6%) of families were able to afford the surgical expenses without any external aid.

Bearing in mind that only 25 (3.9%) of the families had access to medical cover, the vast majority of the families had to resort to, for example, borrowing from neighbours and taking out loans in order to meet the required cost of the surgical intervention. This accrued debt then had an impact on the family's finances after the surgery with parents reporting that they had to take out further loans and/or mortgage or sell their valuable possessions in order to meet the additional costs of taking care of their child with CHD - as well as paying off the debts incurred from the surgical procedures (Raj et al., 2015).

The 6-month follow-up interviews (n= 557 families only- many did not participate in the follow up interviews) revealed that among the 557 families assessed during this time, 290 (52.1%) of the families reported that they had borrowed money *after* the child's hospital discharge in order to meet the additional treatment expenses, to take care of the child and/or to repay the earlier loan or debt. When they were unable to meet the repayment plans of these loans they had taken out, this led to further stress and strain (Raj et al., 2015).

Other costs associated with caring for a sick family member, like transport to the health services and buying specific food related to a cardiac diet have also been reported to be associated with children with CHD post a cardiac intervention in the rural areas of Namibia (Amakali & Small, 2013). This Namibian study by Amakali & Small (2013) also resonates with the Indian study conducted by Raj et al. (2015) where parents resorted to borrowing money in order to meet the transport requirements for their follow-up appointments. Access to specialised health care for children is free at the tertiary level in the public health service in Namibia but parents will still have to find the money to meet the travel costs to get to the hospital. As a result, Amakali & Small (2013) noted that parents sometimes missed their follow up appointment due to their financial constraints.

Similarly, in a quantitative study using a survey conducted amongst 55 families conducted by Gerber et al. (2010) in Germany it was found that the largest non-medical and indirect medical expenses for families was the overall loss of the parent's income, the cost of their travelling expenses to access medical care and the cost of providing alternate child-care arrangements for the siblings of the child with CHD (Gerber et al., 2010). Parents reported that they lost their jobs due to the care needs of the child with CHD in the first year post a cardiac intervention.

Furthermore, Mughal et al. (2011), in a study involving interviews with parents from a range of SES (low SES- 27%, middle SES- 66.4% and high SES- 6.6%) in Lahore, Pakistan, reported that almost 50% of the 211 families interviewed reported that parents had to take leave without pay or lose their job or business in order to pay for hospital expenses. Parents of children with birth defects may also have to give up their job because their employers may not be willing to grant the time off needed to take care of their child. This phenomenon has been described by Lemacks, Fowles, Mateus, & Thomas (2013) in a study in the United States that reported the insights of parents with children with birth defects. Parents revealed that their employers were not always receptive to the need to take time off from work to attend ongoing follow-up visits and thus sometimes parents lost or changed their jobs in order to attend follow-up appointments for the child with CHD. Another meta-analysis study by Pelentsov, Laws, & Esterman (2015) that focused on the supportive care needs of parents with children with rare diseases, such as birth defects, found that often mothers lost their jobs as a result of unfavourable working arrangements where mothers were not able to take time off for the care needs of child with CHD and as a result had quit or lost their jobs in the process.

The negative impact that caring for a child with CHD has on the employment or income generation of one or both parents is evident from the above mentioned studies. In part this points to a lack of understanding by some employers who are not aware of the needs of children with CHD and how the parents are required to visit doctors regularly (and during normal working hours) and how significant the impact of caring for a child with CHD is in terms of additional time, responsibilities and resources. The lack of responsiveness of the workplace often results in only one parent working, significantly reducing the income within the household and creating financial strain on the employed spouse to meet with the financial needs of the home (Lemacks et al., 2013).

The burden of having to accommodate additional costs as a result of a child with CHD, is not obviously limited to material resources. For example, a study by Connor et al., (2010), in the state of Massachusetts, United States, described the meaning of cost when taking care of a child with CHD. Off the 20 families interviewed (12 paired and 8 single parents), many of whom were from a low to middle socioeconomic status group, described how the burden of cost went *beyond* a monetary value and also included their emotional well-being. Parents in the study described that there was a constant presence of emotional uncertainty based on the survival of their child with CHD. Parents described their emotions as an “emotional roller-coaster” from the time of diagnosis, prognosis and during the recovery period (Connor et al., 2010).

2.3.2. The familial and relationship challenges of primary caregivers

In addition to the financial burden that is placed on families looking after a child with CHD, there are also social and familial challenges associated with taking care of a child with CHD. The adverse impact of children’s illness on parents can be expressed in terms of a series of losses: the loss of financial security, the loss of and constraints on their social life, a reduction in time spent with other family members as well as the presence of significant distress or strain (Almesned et al., 2013).

According to a study by Mughal et al. (2011), Lahore, Pakistan, amongst 211 and their families, the financial stress of parents also impacted on the physical and mental health of siblings which affected their schooling and their wellbeing (22.7% and 26.1% respectively). For example, travelling to and from hospital for appointments – especially if living in a rural area - might necessitate that family members are separated as found in a qualitative study amongst 28 families (90 % of primary caregivers married) in North Carolina, USA (Janice et al., 2003). Families viewed the separation as disruptive to the family routines and the fathers specifically, who were for the most part the parent left at home, struggled with running the home. Furthermore, siblings were emotional about not having their mothers at home with them. This created feelings of guilt and uneasiness for the mothers accompanying the child to the hospital (Janice et al., 2003).

In relation to the impact CHD has on other siblings, Almesned et al. (2013), suggests that upon returning home from a hospitalization the attention given to the child with CHD might mean that other siblings feel they receive less attention. An explorative study conducted in Massachusetts, USA amongst 20 families (12 couples and 8 single parents), found that the siblings of children with CHD - post-cardiac intervention, had decreased their school and social activities in order to reduce the risk of bringing home viral or bacterial illnesses to the affected child (Connor et al., 2010).

In addition, a review of parent's insights into the care of a child with birth defects by Lemacks et al. (2013), reported that siblings tended to experience the impact of a diagnosis of a birth defect, like CHD, negatively. The authors reported that whilst parents felt guilty for not spending adequate time with the sibling(s) of the child with CHD, the siblings felt resentful and neglected (Lemacks et al., 2013). These findings were similar to the meta-analysis review conducted by Parker, Houghton, Bichard, & Mckeever, (2020), where it was reported that parents of children with CHD, reported that siblings sometimes felt jealous, resentful and insecure. Similarly, a study by Azhar, Al Shammasi & Higgi (2016), amongst 180 primary caregivers in Jeddah, Kingdom of Saudi Arabia reported that 32.8% of the caregivers noted that siblings felt jealous towards their sick brother/sister and 19.4% felt neglected by their parents due to their ill sibling. As Mughal et al. (2011) note, caring for a sick child with CHD inevitably affects the other children in the family. These difficulties might well be exacerbated in resource-constrained settings when it becomes increasingly difficult for parents to run a household and make ends meet in the presence of a child with CHD.

The impact of a child with CHD is, however, not all negative. A survey conducted in the United Kingdom by Wray & Maynard (2005) with 209 families who had a child living with a CHD, 43% of the families interviewed experienced a feeling of 'togetherness', with only a small percentage (8%) suggesting that they felt as though their families were ‘heading for separate paths’. According to the study, almost half the children with CHD had other health related problems in conjunction with CHD. The study revealed that the children with other health related problems were associated with greater levels of sibling jealousy due to primary caregivers increased time spent with ill child (J. Wray & Maynard, 2005).

Caring for a vulnerable or sick child can obviously also impact on the relationship between parents or partners. A Canadian study involving the experiences of 40 families, reported the dissolution of six marriages after the surgical intervention of a child with CHD (Finley et al., 1979). This was in keeping with the study findings reported by Lemacks et al. (2013), where parents with children who had birth defects experienced a high divorce rate. Mughal et al. (2011), also reported that of the 211 families they interviewed with a child who had CHD, 97.3 % (n= 206) parents experienced insomnia, anxiety, tension and uncertainty about the outcome of a defect like CHD.

In a study by Lemacks et al. (2013), that explored the insights of parents of children with birth defects reported that whilst mothers, most often the primary caregivers, may feel inundated with taking care of their child, fathers felt hopeless and defeated in their role as primary protector of their child and family. Furthermore, a study amongst 48 fathers of children with chronic illness like CHD, in the United States by Hovey (2005), found that fathers felt isolated and were in conflict with wanting to be physically present with their ill child and maintaining their employment in order to satisfy the financial needs of the family.

Other factors like decreased social interaction and burden of care for a child with CHD may also contribute to the psychosocial wellbeing of both the primary care giver and other family members. According to Smith et al. (2017), primary caregivers experienced decreased social interaction in their life due to the amount of time spent caring for their sick child. This decreased social interaction coupled with financial constraints has the potential to materialise into long term psychosocial issues (Smith et al., 2017).

The impact of an illness or disease such as CHD within a family can also affect the sex life of the parents of the child with CHD due to a lack of time they have to spend with each other (Golics et al., 2013), and the added stress they have to manage. Thus, relationship difficulties between a couple – or the parents of a child with CHD may require a referral for marital counselling to assist the parents individually and as a couple (Leon et al., 2013).

In a study by Berant et al. (2003) which explored the marital relations of 85 mothers residing in a central urban area of Israel and who had been married from between 1 and 7 years, found that there was significant marital dissatisfaction during the infant's first year of life. However, the study noted that the level of marital dissatisfaction was dependent on a variety of different factors: the severity of the infant's CHD, the nature of the mother's relationship with the child, and the way in which she managed tasks related to motherhood and her level of general anxiety.

Understandably the multiple sources and layers of stress faced by the primary caregivers of a child living with CHD will likely have a negative effect on their coping mechanisms, with increasing levels of stress impacting negatively on their ability to cope with the various responsibilities they face in caring and supporting their child with CHD. Ultimately this is likely to impact on the care of their child with CHD as well as the care of other siblings within the family unit (Singh & Ghimire 2017).

2.3.3. The psychosocial challenges of primary caregivers

According to a review of the mental health problems in parents of children with CHD living in the United States, stress and fear amongst parents relating to parents who have to face overwhelming emotions at the time of diagnosis and also extra physical, financial, and other practical challenges post-cardiac intervention, make them vulnerable to acute stress disorder (ASD) as well as post-traumatic stress disorder (PTSD) (Kolaitis et al., 2017). Primary caregivers also experience a significant amount of guilt and blame themselves for their child's CHD condition which can push them into depression (Lemacks et al., 2013).

A study conducted at a central cardiac hospital in the city of Melbourne, Australia that measured the trauma symptoms of 77 mothers and 55 fathers of infants - one month after cardiac surgery - found that 33.8% of mothers and 18.2 % of fathers had ASD (Franich-ray et al., 2013). Whilst a study by Farley et al. (2007) amongst parents of 52 paediatric heart transplant recipients – explored a slightly different but related health issue, the authors found that approximately 40% of parents experienced fairly significant to significant post-traumatic stress symptoms. Parents specifically reported experiencing considerable levels of stress when communicating about the child's illness, their emotional distress, coping with the child's medical care, and balancing the various roles they had to manage.

An increase in stress levels of a caregiver is, understandably, likely to have an impact on a parent and/or caregiver's capacity to care for a sick child. In Iran, a study by Sabzevari, Nematollahi, Mirzaei, & Ravari (2016) conducted interviews with 18 primary caregivers - 17 of which were the mothers and 1 the father of a child with CHD. In this study the authors suggested that the mental state of the primary caregiver has an impact on their delivery of care in relation to the child. For example, some mothers in this study felt alone and isolated during the care process and showed increasing concern for the future of their child with CHD and this in turn negatively impacted on how they took care of their child due to ongoing fears for the future of their child. In some cases, prior to a diagnosis, the mothers dreamt of the type of education and careers their child would obtain and upon diagnosis they all but gave up in dreaming of the possible achievements of their ill child (Sabzevari et al., 2016).

Similarly, a phenomenological study by Amakali & Small (2013) involving five (5) primary care givers in Namibia, reported that parents also expressed anxiety that the child with CHD will experience delays in their educational milestones. This emerged as a result of their fears of the child's inability to attend school or complete school due to their ill health and having to attend regular hospital visits which could give rise to social isolation as a result of their poor health and falling behind in their education (Amakali & Small, 2013).

A study conducted by Simeone et al. (2018) in Naples and Masses, where 24 primary caregivers were interviewed (75% of which were women), described their lived experience post a cardiac surgery for CHD, stated that whilst most felt a feeling of joy and relief upon returning home, feelings of uncertainty, fear and loneliness surfaced soon thereafter due to the unanticipated sudden lack of support from the hospital and the cardiac team. This further materialised into chronic psychological fatigue (Simeone et al., 2018).

A study conducted in Sweden by Lawoko & Soares (2006), where 632 participants (58% of which were mothers) were caring for an infant with CHD, found that parents who reported long-standing difficulties with living expenses or were experiencing increasing difficulties with living expenses as a result of an infant with CHD, were two to three times more likely to experience psychiatric stress including depression, somatization and suicidal thoughts.

Thus, the mental well-being of primary care givers, many of whom are mothers, has a far reaching impact on the psychosocial wellbeing of children with CHD - more often than the severity of the illness itself (Casey et al., 2010; Stephen Lawoko & Soares, 2006; McCuske et al., 2012).

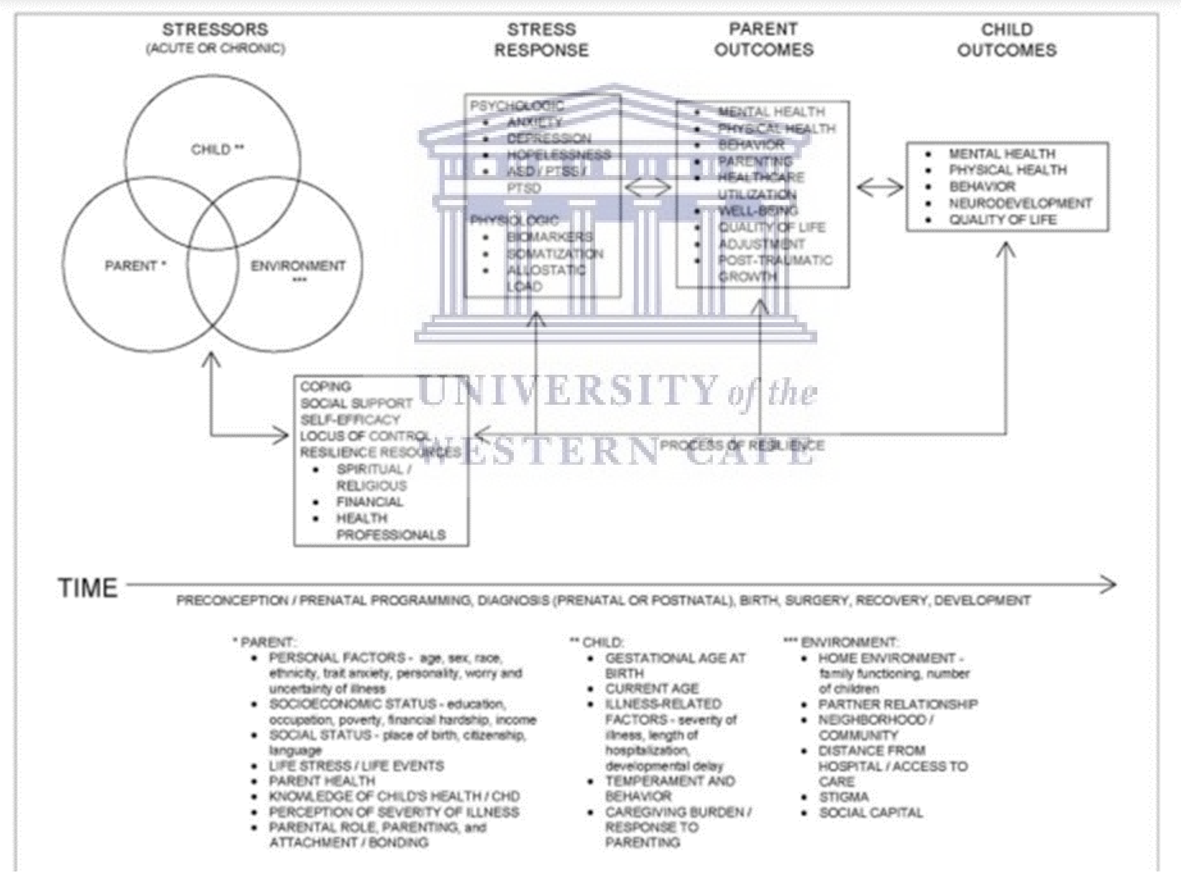
In summary, it is clear that the limitations that are placed on the primary caregiver's daily life, such as the reduced time they have to engage with significant others and other family members, and the heightened personal distress or strain that they might experience in taking care of their child, impacts negatively on primary caregivers and families of a child with CHD post a cardiac intervention (Almesned et al., 2013). This has been illustrated by a number of studies conducted in United States, India, Namibia, Pakistan, Germany, Kingdom of Saudi Arabia, Sweden, Iran and South Africa (Almesned et al., 2013; Amakali & Small, 2013; Connor et al., 2010; Gerber et al., 2010; S Lawoko & Soares, 2003; Mughal et al., 2011; Raj et al., 2015; Sabzevari et al., 2016; R Smith et al., 2017; Robyn Smith, 2017; L. Vivian et al., 2018).

Only two of these studies were conducted in South Africa, namely the effect of cardiac surgery in young children with congenital heart disease on parenting stress (Smith et al., 2017) and a first qualitative snapshot: cardiac surgery and recovery in 10 children in the Red Cross War Memorial Children's Hospital (Vivian et al., 2018) in the Free State and Cape Town provinces respectively.

2.3.4. The Parental Stress and Resilience in CHD Model

In relation to the literature review, the evolution and factors contributing to parental stress and caring for a child with CHD, the Parental Stress and Resilience in CHD Model holds a place in understanding the framework of which parental stress can be demonstrated.

This model explains that parental stressors originate from preconception period including the surgical/ interventional period as well as the recovery and development period. The three interrelationships between parent, child and environment are all considered as stressors in parental stress. Child related factors refer to the severity of the illness, length of hospitalization, caregiving burden and temperament and behaviour of the child. The parent’s socioeconomic status and social status, any past or current life stress or life events, as well as the parent’s own health contribute to the stress faced by parents. Environmental stressors can occur from the home environment (such as family functioning and number of children) as well as the parent partner/marital relationship. Neighbourhoods or communities with violence, crime, poor resources, and pollution generate an added challenge for parents. As Lisanti (2019) notes, parents living in neighbourhoods located a far distance from a children’s hospital or who have poor access to care may also experience greater stress.



Adapted from Lisanti (2019)

Thus this study explored parents experiences bearing this model in the background.

2.4. Summary of the literature review

As can be seen from this review of literature review little is known about the nature and extent of the psychosocial, familial and financial challenges experienced by primary caregivers of CHD patients attending public health facilities in South Africa. This study has thus attempted to explore and describe such challenges with the intention of providing the Paediatric Cardiology Team (specifically within the tertiary level hospital in KwaZulu-Natal where the majority /all of public sector CHD surgeries and cardiac catheterisation interventions are performed for the KwaZulu-Natal Province and parts of the Eastern Cape Province) with a set of suggestions and recommendations of how they might be able to offer additional support to the primary care givers once their child has been discharge from hospital post a cardiac intervention.

The next chapter, Chapter 3, will describe the research design and methodology and provide details on how the research was conducted in the study context.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

This chapter describes the methodological approaches to the study and describes the research design and strategies in detail.

3.1. Aim of the study

The **aim** of the study was to explore and understand the reported experiences of primary caregivers who were taking care of a child who recently underwent a cardiac interventional procedure at a tertiary level hospital in KZN, South Africa.

3.2. Objectives of the study

The **primary objectives** of the study were:

1. To describe the sociodemographic characteristics of parents of children with CHD undergoing cardiac intervention at the IALCH and their families.
2. To explore and describe the experience of primary caregivers in caring for their child with CHD in the first 6-8 weeks' post-hospital discharge following a surgical or catheter-based cardiac intervention.

The **secondary objective** of the study was:

3. To explore the type of support services primary caregivers, need access to through the cardiac team at IALCH post-hospital discharge following their child's cardiac intervention, but before follow- up visit

3.3. Study design

Given the aim of this study was to achieve a greater understanding, from the perspective of the primary caregiver, about their experience of caring for a child with CHD is, a descriptive and explorative qualitative approach was considered to be most appropriate approach to use. According to Hammarberg et al. (2016) a qualitative approach is able to provide insight and depth about participant's experiences. Similarly, Pope and Mays (1995) have noted that qualitative research methods provide a deeper understanding of an individual's experiences.

A qualitative research approach thus permitted the researcher to gain a first-hand account of the lived experiences of the primary caregivers – from their personal perspective (Hammarberg et al., 2016). It also provided them with the opportunity to share an unrestricted account of their experiences within their context – not bound by pre-determined categories (Pope & Mays, 1995) as would be the case were a quantitative approach to have been utilized. Exploring and situating the daily experiences of the primary caregivers within their physical, material and familial context is critical given that the majority of users of the public health system in Kwa-Zulu Natal face numerous social and economic challenges (Department Of Health KZN, 2015) . A qualitative approach thus also provides one with a rich contextual description of the experiences of study participants and the meanings they attached to them (Agius, 2013; Sofaer, 1999).

3.4. Study population

The population for this study were the primary caregivers of children that underwent surgical or catheter based cardiac interventions at the IALCH, Kwa-Zulu Natal province, and who attended the first follow-up appointment of their child at the IALCH Paediatric Clinic. The Pediatric Cardiology and Pediatric Cardiac Surgery Departments in the hospital offer pediatric cardiac services and perform approximately 150-200 interventional procedures per annum for children with congenital heart disease. These services are only provided based on an appropriate referral from a regional hospital within the public health service.

A primary caregiver was defined as either the parent, family member or guardian of the child with CHD. Given that the catchment area for referral to IALCH covers the entire province of Kwa-Zulu Natal - up to the OR Tambo district in the Eastern Cape, primary caregivers are those based in any one of the districts within this area.

3.5. Sampling procedure and sample size

The study sample was selected using a purposive sampling method. Etikan (2016) notes that this sampling method permits the researcher to select participants, who are able to share information and give consent to share information, by virtue of their experience and knowledge. Furthermore, this sampling method allows for participants or group of participants who are available and willing, to share their experiences in an articulate, expressive and reflective manner (Palinkas et al., 2015).

A purposive sampling strategy also aligns with the research aims and objectives where certain type of individuals may hold different and important views about the experiences at question and thus should be included in the sample (Campbell et al., 2020). Thus the researcher selected participants bearing in mind the above criteria.

Saumure and Given (2008) describe this method as one in which study participants are selected based on the participants meeting pre-requisite criteria determined by the researcher. In this study, the pre-requisite criteria for study participants were as follows:

- Identified as the primary caregiver of the child with CHD.
- English and/or isiZulu speaking – with isiZulu being one of the indigenous languages commonly spoken amongst the sample population within the Kwa-Zulu Natal area and the OR Tambo area in the Eastern Cape.
- Being above the age of the ages of 18 years. The lower age limit of 18 years was chosen given the ethical consideration that consent for participation in a study can only be given from a primary caregiver *above* the age of 18 years old. Participants below the age of 18 are considered as minors in South Africa and would require the consent of their parents/ legal guardians in order to participate in a research study (Strode et al., 2011).
- Being the primary caregiver (either single or married/cohabiting) of a child up to 14 years of age with CHD who had undergone a cardiac intervention either surgical or catheter-based during February and May 2020.

In relation to the sampling procedure, in February 2020, the researcher approached a Senior Consultant Paediatric Cardiologist at the Paediatric Cardiology Department at IALCH to get their assistance in identifying children with CHD (i.e. neonates – children up to the age of 14 years) who were currently admitted for a surgical or catheter based intervention at the hospital. Such patients are either admitted to the hospital's intensive care unit (ICU) or a paediatric ward. Following the advice of the Senior Consultant, primary caregivers of children with CHD in the ICU were *not* approached by the researcher at this stage of their journey given the fragility of the CHD patients in ICU and the emotional strain their primary caregiver would be under at this time.

The Senior Consultant did however provide the researcher with the necessary permission to approach the accompanying primary caregivers of the CHD patients during the time that they were admitted to the paediatric ward and were awaiting either a surgical or catheter based procedure. Over a period of 6 weeks during February and March 2020, the researcher was able to meet 15 prospective study participants face to face at IALCH. Their interventions were scheduled between the middle of February 2020 until the first week in March 2020. One participant had their child with CHD rescheduled for a time towards the end of April and thus interview was conducted in June 2020. In each case, the researcher explained the purpose of the research study to the primary caregiver and invited them to consider being a participant in the study. The researcher requested the assistance of an isiZulu interpreter, such as a ward nurse or medical officer, to introduce the study to the primary caregivers who indicated isiZulu to be their preferred language of communication during the recruitment process.

Whilst verbally introducing the study to each of the 15 prospective primary caregivers, the researcher also provided each caregiver with written information about the study (See Appendix 1 and 6 for the participant information sheet in English and isiZulu respectively) and a consent form (Appendix 2 and 7) for them to review. The researcher then informed all potential participants that she would contact them again one week prior to their child's first follow up appointment after the surgery and discuss with them their decision to voluntarily participate - or not in the study. She thus explained to them that they had some time to contemplate whether they felt comfortable participating in the study or not over the next period (i.e. before their first follow-up appointment – in approximately 6 – 8 weeks' time). The researcher then requested the telephone contact details of each of the 15 primary caregivers with whom she had introduced the study to and recorded the approximate likely date of their first 6 - 8 week follow up appointment with the Paediatric Cardiology Department.

Whilst the size of a sample in qualitative research is theoretically determined at the point of data saturation (i.e. when there is little new information being shared by participants (Isaacs, 2014), for the purpose of this mini-thesis, the sample size of 8-12 participants was established as an appropriate sample size. A week prior to their child's first follow up appointment with the Cardiology team, the researcher telephonically contacted all of the 15 prospective participants who she had previously introduced the study to. Three of the 15 prospective could not be reached; they did not respond to the researcher's call, or the voice messages she left for them. Additionally, a further four of the 15 prospective participants no longer met the study criteria given their child had yet to undergo their surgical interventional. The researcher thus collected data from 8 of the 15 prospective participants.

3.6. Data collection tool

Data was collected in the form of semi-structured interviews using an interview guide (Appendix 3 with the isiZulu translation in Appendix 8). In keeping with the study objectives, the broad topics that were covered in the interview guide included demographic information about the child with CHD, members of his/her family and the household as well as specific information relating to primary caregivers' experience of taking care of the child with CHD post-cardiac surgery. The semi-structured nature of the interview format enabled the researcher to explore in greater depth the care-giver experiences of caring for their child by adding additional, probing questions - and, where appropriate, requesting for further explanations from participants.

3.7. The process of data collection

The face to face interviews with the 8 primary caregivers were originally organized to be conducted in April and May 2020 at a pre-booked consultation room at the Paediatric Outpatient Clinic at IALCH – located conveniently close to where the primary caregiver would have taken his/her child's for their first follow up visit with the Paediatric Consultant or Registrar. Practical and financial arrangements had also been made by the researcher for the child to be taken care of by another family member who was asked to accompany the primary caregiver to the appointment, so that the interview could be conducted without him/her having to take care of their child at the same time.

However, because of the increasing rise in COVID-19 cases, the implementation of a national lockdown in March 2020, and not wanting to place any further pressure on any health services or facilities during the pandemic, the University of the Western Cape immediately requested that all field-based research work be halted during this time.

It was decided that holding telephonic interviews with study participants would be the most appropriate alternative method of data collection. The researcher then awaited approval from the University to conduct interviews using either telephonic communication and/or video call communication between participant and researcher. Permission was received to use either of the above mentioned mediums and the necessary changes in data collection procedures were made to the original study protocol.

The researcher conducted an initial telephonic call to each participant requesting an appropriate day and time to conduct the interview telephonically during April through to June 2020, in keeping with 6 weeks or more post their Childs' cardiac intervention. In order to support their participation in the study the researcher purchased sufficient airtime to conduct the hour long call and when she attempted a WhatsApp video call, she also purchased data for the participants so as to ensure no cost to the participant.

At the start of the data collection process, the researcher attempted to conduct the interviews using the video call function on the WhatsApp application. This was done in part to emulate a face to face interview. Unfortunately, due to technical challenges like poor signal/Wi-Fi connections in many of the areas in which the participants lived, this method had to be abandoned at the onset of the first interview. All the 8 interviews were conducted telephonically, without any video function being used, and were all recorded with the permission of the interviewees.

Informed consent from all participants was obtained verbally prior to the commencement of the interviews. This consenting process is explained in detail later on in this chapter when ethical issues related to this study are discussed.

In relation to the need for interpretation, the first 4 interviews did not require the use of an interpreter and were thus conducted solely by the researcher. In the last 4 interviews an isiZulu interpreter (an isiZulu IT manager) assisted the researcher with the 1st of the 4 interviews. The first interpreter was physically present alongside the researcher (social distancing was practiced) whilst the researcher facilitated the telephonic interview. The need to change interpreters for the last 3 interviews occurred as a result of the first interpreter having to attend to work commitments and thus his assistance was no longer available. The second interpreter (an isiZulu lecturer at the researcher's place of employment), being in possession of a smart phone was able to conduct interpretation via a 3-way telephonic interview. A WhatsApp voice group call that included the researcher, the participant and the interpreter was set up which allowed for 3- way communication. The researcher posed the questions to the participant in English, the interpreter translated the question for the participant and thereafter the participants' responses was fed back to the researcher in English again.

Prior to the interviews both interpreters were introduced to the study and given an opportunity to review the interview guide in English and isiZulu so as to familiarize themselves with the interview process and clarify any questions they had in relation to the study, the interview guide and/or the study participants.

To protect the confidentiality of the information that was shared by the participants, all data and information obtained through the process of field work as well as transcripts was digitally stored and protected by Microsoft Word password protected file.

The researcher ensured that the identity of each participant was protected by assigning a code to each participant that was known only to the researcher – and kept elsewhere i.e. in a different, but secure, location from the data. In addition, both interpreters were informed about the importance of maintaining the confidentiality of the participants' identity as well as the data shared by the participants.

3.8. Data analysis

According to Pope, Ziebland and Mays (2000) analysis of data begins whilst its being collected. Thematic coding analysis was used, following the five steps described by Robson (2011): familiarization with the data; generation of initial codes; identification of themes; developing thematic networks; cross-examining data and exploring, understanding and demonstrating patterns (Robson, 2011). In line with this process the researcher began by reading and re-reading each transcript and re-listening to the interview recordings so as to familiarize herself with the data and writing her impressions down as she moved from transcript to transcript (Pope et al., 2000 and Robson, 2011).

Thereafter, the researcher used the NVIVO 12 pro software (QSR International, 2018) for data analysis. The researcher first downloaded the software and imported the transcripts into the software. The researcher requested the assistance of a proficient user of NVivo 12 pro software, referred to as the second coder, who also assisted the researcher in analyzing the data. She holds a PHD in Occupational Therapy and was employed as an Associate Professor OT- Chicago State University. The second coder began the process by familiarizing herself with the data from the uploaded transcripts via the NVivo 12 pro software.

The second stage involved digitally coding the data- initially by the researcher only and later by both the researcher and the second coder. This was an iterative process between both the researcher and the second coder in order to establish inter-coder consistency and descriptions of the various categories coded which, in the software, are referred to as nodes. This iterative process was facilitated by Zoom meetings and screen sharing between both the researcher and the second coder. Annotations were constructed as reminders and clarifications on issues arising out of the transcript. Memos were used to capture researcher thoughts and insights relating to emerging ideas and reflections of the transcript coding.

Once all possible codes from the data were identified, the third stage revolved around regrouping data codes according to common experiences, ideas and relationships and emerging themes were identified. Thereafter a conceptual map was developed (Appendix 13) and the interconnectedness between the various themes was plotted.

Once the thematic networks were identified, the fourth stage of cross examining data, data explorations, understanding and displaying of patterns commenced. The second coder assisted the researcher in demonstrating how to utilize the NVivo 12 pro software to action the above data queries. Data outputs included word clouds, tree maps and cluster analysis generated via the NVivo 12 pro software.

The final stage of data analysis was to inductively weave the analytical categories and explanations emerging from the data into a logical persuasive narrative taking into account the research question and objectives of the study (Pope et al., 2000). In writing the narrative, some information was quoted and presented verbatim from the sources to reinforce findings of the study. In addition, data outputs like word clouds were also used to support the findings in the study.

3.9. Trustworthiness and credibility of the study

According to Saumure and Given (2008) rigour in qualitative research can be conceptualized as quality in all steps of the research process and is generally referred to as the level of trustworthiness in a qualitative study. Furthermore, Cypress (2017:254), defined rigor as “the strength of the research design and the appropriateness of the method to answer the questions". In this study, rigour was achieved by

- an initial detailed declaration of reflexivity,
- confirmability by keeping an audit trail,
- credibility of data coding.

Firstly, in relation to reflexivity i.e. acknowledging the perceptions and the position that a researcher holds is a subjective one, and in line with Malterud (2001) the researcher made known her values, beliefs and biases that may influence the study. Before embarking on the data collection process, the researcher documented her initial opinions and beliefs on her understanding of the marital/partner status of the primary caregivers', their roles and their perception of taking care of their child with CHD post-cardiac intervention a cardiac intervention. The researchers' perception was that primary caregivers would most likely be both mother and father, married and that both would be involved in taking care of their child. Furthermore, the researcher thought that culture no longer played a key role in/ is a challenge/barrier to the involvement of fathers in taking care of the child with CHD. This exercise of sharing one's own perceptions and assumptions about the subject being studied enables both the researcher and reader to be aware of the researcher's position and thus be more mindful in ensuring that the researcher's bias will not exceedingly influence the results of the study (Creswell & Miller, 2000). In this regard, the researcher ensured that the researcher presented the information just as it was said by the primary caregivers. The researcher also recorded her reflections after each interview in her fieldwork journal.

Secondly, in relation to confirmability, which can be described as the extent to which the results match the research purpose without having been amended by researcher bias, was ensured by employing an audit trail of the qualitative study design (Korstjens & Moser, 2018; Lietz et al., 2006). There was ongoing development of an audit trail by the researcher through a reflexive fieldwork journal together with all digital recordings field notes and data analysis notes. Through the recording of such an audit trail, this ensured that the research process was well documented and clear, while also ensuring accuracy in research findings. Any changes to the data collection tool or methods, data analysis process as well as the reasons for theses change was clearly documented in the research write up.

Thirdly, in relation to the credibility of the study which can be described as maintaining consistency between the readers and participants' perspectives against the researchers' interpretations of that perspective (Jensen, 2008) was maintained by repeated reading of the transcribed data by the researcher and the checking of codes by the researcher's assistant second coder for all of the transcribed scripts (Bailey, 2008; Korstjens & Moser, 2018). In addition, the researcher met with the second coder on various occasions and coding was sometimes done together after much discussion about the transcripts and at other times the researcher and second coder annotated areas of uncertainty then reached consensus upon the next meeting. To evaluate the interpretative rigour of the analysis, the researcher implemented inter-coder agreement to control the coding accuracy and monitor inter-coder reliability among the researcher and second coder all through the analysis stage.

Given that the researcher utilized the assistance of an interpreter, the researcher ensured that the interpreter checked the transcripts to ensure correct English translation. This was done in part by the interpreter and at times with both the researcher and the interpreter.

Presenting thick rich detailed descriptions rather than only facts and analysis, offers the readers' numerous benefits; it creates an immediate familiarity bringing the reader close to the actual situation – credibility (Creswell & Miller, 2000) and also enhances credibility (Sandelowski, 1986). The assessment of literature confirms that multiple contextual elements may affect the experiences of primary caregivers in different settings; and the setting of this study has many distinctive characteristics. Thus, an effort has been made to use thick rich descriptions to demonstrate the themes emerging from the study wherever appropriate, so that the reader may be able to get a direct sense of the particular context of the findings. Though this qualitative study is not intended, by design, to arrive at generalisable conclusions, it is hoped that the use of thick rich descriptions will enable credibility and allow readers to come to their own conclusions of transferability of the findings to other settings.

3.10. Research ethics

In February 2019 ethical approval for this study was obtained from the University of Western Cape's Biomedical Research and Ethics Committee and thereafter by the Senate Research Committee of UWC before the study commenced (Appendix 12). An online application was made to the South African National Research Health Database for permission to conduct the study at the health facility, and a similar request was made to the KZN Provincial Health and Research Ethics Committee (Appendix 4). A letter was also submitted to the Hospital Manager at IALCH requesting permission to conduct the research study (Appendix 5). Once all three applications were approved (Appendix 9, 10 and 11), the necessary arrangements were made with the IALCH Hospital Manager to commence the study on site. As has been clarified earlier in this chapter, because of Covid-19, the necessary changes were made to the study protocol, re-submitted to the University of Western Cape and once approval was received from the School of Public Health, these approvals were communicated to the Paediatric Cardiology team.

Participation in the study was entirely voluntary and participants were informed that they can withdraw from the study at any point without any implications and would receive continued care irrespective of participation or not. All participants in the study were given an information sheet providing them with information about the study. This described the nature of the study, how the information they share with the researcher will be kept confidential, and how their identity will be protected in the reporting on and dissemination of the study results. This information sheet was available in English (Appendix 1) and isiZulu (Appendix 6).

A comprehensive informed consent process was intended to be carried out with all participants in the clinic room previously booked for interviews. Consent forms and information sheets were available in both English (Appendix 2) and isiZulu (Appendix 7) and these were given to the potential participants prior to the national lock down. The consent form was explained to patients in their preferred language. However, due to the COVID-19 pandemic, even though participants were in receipt of a consent form, they were not able to return these consent forms to the researcher. Thus the researcher proceeded with asking the participants for their verbal consent telephonically when conducting the telephonic interviews, and when required the interpreter assisted the researcher to obtain the verbal consent of the participant in isiZulu.

The use of both the information sheet and the consent form ensured that participants fully understood the nature and purpose of the research, and that their participation in the study was entirely voluntary. They were reassured that their decision to not participate in the study – or their decision to withdraw from the study, did not in any way negatively impact on the services and treatment that they or their child received from the hospital. Where necessary, a translator assisted the researcher in conducting interviews in isiZulu using the interview guide translated to isiZulu (Appendix 8). If participants required counseling and/or emotional support following the interview the researcher made certain to communicate with the Paediatric Cardiology Department for the services of a health professional was on hand to support them at the hospital. Prior arrangements were made with the Paediatric Cardiology Department to secure the availability of the Paediatric Cardiologist for immediate urgent counseling and thereafter, based on their assessment, follow up counseling would have been sought via the regular hospital referral system.

3.11. Limitations

The onset of the COVID-19 pandemic in South Africa and the resultant lockdown across the country coincided with the study's data collection period, originally scheduled between April through to May 2020. This necessitated the researcher to fundamentally change the way in which she engaged with participants during the course of the interviews – essentially changing the (planned) face to face interviews into telephonic interviews. This meant that the researcher lost the opportunity to record the facial expressions of the participants during the interview process which could have supplemented the participant's verbal retelling of their experiences with their child with CHD post -cardiac intervention.

In addition, given that English is the first language of the researcher, when interviewing participants who spoke isiZulu, the assistance of a translator was required. Some terms or phrases that are culturally understood by the participant and the translator were not able to be literally translated to English thereby posing a limitation in the researcher's understanding of what some of the experiences described by participants meant.

The sample size of 8 participants may not have been sufficient for what authors describe as the saturation of data (Pope et al., 2000). This may have impacted somewhat on how the researcher gained a truly in-depth understanding of the various challenges identified by primary caregivers and what they meant to participants in the different settings and circumstances living in areas served by IALCH.

This research study did not include the accounts and considerations of members of the multi-disciplinary medical team at IALCH – who, in hindsight, would have been valuable key informants to have included in this study. Their account of what they perceive to be the key experiences of the primary caregivers' post-cardiac intervention– and how this differs from the caregivers themselves, along with their description of the various counseling and social work services offered to the caregivers would have been beneficial information to include in the study. However, in presenting the results of this study to the IALCH team (as is planned in the future), this can certainly be explored further with the team.

CHAPTER 4: FINDINGS OF THE STUDY

This chapter describes the main findings of the study drawn from the semi-structured interviews conducted by the researcher between April – June 2020. A detailed profile of the 8 study participants is first provided in Section 4.1 which highlights key aspects of their demographics, their socio-economic status and their living conditions. This data helps situate the children with CHD who attend the Paediatric Cardiology department at IALCH and their primary caregivers, within a familial and socio-economic context. Thereafter, and in line with the second study objective, the various financial, familial, environmental and psychosocial factors that the primary caregivers experience whilst taking care of their child post-cardiac intervention are described. In addition, this section also captures the accounts of the primary caregivers of how they responded to and managed the initial CHD diagnosis and in particular their emotional and psychological well-being at the time of diagnosis.

4.1. Description of study participants

4.1.1. The primary caregivers and the children with CHD: demographic data

Basic demographic data from the 8 study participant interviewed is presented below.

Table 2: Demographic data

				N=8 participants				
Participant (P) (Primary Caregiver)	P1	P2	P3	P4	P5	P6	P7	P8
Age	23	23	21	23	37	32	43	25
Sex	F	F	F	F	F	F	F	F
Relationship to child with CHD	BM	BM	BM	BM	BM	BM	BM	BM
Marital status(Primary Caregiver)	Married living with husband	Single living with partner	Single living with partner*	Single not living with partner	Married living with husband	Single no partner	Single no partner	Single living with partner
Race	I	B	B	B	B	B	B	B
Religion	H	C	C	C	C	C	C	C
Education Level	Grade 10	Grade 12	Grade 11	Grade 12	Grade 11	Grade 11	Grade 11	Grade 11
Child with CHD								
Age	10m	15m	8m	3yrs	7m	1yr	9yrs	8m
Sex	F	F	M	F	M	F	F	F
Diagnosis	TGA &PDA	TA	PDA	VSD	PDA and VSD	TOF /VSD	Congenital Heart Block	Situs Solitus Non-obstructed Cardiac TAPVC
Intervention	Senning Procedure &PDA Ligation	Truncus Arterious Repair	PDA Ligation	VSD Closure Surgical	Transcatheter Closure	Corrective Surgery and VSD Closure	Pacemaker Insertion	Repair of TAPVC-Surgical
Sibling Age(Sex)								
	7 yrs(M)	Nil	Nil	4 yrs (F)	4 yrsM)	7 yrs(M)	13 yrs(M)	Nil

As can be seen from Table 2, all the primary caregivers were the biological mothers of the children with a congenital heart defect.

The mother's ranged from 23 - 43 years of age. Three of the primary caregivers (Participant 2, Participant 4 and Participant 8) were in a relationship, unmarried and living with their partner. One (Participant 3) was in a relationship, unmarried and not living with their partner.

Two (Participant 1 and 5) of the primary caregivers were married and living with their husbands and two (Participant 6 and 7) were not in any relationship and living by themselves.

The age of the 8 children with CHD ranged from 7 months to 9 years of age – with 6 of the 8 children being 1 year and below in age. The sex of the children with CHD comprised of 6 females and 2 males. Three of the children with CHD had no siblings whilst five of the children with CHD had siblings. All of these five children had only biological sibling each. One (Participant 1) primary caregiver was of the Indian race and the remaining seven (7) were Black Africans.

The average grade level passed for most participants was Grade 11. According to a report published by the Department of Higher Education and Training, any person who has successfully completed Grade 7 is considered literate Khuluvhe (2021) and thus all participants in this study are considered literate and has the "ability to identify, understand, interpret, create, communicate and compute, using printed and written materials associated with varying contexts" (Khuluvhe, 2021:4)

4.1.2. Average monthly household income and costs associated with visiting the hospital

As can be seen from Table 3 below the size of the family varies from a small family of 3 (Participant 3 and 5) which includes the child with CHD and their mother and father up to a total number of 11 household members (such as with Participant 1). This latter household included grandparents as well as extended family members like uncles to the child with CHD. Most households however amongst those interviewed were between 4-5 members per household.

Table 3: Employment status, monthly income and hospital expenses

(April – June 2020) Participant	P1	P2	P3	P4	P5	P6	P7	P8
Participant Employed	No	No	No	No	No	No	No	No
Participant Previously Employed	Yes-PT	Yes-PT	Yes- PT	Yes-PT	Yes-FT	Yes-PT	Yes-PT	Yes-PT
Family member employed	Husband and Brother in law	Father, Sister, Boyfriend	Biological Father, Partner	Mother	Husband	Nil	Nil	Partner
Social grants	3x CSG; 1x PG	2 x CSG	1xCSG	1xCDG-; 1xCSG	1xCSG	3xCSG	2xCSG	2xCSG
Grants total (monthly)	**R3 180**	**R880**	**R440**	**R2 300**	**R440**	**R1 320**	**R880**	**R880**
Other income type*	Informal- PT	Informal- PT	Informal-PT	Informal-PT	Informal-PT	Nil	Nil	Informal-PT
Average Monthly*	**R1 000**	**R1 200**	**R1 200**	**R1 000**	**R1 500**	**0**	**0**	**R2 000**
Total Income (monthly)	**R4 180**	**R2 280**	**R1640**	**R3 300**	**R1 940**	**R1 320**	**R880**	**R3 000**
Total No. in Household	***11***	***6***	***3***	***5***	***4***	***5***	***3***	***4***
Monthly allocation per person	***380***	***380***	***547***	***660***	***485***	***264***	***293***	***750***
Hospital Transport Type	Public Transport	Public Transport	Public Transport	Public Transport	Private-Family	Public Transport	Public+ Hospital	Public
Distance from hospital	35km	35km	35km	15km	>200km	>200km	>100km	>100km
Transport cost per visit	**R100**	**R100**	**R50**	**R60**	**R200+**	**R200**	**R150-R180**	**R250**

PT-Part time; FT-Full time; CSG-Child Support Grant; DG-Disability Grant; PG- Pensioners Grant

***- this refers to the average monthly income earned by primary caregivers partner from part time employment opportunities**

All primary caregivers were unemployed at the time of conducting the interviews (Table 3). Importantly, when asked about their employment history, all participants noted that they were previously employed of which 7 participants were employed in the informal sector as helpers in places such as salons and butcheries on a part time basis. One participant (Participant 5) worked as a teacher on a full-time basis, however, she too no longer worked at the time of the interview. Many of the participants stated their loss of employment was in some ways related to taking care of their child with CHD either during the diagnosis of the CHD or post the CHD intervention.

In relation to the employment status of the other members of the household, two households (Participant 6 and 7) relied exclusively on social grants from the State. In 2020, the year in which this study was conducted, there were six types of social assistance grants provided by the South African government to its citizens, namely: the grant for Older Persons (Pensioners Grant[PG]); Disability grant (ages 18- 59 years); War veterans grant; Care dependency grant (ages 18 and below) (CDG); Foster child grant; Child support grant (CSG); Grant-in-aid grant; Social relief of distress grant (SASSA, 2020). All recipients of the above mentioned grants must be permanent South African citizens (permanent resident or refugee), with proof of identification and not in the care of any other State institutions whilst receiving the grant benefit.

Particular relevance to this study are the following three grants: The Grant for older persons (PG), the Child support grant (CSG) and the Care dependency grant (CDG). A recipient of the grant for older persons must be 60 years and older; a recipient of the CSG must be the primary care giver, with a valid South African identity card, who has a child under the age of 18 years (who in turn is in possession of a valid birth certificate). A recipient of a CDG must be an individual taking care of a child under the age of 18 with a permanent, severe disability. The applicant is required to submit a medical / assessment report confirming the child's permanent, severe disability.

4.1.3. Living conditions of the study participants and their households

All of the 8 study participants lived in low-income suburbs either at close proximity to the city (4 participants) or further away from the city of Durban (4 participants) – the city in which the tertiary level hospital is located. Some of the participants were living in informal communities (i.e. without owning the land on which they had erected their house), and their access to basic utility services was limited. This was the case of Participant 1, 3 and 4 with the primary caregiver and other members of the household having to fetch water from a communal tap and access electricity, if available, through illegal wiring. Two participants, who were also from a low-income suburb, however, paid monthly rentals and also had limited access to basic services. This was the case for Participant 8 who fetched water from a river and had poor sanitation facility like a pit hole toilet system. Only one participant owned her property (Participant 5), however, it was a low cost housing scheme property that was given to her family under the Reconstruction and Development Program(RDP) that commenced in South Africa post the apartheid period (Deapartment of Human Settlements, 2021). This participant had access to both running water, legal electricity as well as proper sanitation services. All participants lived in places where there were no recreational facilities such as parks and play grounds near their home (Table 5).

More than 50 % of the participants' homes (5 homes) were made from structurally weak building materials, like mud and tin materials. that was erected by the family of the participants themselves. Only three participants lived in brick homes. The average number of bedrooms per household was between 1 and 2 bedrooms and had to accommodate for an average of 4-5 people. The number of bedrooms per family size was insufficient for most of the participants. This was the case for example Participant 4 and 6 where their homes consisted of only 1 bedroom but had to accommodate 5 family members in total (Table 4). This was especially evident in the case of Participant 1 who had 3 bedrooms but had to accommodate for 8 adults and 3 children.

Most participants cooked using an electrical stove within their homes (Table 4). This was the case for example Participant 3, 4 and 5. However, 2 participants cooked under unsafe conditions like open fires and paraffin. Participant 1 had no electricity and cooked her food on an open fire whilst Participant 2 cooked inside using a paraffin (gas) stove.

Table 4: Living conditions of the study participants

Participant	P1	P2	P3	P4	P5	P6	P7	P8
Dwelling type	Tin house	Mud house	Tin house	Tin house	Brick house	Tin house	Brick house	Brick house
Bedrooms	3	2	1	1	2	1	2	2
Total # of family members	**11**	**6**	**3**	**5**	**4**	**5**	**3**	**4**
Adults	8	4	2	3	2	2	1	3
< 18years	3	2	1	2	2	3	2	1
Kitchen	yes	yes	no	no	yes	no	yes	no
Living area	no	yes	no	no	yes	no	no	no
Cooking method	outside fire	paraffin stove	inside 2 plate stove	inside 2 plate stove	inside stove	inside stove	inside stove	nil report
Electricity	no	yes	illegal	illegal	yes	yes	yes	yes
Water	local tap-1km	tap in house	local tap	local tap	tap in house	tap outside house	tap outside house	river water
Sanitation	outside-flush type	communal-pit hole	communal-pit hole	communal flush type	in house flush toilet -	outside-flush type	outside-flush type	outside toilet- Pit hole
Recreational	nil	nil	nil	nil	nil	nil	nil	nil

4.2 Overview of themes and sub-themes from the study data

In the course of the interviews the participants reported both positive and negative experiences when taking care of their child post-cardiac intervention. This is outlined in Table 5 below. The negative experiences related as far back as the diagnosis of their child up to, and including, their current situation. Thus, included in the analysis below is also the experiences of the primary caregivers at the time of their child's diagnosis. This is presented here to reflect as to whether there were any changes from diagnosis to post-cardiac intervention amongst the primary caregivers.

Table 5: The themes and sub-themes arising from the participant interviews

Categories	Themes	Sub Themes
Negative Experiences	4.3 Primary caregivers experiences at the time of the diagnosis of their child	4.3.1. The timing and misdiagnosis of a congenital heart defect 4.3.2. Processing and managing the diagnosis 4.3.3. Primary caregivers' understanding of their child's health condition
	4.4. Primary caregivers financial experiences within their home environments	4.4.1 The financial challenges faced by the primary caregivers 4.4.2 Facing the additional expenses required to support their child with CHD 4.4.3. The mechanisms used by primary caregivers to cover their additional expenses
	4.5. The familial and relationship challenges experienced by the primary caregivers	
	4.6 The challenges of providing care in poor living conditions	
	4.7 The challenges of multiple roles of primary caregivers within their household	
	4.8 The social isolation of the primary caregivers	
	4.9 The emotional health of the primary caregivers	
	4.10 Counselling services available to the primary caregiver	
Positive experiences	4.11 Reported benefits of the cardiac intervention	
	4.12. Coping Mechanisms used by the primary caregivers.	

To complement the themes listed in Table 6, the researcher also developed a diagram which illustrates the interconnections between the positive and negative experiences reported by primary caregivers.

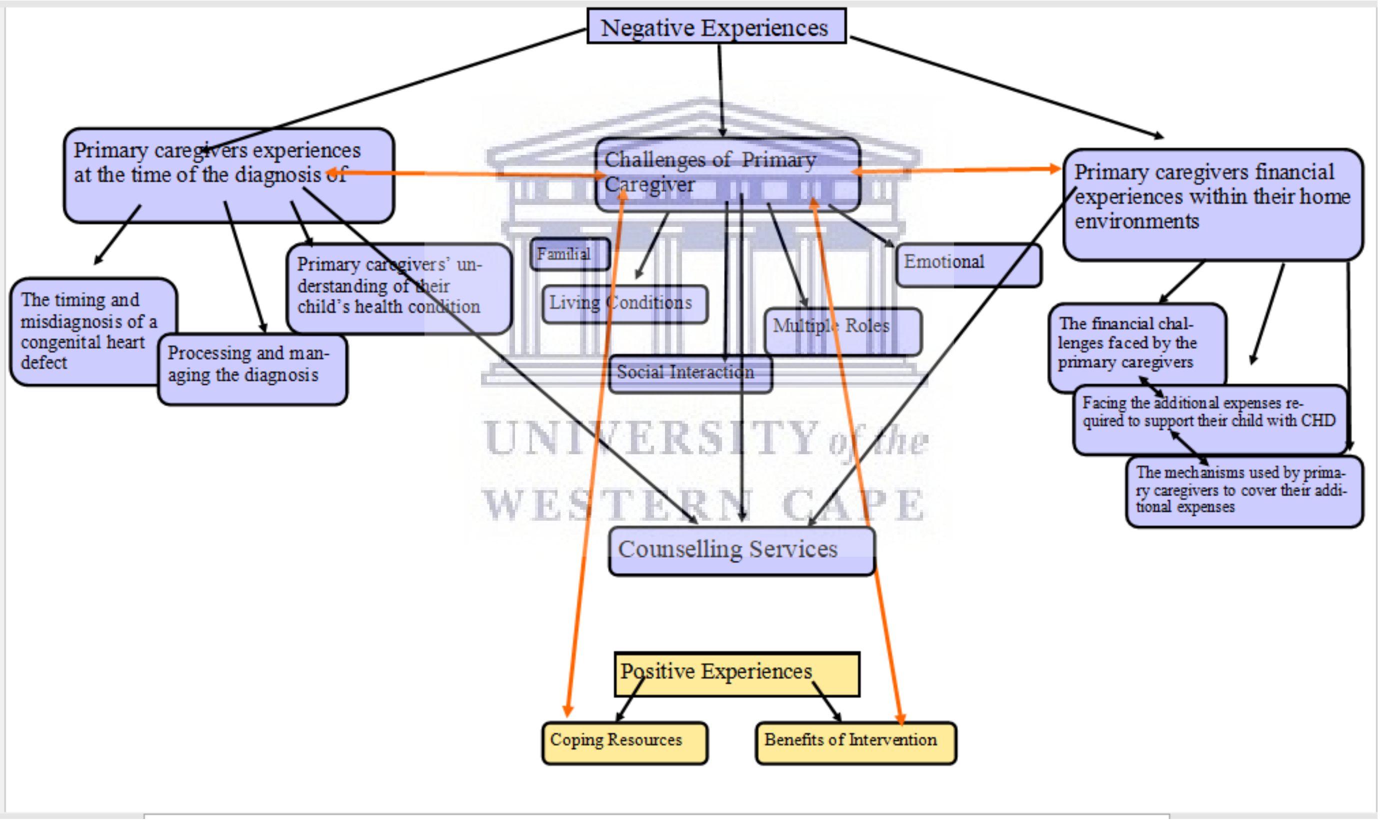


Figure 1: Interconnectedness of Themes, NVIVO 12

4.3. Primary caregivers' experiences at the time of the diagnosis of their child

Within the subtheme of the diagnostic journey, there were a number of major factors that contributed to the negative experiences that the primary care givers had had, and these will be presented below.

4.3.1. The timing and misdiagnosis of a congenital heart defect

Of the total of 8 participants, five participants (Participant 2, 3, 4, 5 and 8) reported that their child was correctly diagnosed as having a cardiac condition upon the first contact made with a healthcare service provider.
Two of the children with CHD (Participant 1 and 6) were however initially misdiagnosed at the time of presenting to the healthcare service provider:

> *"So I went to the local doctor, and he told me my baby has got asthma. So then he nebulised her and then she became worst..."* (Participant 1, 23 years with 10 months old daughter)

> *"…initially it [difficulty in breathing and blue lips, hands and mouth] started when she [the baby] was young, then I went to the local clinic…and when I told them what has happened…or what is happening to the baby...and then they asked me about the father…how does the father look, the complexion..and when I said the father was dark in complexion then the nurses there they told me the baby was gonna be like the father so it was a process of transition...he would also be dark...and then that was it...and then we went home...they sent me home...and when it happened again [difficulty in breathing] they told me the same thing again.."* (Participant 6, 32 years old with 1year old daughter).

One participant (Participant 7) reported that at birth the doctors did notice that something was amiss with her child, however, the actual diagnosis was only made much later in the child's life. She shared how the initial diagnosis was not actually indicative of a cardiac condition:

> *"at birth in the hospital, they said she [the child] had no problems but what they noticed is that her heartbeat was irregular, so whenever they would put their hand by the area of the heart it would beat as if it was going to stop at any given time without continuing…. I went [clinic in local area] and then they consulted the first time, then they gave her antibiotic. Then [they said] if she doesn't get better they must come back. So when I went back after 5 days...so she[the child] wasn't getting better...then the nurse said this is not normal, antibiotics did not help…..this all started around when she was 5, the doctor that we went to consult at Prince Mshyeni thought it was TB, and they gave her TB treatment*

> *and 6 months later, before she could finish the treatment, the results came and it showed she was negative of TB, but they said she must continue anyway, because she has started and then they started querying about the family history, to find out if anybody had cancer in the family, and I said yes, her uncle who died in 2003 had cancer but child with CHD was not born yet…"*(Participant 7, 43 years old with 9 year old daughter)

The time frame of receiving a confirmed diagnosis of their child having a cardiac condition amongst those interviewed ranged from in utero, to the time of birth and up to a period of three years. One participant was informed about their child's cardiac condition whilst she was pregnant with her child (Participant 4) two participants were informed about their child's cardiac condition at around the time of delivery (Participant 3 and 5) a few days after giving birth.

Four of the participants followed the recommended pathway of seeking medical attention first at their local clinic or doctor and were then immediately referred up to the next (secondary) level and finally reached Inkosi Albert Luthuli Central Hospital, in which the Cardiac Unit is based.

However, as illustrated previously, two participants (6 and 7) experienced significant delays in receiving the diagnosis of their child's heart condition. As one participants explains:

> *"I only got to Albert [Cardiac Unit] when she [the child] was 8 years old... okay, I did go to the clinic [local clinic] ...[but] they told me they would give me vitamin tablets, vitamin A, vitamin C and then they said if her [the child's] blood is purified and cleaned...then her irregular heart beat will be gone"* (Participant 7, 43 years with 9 years old daughter)

Furthermore, the time to the cardiac intervention for the child with CHD from receiving confirmed diagnosis varied from 3 months up to a significant delay of 9 years amongst the 8 participants.

> *"oh...okay...I can say child with CHD was born with this heart problem. Err…I went to the hospital into the ultrasound at King Dinizulu [local hospital], and they said I'm not going home, the baby have got a problem of heart, now they are going to do the operation...yeah I was 6 months pregnant yeah, they said I am not going home, they are going to the operation to save the baby's life..."* (Participant 4, 23 years with 3 year old daughter [child with CHD born in the year 2017])

Child with CHD intervention of Participant 4 was 3 years later

> *"err...they did the operation in this year, on the 03rd March…yeah, they explained it to me, they said there are so much babies need operation that are better than…yoh…. child with CHD is better than those babies...yeah...yeah…I must wait".*

Similarly, another participant stated that from time of diagnosis to intervention, the doctors were issuing her with letters back and forth from the hospital

> *"the doctors confirmed that there is a hole in the heart...and then...so they gave me the letters of the appointment when I must come back, they keep giving me the hospital letters and then I come back and then they check it and then I must go, and then they give me the letters for the next date...and then I do the same thing, and do the same thing until they ..until they called me on February…mmm..I think they give me like 3 letters for those 3 months"* (Participant 5, 37 years with 7 month old son)

The missed and/or delayed diagnoses that some of the mothers experienced obviously had a significant impact on the mothers as they were seeking explanations for their child's illness. It created heightened feelings of uncertainty around what is wrong with their child and this in tun g

4.3.2. Processing and managing the diagnosis

The interviews revealed that at the time of diagnosis all of the participants experienced significant emotions of pain, fear, stress and sadness. Their immediate response was fear of what could happen to their child in the future and if their child was going to overcome their heart condition. A great concern of all participants was the possibility that their child was not going survive as these two quotes indicate:

> *"Yoh…. I was feeling a lot of pain, I was like crying ...you know…this like I was thinking my baby is going to die…and it was my first time getting a baby so I didn't understand like what was that they were talking about…I never heard of it…how does a baby breathe, how does a baby live with a hole in the heart…all this stuff"* (Participant 2, 23 years with 15 month old daughter)
>
> *"I was thinking my baby...is not going to be survive...yeah…everything…my baby is going to die...ay..."* (Participant 4, 23 years with 3 years old daughter)

Two participants (Participant 1 and 2) specifically expressed feelings of self-blame and a sense of hopelessness. As mothers they felt responsible for not noticing their child's condition and to some extent also felt angry for the situation they and their child was in:

> *"…I was terrified when I came to know what is wrong with my baby for so many months, like from the time she is born, she's[been] suffering and me as a mother I am helpless and I couldn't do anything about it. It made me feel terrible"* (Participant 1 23 years with 10 months old daughter).

> *"Well, I was like...I was like...losing my mind…you know… I was thinking like…I was sad all the time…I was angry...every time … I was like…feeling like the world is unfair to me…like everything is going bad you know...theres nothing working out for me...and every time I was sad and crying, crying"* (Participant 2, 23 years with 15 month old daughter)

4.3.3. Primary caregivers understanding of their child's heart condition

During the interviews, primary caregivers shared how they were aware that there was *"really something wrong"* with their child's heart. This was particularly important when they were engaging in communication with the health care facility that they attended. For example, one participant was clear in communicating and confirming with the local clinic at her district that something was wrong with her baby

> *"…well, I noticed these things on my own and when I went to the clinic, you know we have to go every month, yeah…when I went to the clinic they weigh my child and then they told me, they tell theres something wrong with her and then and I. I… they I ask if I see if theres anything wrong with her and then I said yes..."* (Participant 2, 23 years with 15 months old daughter)

However, one primary caregiver shared that even though she took her baby for the regular follow-ups at her local clinic and brought to their attention her observations such as *"blue lips and hands"* she was not referred to the next level of care, instead it was out of her own misgiving that led her to seek alternate care such as the pharmacy as quoted below that eventually led to the diagnosis her baby's heart condition

> "*and then they [primary caregiver and baby] went home…they [nurses at local clinic] sent her home...and when it [blue lips and hands with difficulty in breathing] happened again they [nurses at local clinic] told her the same thing again [the baby was gonna be [dark in complexion] like the father…until it [blue lips and hands with difficulty in breathing happened when it was weekend so she decided to go to the local pharmacy and when she got to the pharmacy they told her no this is an emergency"* (Participant 6, 32 years with 1 year old daughter)

Another participant was quick to act when she noticed that in spite of her visiting her local doctor there was a deterioration of her baby's' condition and thus sought medical assistance at a nearby hospital.

> *"So then he (local doctor) nebulised her [baby] and then she became worst. That's what made me think that you know what, she's really sick and really something wrong with her and I need to take her to the hospital"* (Participant 1 with 10 months old daughter)

Understandably, whilst the primary caregivers were not clear on the exact diagnosis and did not understand the mechanics and details of the problem initially, many of the participants described how they were able to identify some of the symptoms of their child's heart condition, and in some cases this assisted them in accepting the diagnosis that had been made by health professionals:

> *"So I can't pronounce the term that was used to describe the condition...I can't...factory or factory...but what they told me was…the valve...the baby's valve was small so then it was allowing the mixing of blue and red blood* (Participant 6, 32 years with 1 years old daughter)

And when asked what the participant understood by this, she said

> *"So I understood that it was a heart condition and the heart was swollen..."* (Participant 6, 32 years with 1 years old daughter)

4.4. Primary caregivers' financial experiences within their home environments

Rather than a single or a set of stand-alone factors, the interviews revealed a complex interplay of a number of different and intertwined factors that collectively contributed to the economic and familial challenges that the primary caregivers' experienced whilst taking care of their child post-cardiac intervention. These factors created a web-like relationship around the primary caregiver. The factors all impinged on the well-being of the primary caregiver, and naturally also had an impact on the family relations between siblings and other household members. The severely constrained economic environment in which the primary caregiver found themselves, only made things more challenging. Of importance to mention is the onset of COVID-19 and the country plunging into lock down that participants alluded as additional reasons why securing employment was a struggle. The account of these and other lock down challenges can be found at the end of Chapter 4.

4.4.1. The financial challenges faced by the primary caregivers

Participants experienced a number of financial challenges as they cared for their child with a CHD. These challenges related to their reduced potential to work – and how they had often had to stop working as a result of having to care for their child (and how this was compounded by the lack of employment of other adult members in the household); the particular nutritional requirements of the child with CHD, medical needs (like medication for child with CHD, transport to the hospital) and the care giving needs like clothes and toys for child with CHD and other dependents.

As can be seen by the word cloud generated by NVIVO 12 (Figure 2), the most frequently occurring word amongst all eight participants when asked about their employment pre and post-cardiac intervention the cardiac intervention were: working, operation, activities, changed.

Figure 2: Employment Status Word Cloud, NVIVO 12

A word cloud is a collection, or group, of words represented in various sizes. The bigger and bolder the word appears, the more frequent it's mentioned within a given text or data set and the more important the word is.

This word cloud assists in clearly demonstrating the change or shift in work and income-generation possibilities the primary caregivers have had to face post-cardiac intervention for the child with CHD. This is affirmed by the fact that all eight participants were unemployed at the time of the interview.

The following quotes describe the challenges and subsequent changes primary caregivers had to manage in relation to work and in having to meet the additional care needs of their child:

> *"It [the ill-health of the child and the operation] impacted on us [both husband and wife] heavily, because I had to stop doing my normal business of baking because now I have to look after the child, go to the hospital now and again."* (Participant 5, 37 years with 7 month old son)
>
> *"Actually I was at work, but in [the child's] condition I can't...* (Participant 1 with 10 month old daughter)

Participant 1 went on to explain why she could not continue work, as quoted by the following:

> *"okay, I was employed before [before intervention]. I was working at the salon and the spaza shop. After [the child] was born…[before diagnosis of CHD] in terms of me working I feel I can work but the problem is there's no one to take care of baby because my in-laws are too old. ...*

And when asked how she felt about going to work now after operation, she shared

> "*it makes me feel very terrible to leave my baby in this type of condition, especially when I know there's something is gonna wrong with her like the last time"* (Participant 1 with 10 months old daughter)

Similar experiences were shared by 3 other the participants, who talked about having to give up work because of *"the child's condition"* (Participant 4) or how *"(s)he was sick and every time (s)he was sick"* (Participant 3) and did not want to leave the child *"with anyone else"* (Participant 6).

Sadly, for one participant her unemployment was associated with both the cardiac condition of her daughter as well as an adverse episode in the life of the child with CHD as can be seen in the quote below:

> *"I stopped working when [child with CHD] was 2, part of the reason that contributed to the entire thing (not working) was [child with CHD] was raped at the age of 2, in the preschool she used to go to"* (Participant 7, 43 years old with 9 year old daughter)

Not only were the 8 primary caregivers unemployed, but other family members were also unemployed. Just as the above participant (Participant 1) reported that the employment status of the father of the child had also been impacted on by the child's heart condition, so too was the employment status of another partner (Participant 5).

> *"Before the operation the baby's dad had a good job that he could give us things what we need but now after the operation he lost his job because he had to come every day to see baby if she is OK or not that why I am saying thing have changed and it's hard."* (Participant 1 with 10 months old daughter)

> *"and my husband as well has lost some opportunity to go and work because he has to support his wife, to be there at the hospital with her*" (Participant 5, 37 years with 7 month old son)

Ironically, it seems that whilst the primary caregivers recognized the need to be with their child after the intervention, their lack of employment along with part time unstable employment of other family members at the time of the interview, was also a source of great stress for the primary caregivers.

Employment amongst other adult family members was minimal and often ad-hoc or temporary in nature. None of the family members of the participants had full time jobs and most of them worked in informal activities. These were mentioned by many of the participants as can be noted below:

> *"My…my sister is not working...my mother and my father is not working…actually we all not working."* (Participant 2, 23 years with 15 months old daughter)

> *"The husband [of the primary care giver] is working with the brother, the brothers got a business, side business - he does Wendy houses, so whenever the brother has work then my husband joins… so it's sort of part time, as and when there is a job."* (Participant 5, 37 years with 7 month old son)

4.4.2. Facing the additional expenses required to support their child with CHD

Another significant factor that many participants (6) reported as contributing to the household's economic challenges was the increased food and nutritional requirements of the child with CHD *"as baby is eating a lot now"* (Participant 3)

As one participant noted, whilst the increased appetite of the child with CHD was a welcome development as it indicated recovery and improved health, their ability to provide adequate nutritional support for the child was limited given the financial strain that the household was under and their vulnerability to food insecurity:

> *"Before the op she was barely eating much food which was different and difficult. Like before she should only eat purity and stuff…. now after the op, she's eating normal kinds of food which costs more …okay, it's quite difficult because when we don't have those stuff, like mainly we need rice to cook- and we don't have rice, (because) there's no money, other people like our neighbours or whatever buy the rice and put in the house."* (Participant 1, with 10 month old female)

Another participant also remarked about the difficulty in providing food for the family:

> *"Mostly it [unmet needs of the child] was the food because I would buy the food but it doesn't last for the whole month because it gets finished and sometimes there is (also) no money for clothes."* (Participant 8, 25 years old with 8 month old daughter).

Some of the participants also stated that besides not being able to meet the quantity of the nutritional needs of the child with CHD, the type of food that they were not able to provide their child also played a major role in creating worry and concern amongst them:

> *"and the type of milk that I am giving her. Usually I am giving her a Nan. But now I'm thinking of adding like, there's a milk that is called Pedisure, but too expensive for her, but I wish that she could get it, you know."* (Participant 2, 23 years with 15 month old daughter)

> *"…child with CHD had an operation on the 19th March, so after she was discharged the doctors told her that, she mustn't eat the normal food or she must have a special diet. She can't be eating what they are eating, so after she got sick she went on as normal, but I will see what I can change, how I can change, once the grant is been approved…so that now she must eat special food and that might tend to be expensive so that is my biggest concern."* (Participant 7, 43 years with 9 years old daughter)

Whilst primary caregivers shared how their financial constraints affected their ability to meet the nutritional needs for their child, the cost of transport to and from the hospital for their child, also caused their "*budget is [to be] deeply disrupted*" (Participant 7). Interviews revealed that the cost of transport for the child with CHD was particularly steep when compared to their average monthly earnings as can be seen in Table 3 for all participants.

Furthermore, two primary caregivers (Participant 6 and 7) had no other source of income except for the social grants and they shared how the transport cost was "*quite stiff*" (Participant 7) and this further exacerbated their financial challenges because,

> *"taking the taxi or a cab to get here [to Cardiology department] costs around R200 so then it affects me financially and it is worsened by the fact that [the child's] father is no*

> *longer around to support me and there's no one else supporting me...usually all of these activities must happen using the grant money with no additional financial support"* (Participant 6, 32 years with 1 years old daughter).

Not only did the cost of transport impact on the food availability in the home, one primary caregiver also mentioned how she would *"suffer"* when ensuring her baby attended her hospital appointment. When asked how this particular primary caregiver would cope during those months, she said

> *"No, I would rather suffer because it's important for [the child] to go to hospital for her check-up, they [Cardiology staff] need to verify if it's [child with CHD medical device used for operation] in position, so that's important that [the child] can go back to hospital..."* (Participant 7, 43 years with 9 years old daughter)

Unfortunately, at some point these transport challenges sometimes placed a primary caregiver like Participant 7 above, in a position where they *"cancelled"* attending an appointment *"because of the money, R180 or something*" (Participant 7).

Nonetheless, at the time of the interview, one participant was optimistic that after the operation *"things [cost of transport] will be better because I don't have to go up and down all the time to the hospital"* (Participant 5), whilst 2 other participants said "*it's (budgeting for transport cost) not changed a lot because the appointments are about after a month or so"* (Participant 2) and *" it [transport cost after intervention] has changed because it's mostly for medical things because I have to take [the child] to the local clinic for a check-up and sometimes I will have to come to Durban"* (Participant 6) demonstrating that transport costs is an ongoing challenge for primary caregivers of a child with CHD, even after the intervention.

Notably, whilst the primary caregivers shared significant challenges with particular reference to employment and transport costs, many primary caregivers also shared how other basic material requirements like *"sometimes if my children need clothes and toys and stuff"* (Participant 1) or *"Like winter is coming, I don't have enough money to buy things say some clothes, something that will make her warm"* (Participant 2) were difficult to obtain due to financial challenges. In addition, many primary caregivers shared how energetic their child was after the intervention like for example, *"his playing…rolling on the bed"* (Participant 3) and Participant 2 shared that after the intervention, her baby was *"very very very active"* and thus she sited that *"she [the child] likes to play a lot"* and items like *"getting her toys"* were difficult to purchase due to her financial challenges.

The lack of a stable income within the households also impacted on a basic need like for example the ongoing access to electricity.

> *"and sometimes electricity would run out and I don't have money to buy electricity and me and my child have to stay in the dark until I have made a plan to borrow money from someone so the challenge is my unemployment status."* (Participant 6, 32 years with 1 years old daughter).

4.4.3. The mechanisms used by primary caregivers to cover their additional expenses

Understandably, the financial constraints as stated above placed a heavy burden on the primary caregivers and their families, and thus this translated to a few primary caregivers (Participant 1,3 and 7) resorting to borrowing of money in order to meet some of their basic needs as can be seen by the quotes below:

> *"I do borrow money from time to time especially for nappies for [the child] and yes things do run short in the house and I have to go borrow money from the neighbours and it tends to come to an end… around the 15th that I have to go and borrow money for additional purposes around the house..."* (Participant 6, 32 years with 1 year old daughter)

> *"child with CHD when she is sick at night…yeah…I wanted to go to the hospital...I went to my neighbour and borrow the money"* (Participant 4, 23 years with 3 year old daughter)

Subsequently, this borrowing of money meant "*he (the husband) has to pay this person and that person, so he gives me the money to (pay)… you know what, hand it over to this person you (primary caregiver) owe that person that amount of money, you owe that person that amount of money, so…that's how we manage.*" (Participant 1) resulting in an additional financial commitment giving rise to short-term debt for some families. In addition, this borrowing of money increased after bringing their child home post-cardiac intervention:

> *"She [the child] really needs this and that stuff, and err… she [the child] likes really run short of medication. We have to go back to the hospital to get medication, so we have to*

> *use up that money to go to the hospital, so it's like more borrowing, now (after the operation) than before (the operation) ..."* (Participant 1 with 10 months old daughter)

4.5. The familial and relationship challenges experienced by the primary caregivers

Not only did all the households of the primary caregivers' experience financial challenges, interviews revealed that pre- and post-cardiac intervention, other familial challenges became apparent within the context of the primary caregivers' household. These challenges related to, for example, stress experienced by the mother and strain being placed on the relationship between the primary caregivers and their other children as well as their partner. This will be presented below:

A few siblings also experienced a significant amount of stress and concern for their ill brother/ sister as described by the quote of a primary caregiver below:

> *"He (7 year old brother) does show concern (for child with CHD) ...and asks how is child with CHD especially when (child with CHD) is showing signs of not being okay...my other child will continually ask how is child with CHD...eventually when she's [child with CHD] okay then my other child is also...or looks relieved or feels relieved because they can play together again... "* (Participant 6, 32 years with 1 year old daughter)

Another participant (Participant 4) also expressed how the sibling of the would feel isolated from her mother (the primary caregiver) and the , thinking that they were "going on holiday" without the sibling, when attending their hospital appointments. According to the mother (the primary caregiver) the sibling would express how "she (the 4 year old sibling) wanted to go too (with primary caregiver to hospital) and starting to cry" and would "Not eat (and) not play" whilst they were visiting the hospital or when the was admitted.

Similarly, another participant (Participant 1) also shared how her 7 year old son – the sibling to the , often expressed feelings of concern at the time of their hospital trip and was anxious about the potential admission of his sibling:

> "*He (7 year old sibling) actually asks err... like when she' s [] crying, if she's crying a lot, he asks me mum, is baby gonna get sick again, are you going to stay in the hospital? And I tell him no baby, I can manage her. So what he says in return, he says mum can I*

> *please help you so my baby sister won't go back to hospital."* (Participant 1 with 10 months old daughter)

In addition, one participant (Participant 7), shared how she "had to leave him (13 year old mentally challenged sibling) with neighbours" during their hospital trips and admissions. Another participant (Participant 5) shared how hospital trips "used to frustrate the other child (4 year old sibling)".

Furthermore, two primary caregivers (Participant 1 and 4) specifically mentioned how jealous siblings were of the attention that was given to the child with CHD:

> *"I have to give baby her medicine ..and err…he (7 year old sibling) gets all emotional and says you only care for her and not for me ….he (7 year old sibling) says mum you only like her and not me.."* (Participant 1 with 10 months old daughter)

> *"Like she (4 year old sibling) even complains that I don't love her like the way I do to child with CHD."* (Participant 4, 23 years with 3 year old daughter*)*

However, in spite of these instances of jealousy, the same two primary caregivers shared how important it was when siblings assisted them with keeping the child with CHD company. For example, Participant 1 noted that:

> *"My son (7year old sibling) watches her [child with CHD] while I'm cooking or washing dishes or taking a bath."* (Participant 1 with 10 months old daughter)

Participant 4 mentioned that she "leaves them (the sibling and child with CHD) alone" when she has to go and fetch water (which is about 1km away at a communal tap).

In addition, post-cardiac intervention, when asked about how primary caregivers routines had changed, many of those interviewed alluded to how much more time they took taking care of their baby and how certain routines, for example, meal times are delayed:

> *"Supper is delayed, because of baby fussing and crying"* (Participant 1 with 10 months old daughter)

Two of the eight participants who were married (Participants 1 and 5) also shared how their sexual relationship with their partner, post the child with CHD's cardiac intervention, changed:

> *"After the op, from the time we came home from the hospital, it (sexual relationship) is err… what can I say...it's not so ...quality related.*" (Participant 1, 23years with 10 months old daughter)

> *"Its (marital relations) better than before because (before) I had to go to hospital. So it's better now (after intervention)".* (Participant 5, 37 years with 7 months old son)

In summary, familial relationships within the various households were under considerable stress and strain as a result of the child with CHD's ill health. These adverse challenges were reported to start around the time of diagnosis of the child with CHD and continued even after the Child with CHD had had a cardiac intervention and returned home.

Unemployment was another major common occurrence for all participants at the time of the interview - a situation which was sometimes precipitated by the special care needs of the child with CHD after CHD intervention, like in the case of Participant 6 who shared that her child is on "treatment" and "some people might not give the treatment accordingly" so she cannot leave her child and "go job hunting".

Other adult members in the household earned very little, were employed informally and on a part-time basis and in two instances (Participants 6 and 7) the other adult member(s) of the household were also unemployed at the time of the interview - compounding the financial stress placed on the household.

Notably, the two households where no adults were employed as mentioned above (Participant 6 and 7) comprised of 5 and 3 family members respectively. In addition, three households (Participant 4,5 and 8) had only 1 adult member employed and this income had to take care of family sizes of 5,4 and 4 respectively. The remainder of the households (Participants 1,2 and 3) had about 3 adult family members employed, however here too, the combined income had to address the needs of as many as 11, 6 and 3 family members respectively. Of importance to bear in mind is that all adults that were employed within in each household held part time informal jobs. These jobs were inconsistent, like for example, Participant 2 had a family size of 6- 2 children and 4 adults- with adult members employed in jobs like "putting mud on houses" on a temporary basis or "selling newspaper" where sometimes "they (newspaper company) don't hire, and sometimes they do hire". Similarly, in the case of Participant 1 whose family size consisted of 11 people- 3 children and 8 adults- had adult members engaged in the selling of “scrap metal” which understandably brought in a menial income on an irregular basis.

The overall average monthly income for the participants at the time of interviews, placed six participants below the “extreme” poverty line of less than R585 per person per month (Table 3) and two participants below the “lower-bound poverty line” of less than R840 per person per month, thus re-confirming their many financial challenges. Furthermore, these financial constraints deprived many families of adequate basic needs like food (for all family members) and basic necessities like clothing for the child with CHD and their siblings. In addition, both the financial constraints and the living conditions of many of the participants also limited their access to legal electricity, water and proper sanitation as can be seen in Table 5. As has been elaborated previously Section 4.2.2 the interconnectedness between the economic and familial factors impacted on the well-being of the primary caregivers and subsequently on the overall recovery care of the child with CHD whilst primary caregivers were facing many challenges.

The next theme will discuss how the range of challenges such as living conditions, financial constraints and relationships with siblings were described as impacting on the day to day lives of primary caregivers themselves.

4.6. The challenges of providing care in poor living conditions

All of the 8 primary caregivers belong to the low income socioeconomic class (POLITY, 2019). As has been highlighted previously, their financial vulnerability and poor living conditions imposed a number of challenges on them whilst taking care of their child post-cardiac intervention. At the time of the interviews, many of the primary caregivers (five) lived in informal homes with limited access to basic necessities like electricity, water, sanitation and there was no access to recreational facilities. Participant 1 described the space she lived in as *“insufficient”* and structurally unsafe as *“everywhere inside our house is actually leaking water (it was a rainy day). Our beds are getting wet everywhere”.* This was also the sentiment shared by another primary caregiver as shown in the quote below:

> *“The house is very small so that it makes it very difficult...sometimes the house will leak and that makes everything traditionally very difficult.”* (Participant 6, 32 years old with 1 years old daughter)

In addition, only 2 primary caregivers had access to water inside the house (Participant 2 and 5). Thus, for the majority of the primary caregivers, access to water was at a communal tap, and in evidently some distance from the home. As a result, for some primary caregivers, fetching water for their household was a fearful experience:

> "*I have to manage carrying her either sides of my hip, and carry the buckets from the tap, so it's quite difficult. It (fetching water) actually makes me feel terrible, because my conscious is if I'm carrying that heavy bucket of water or the tub of water, and if she (the child) falls, then I have to leave (put) the tub down or the bucket down, which really hurts…It makes me feel terrible, because sometimes she ends up with a running nose, and a terrible cough* (Participant 1, 23years with 10 months old daughter)

Another primary caregiver had to *"leave them (the child and sibling 4 years old) alone"* when fetching water and this too created feelings of fear because "*I think that someone can come inside the house and rape them..."* (Participant 4). One primary caregiver had no choice but *"to fetch water from the river"* (Participant 8).

Participant 3 and 4 also described how they had *"illegal"* electrical connections and *" It was dangerous"* because *" it can affect the children because when they are playing outside they can touch the wires".* (Participant 4). Furthermore, primary caregivers shared how these situations left them feeling scared *"because people are dying because of this electricity cos its running down so I'm so scared"* (Participant 4). Other primary caregivers were also fearful as they described their lack of access to electricity meant they prepared food under unsafe conditions like *"open fires"* (Participant 1) and the use of *"paraffin stoves"* (Participant 2).

Another significant living condition challenge experienced by many primary caregivers (six), that impacted on the care and health of the CHD, was the lack of access to proper personal sanitation and waste disposal facility. Understandably, the use of public toilets coupled with a dysfunctional waste disposal service, can be an unhygienic, infectious environment posing many challenges for the recovery of the child with CHD, thus indirectly impacted on the caregiving routines of the primary caregivers. Participant 4 shared that using the communal toilet "impacted" on how she took care of her child as "our place is full of dust and rubbish...everything and it affects (child with CHD) because it has got smelly things and things like that..." (Participant 4, 23 years with 3 years old daughter).

Primary caregivers shared their concern about the lack of recreational facilities and how it made *"them (primary caregiver) feel bad"* because their children "*get so bored"* (Participant 4). Another primary caregiver added how *"it (lack of recreational facility) impacts the baby because she stays indoors all the time"* (Participant 8) and furthermore, playtime would be beneficial for the primary caregiver "*to assess how she [the child] interacts with other kids around her"* (Participant 6), an important social skill for many children.

Thus, the lack of access to water, electricity and a clean toilet heavily burdened the primary caregiver when taking care of their ill child pre and post-cardiac intervention.

4.7. The challenges of multiple roles of primary caregivers within their household

All primary caregivers were involved in the daily running of their home as well as ensuring that the routine tasks before and after the child with CHD's heart intervention remained as undisturbed as possible. However, interviews revealed that 3 primary caregivers (Participant 1, 2, and6) experienced increased difficulties in carrying out their daily responsibilities once returning home from hospital with their child with CHD post-cardiac intervention. This is described by the quotes below:

> *"and if they (family members) get home, it is quite difficult to see to her (the child with CHD) …at the same time or see to her first, or the house chores"* (Participant 1, 23years with 10 months old daughter)
>
> *"It (routine chores) has been impacted... when [the child] is in the house...and (primary caregiver is) doing the laundry, then suddenly [the child] doesn't look okay and I have to leave whatever I am doing and do it later so that I can attend to [the child]...so yes there are things that have changed in my life and the way I am doing things* (Participant 6, 32 years old with 1 years old daughter)

Interviews also revealed that some primary caregivers might not trust someone else to care for their child as she would, as was suggested by Participant 8 when she said that *"someone must just constantly be around (the) child with CHD all the time*". Participant 6 mentioned that "*some people might not give the treatment (take home medication post-cardiac intervention) accordingly...so therefore in this point in time I would like to take care of my child by myself."*

In addition, a few primary caregivers shared that the need to be with their baby all the time because staff at the hospital told them that *"baby must not be distressed"* (Participant 1). She communicated how her role is to ensure this *"distress"* does not happen, but that she really "*needs...a nebulizer… which is oxygen...and it will be really helpful if we could (get) that oxygen to prevent (the child with CHD) from getting distressed"* (Participant 1). Other participants noted that they were *"giving ... more time"* to the needs of the child with CHD and "*waking up so early, early, early so that I make sure when she (child with CHD) wakes up everything is ready for her (child with CHD)"* (Participant 2).

Participant 7 also shared how her other son (the 13 years old sibling) was diagnosed having "*slow mental development"* and was *"slightly abusive*" towards her due to his condition. This added an additional dimension to what she had to manage within her household as she simultaneously managed both children under her care.

Understandably, the multiple roles of the primary caregivers placed them under significant stress- more so when returning home with their child post a cardiac intervention.

4.8. The social isolation of the primary caregivers

Interviews revealed that there were mixed responses from the primary caregivers with regards to how they socialized with friends and family after bringing their child home after the cardiac intervention. Only one participant (Participant 5) felt she would have more time: "*Now I am able to go to Whatsapp, I didn't have time* before" she mentioned. A significant number of primary caregivers (three) shared how they had *"no time"* for social interactions (Participant 1 and 2) and that *"(caring for) baby is (taking up) enough time"* (Participant 3), and they subsequently had experienced a decrease in social interactions. This was especially so, after the intervention, as is highlighted in the quote below:

> *"So after the op, it's like quite difficult, you know you have to see to a sick baby around, and like if I have to (go) for a function or a party, I have to stay back because it's hard to take baby to attend something like that, because you know she's gonna get sick in front of so many people…and its quite frightening"* (Participant 1, 23years with 10 months old daughter)

Furthermore, Participant 1 noted that she could no longer pay attention to her personal care *"like maybe doing my nails and hair or dress up" especially "after (the) baby's op"*. Another primary caregiver (Participant 2) also shared how going to church is *"becoming less"* after the intervention and this made her feel *"bad"* as she *"doesn't t get enough time to pray."*

Thus, overall taking care of the child with CHD post their cardiac intervention significantly impacted on the social lives of a number of primary caregivers in this study, and reduced the opportunities they had to socially engage with others. However, of note is the COVID 19 virus and the effects there of. This is covered at the end of the chapter.

4.9. The emotional health of the primary caregivers

All eight primary caregivers described varying levels of negative emotional and psychological experiences upon returning home with their child post-cardiac intervention. The most commonly expressed words all eight primary caregivers used when asked about how they felt, pre- and post-cardiac intervention, revealed, were: feel, baby, going, hurt, scared and emotions are a some of the most commonly used words. Primary caregivers (five) shared how they were still "*scared*" about their baby's heart problem (Participant 1 and 5), that they *"don't know if this will end or if it (the heart problem) will come back"* (Participant 5). In addition, primary caregivers also shared how they felt alone and unsupported in their role as a carer and a mother and/or a single woman - as is illustrated in the quotes below:

> *"When I tell him (my partner)...he doesn't understand [the child's] situation...my mind was...i was think (ing) about no one cares about me, my family...yeah"* (Participant 4, 23 years with 3 years old daughter)
>
> *"It (financial challenges) is worsen by the fact that [child with CHD's] father is no longer around to support me and there's no one else supporting me*" (Participant 6, 32 years old with 1 years old daughter)
>
> *"When I get asthma and if I am sick there is no one to take care of my baby so I get emotional and cry."* (Participant 1, 23years with 10 months old daughter)

A few primary caregivers mentioned how "emotional" they felt about not giving their other children the same attention (Participant 1) as the child with CHD. Understandably, by having to pay significant attention to the child with CHD, the primary caregivers felt guilty or as if they were neglecting their other child in comparison. One primary caregiver said *"I feel like I gave child with CHD more love than her (4 year old sibling)"* (Participant 4).

When primary caregivers were asked about their emotional or mental state was post the intervention, the most common words mentioned were "worried" and "troubles". Interviews revealed how Participant 6 was "*stressed*" and Participant 1 was "*troubled*" that something else may still going to "*go wrong*" with her baby (Participant 1). The majority of primary caregivers shared that some of the things they were particularly worried about was their *"unemploymen*t" and "*getting food for their baby*" was at the top of their concern. One participant (Participant 7) also said that the required "*type of diet*" was also creating a great deal of "stress" and worry, post-cardiac intervention.

At least three primary caregivers shared how their fears about "*the future*" of their child with CHD *"…like the brain, is not gonna function like….as she's [child with CHD] growing up she is not gonna function well...as a normal child does."* (Participant 2). Similarly, Participant 6 and 7 shared how they were concerned for their child with CHD when they went to school and how *"other children will treat her (child with CHD)"* (Participant 6) or *"how (the child with CHD) will cope where the (school) is overcrowding, and they (school children) running all over, pushing one another*" (Participant 7), thus confirming the concern that many of the primary caregivers live with in relation to their child with CHD.

4.10. Counselling services available to the primary caregiver

In relation to the third study's objective, that queried primary caregivers' specific needs from the cardiac department at the hospital, the following needs were highlighted:

Interviews revealed that primary caregivers shared that *"there was not counselling offered"* (Participant 6) and a many primary caregivers (Participant1, 4 and 5) felt that counselling would have been "beneficial" and that they "needed counselling, even now (after the op), I need counselling." (Participant 4). When asked what are some of the things they would share with the counsellor one participant said

> "*if like I have a situation to counsel myself and to talk about it, actually it (dealing with a child with CHD) might be much more easier and lighter because it's quite difficult at this time because theres no one to talk to, theres just baby to see to, it can feel like lonely and pathetic* (Participant 1, 23years with 10 months old daughter).

Other requests made by participants to the healthcare provider were issues like getting more information about the heart condition, how to take care of the wound/ surgical area post-cardiac intervention a cardiac intervention as well as financial help and how to meet with the dietary needs of the child with CHD:

> *"no, I don't believe that I need a social worker or psychologist because they told me whats wrong, the only thing I need is guidance to what exactly must I feed, because they just told (me) not to feed certain things, that child with CHD must not eat but I don't exactly (know)… if they can create a list for me, what to eat and what not to eat, then that would be easier"* (Participant 7, 43 years old with 9 years old daughter)

, one participant (Participant 1) requested to have access to care for her CHD closer to the home because it is *"quite far"* and this will *"help us with transport".*
Participant 5 highlighted a very significant need when she expressed her need for counselling so that *"This (counselling) will help a lot because maybe I will come across somebody in a similar situation and they will help explain better (the condition of the child with CHD)"* (Participant 5, 37 years with 7 months old son)

4.11. Reported benefits of the cardiac intervention

Many of the primary caregivers, despite the numerous adversities they were experiencing, were resilient and hopefully optimistic about the future health of their child:

> *"Now that she (child with CHD) is alive and no additional problems so I have hope now"* (Participant 6, 32 years old with 1 years old daughter)
>
> *"I am grateful because they are my children and they were blessings from God"* (Participant 7, 43 years old with 9 years old daughter)

All primary caregivers interviewed described feelings of *"happiness"* and *"relief"* after bringing their child home after the cardiac intervention. Participants also shared how their child with CHD was "*eating and gaining weight"* (Participant 3) as well as being "*active and energetic"* (Participant 2) and thus these were notable signs of improvements for their ill child.

Most primary caregivers were pleased with how their child with CHD was doing after the intervention and for some, even their own health, had improved as is illustrated in the quote below:

> *"I actually feel healthy; I feel relieved after the operation because [the child's] condition before was very scary but after the operation [the child] is way much better... I am very*

> *happy in taking care of my child and I see her growing and I can take of my child until my child can take care of herself"* (Participant 6, 32 years old with 1 years old daughter)

Participant 4, whose mum had developed high blood pressure at the time of diagnosis of child with CHD as well as excessive loss of weight, mentioned how even her mother's health was also *"improving"* thus demonstrating the benefit of the intervention on other family members too. Furthermore, this particular participant stopped blaming herself as can be demonstrated by the quote below:

> *"Before, I was having so much stress, and asking my myself why my baby is like this, what I (have I) been done to God… yeah… I'm happy now, I'm not blaming myself anymore"* (Participant 4, 23 years with 3 years old daughter)

4.12. Coping mechanisms used by the primary caregivers.

When asked how primary caregivers coped with the various challenges, three participants shared extrinsic factors like their neighbours in their communities "*bought rice and put in the house*" (Participant 1) or "*oil or groceries for the house, or sugar*" (Participant 7) and sometimes the "*neighbour understands the situation (financial challenges)*" (Participant 4) and thus lends the primary caregiver money in times of need.

Many primary caregivers (Participant 1, 2, 4, 5 and 8) shared how help from "my mother" (Participant 2) or "sister" (Participant 8 and 2) were ways of coping with "daily chores" and *"taking care of other children"* (Participant 4). Similarly, interviews also revealed assistance from primary caregivers' husband/partner when they were home, they "*helped with taking care of the children"* (Participant 1 and 3) as well as *"bath(ing) the child, and spends time with the child whilst I am relaxing"* (Participant 5)

Not only did family members assist with practical help, one participant (Participant 2) shared how her family was *"supporting her with words"* and encouraging her to *"look for a job"* and offering to take care of the baby.

Many of the participants described how they found ways within themselves to cope with dealing with having a child with a cardiac defect. For example, four primary caregivers (Participant 2, 5, 6 and 7) shared how their spirituality and connection to God helped them get through difficult times as can be demonstrated in the quotes below:

> *"I am very spiritual and I open the bible… I open the bible and that's what gets me through this"* (Participant 5, 37 years with 7 months old son)
>
> *"The only things I do is prayer and ask from God to intervene and assist me in ending all the problems I am encountering."* (Participant 6, 32 years old with 1 years old daughter)
>
> *"It's Jesus that gives me strength to go through all this problems"* (Participant 7, 43 years old with 9 years old daughter)

One primary caregiver also added that she (Participant 2) "usually buy the things that I need, more than the things that I want" and thus was sacrificing her own needs to ensure the needs of the child with CHD were prioritized and met.

Many of the primary caregivers, despite the numerous adversities they were experiencing, were resilient and hopefully optimistic about the future health of their child:

> *"Now that she (child with CHD) is alive and no additional problems so I have hope now"* (Participant 6, 32 years old with 1 years old daughter)
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All primary caregivers interviewed described feelings of "happiness" and "relief" after bringing their child home after the cardiac intervention. Participants also shared how their child with CHD was "eating and gaining weight" (Participant 3) as well as being "active and energetic" (Participant 2) and thus these were notable signs of improvements for their ill child.

Most primary caregivers were pleased with how their child with CHD was doing after the intervention and for some, even their own health, had improved as is illustrated in the quote below:

> *"I actually feel healthy; I feel relieved after the operation because [the child's] condition before was very scary but after the operation [the child] is way much better... I am very happy in taking care of my child and I see her growing and I can take of my child until my child can take care of herself"* (Participant 6, 32 years old with 1 years old daughter)

Participant 4, whose mum had developed high blood pressure at the time of diagnosis of child with CHD as well as excessive loss of weight, mentioned how even her mother's health was also "improving" thus demonstrating the benefit of the intervention on other family members too. Furthermore, this particular participant stopped blaming herself as can be demonstrated by the quote below:

> *"Before, I was having so much stress, and asking my myself why my baby is like this, what I (have I) been done to God… yeah… I'm happy now, I'm not blaming myself anymore"* (Participant 4, 23 years with 3 years old daughter)

4.12. Summary of findings

This chapter has presented the results of the study findings. It started off by describing the primary caregivers' experiences at the time of diagnosis of their child.

Thereafter, the findings described in detail, the demographic data of each primary caregiver followed by an overview of the average earnings per family as well as the various living conditions with reference to their family size and access to basic needs like water and electricity.

This situational context of each primary caregiver revealed a number of challenges related to their living conditions and the impact it had on the routines and care needs of the child with CHD and the households. For example, lack of access to clean, tap water within the home made it difficult for primary caregivers to manage their household routine tasks like cooking and cleaning whilst also ensuring their child and other family members had food available on time. The task of fetching the water from a distance and leaving their child/children unsupervised at their homes, also created significant fear for some of the primary caregivers as they were often concerned about the safety of their child/ children during this time. Another significant living condition challenge was overcrowding within the households related to their family size and limited living spaces. This also deprived the family of privacy at times as well as exposing their child with CHD to, for example, uncomfortable sleeping arrangements or play environments, whilst they are in their recovery period after the intervention.

In addition to their poor living conditions, all 8 primary caregivers highlighted the dire financial hardship due to widespread unemployment within each household- primarily, in the case of the primary caregivers, as a result of the special care needs for their child who recently underwent a cardiac intervention. This financial hardship was re-affirmed as all 8 primary caregivers total combined monthly income per participant per household ranged from as little as R264- R750 per person per month placing them below the lower bound poverty line of R840 per person per month, according to the National Poverty Lines in South Africa during the year 2020 (STATS-SA, 2020). However, COVID 19 impact cannot be ignored as presented above.

The financial challenges that they identified made it difficult to provide, for example, the nutritional needs and clothes for their ill child as well as other children under their care. Transport costs to and from the healthcare provider negatively impacted the financial status of the home and subsequently the various needs within the household. In some cases, due to the cost of transport, primary caregivers did not attend child with CHD follow up appointments.

Lacking the time to manage their own health and feeling alone was another challenge that was highlighted by many primary caregivers. This lack of time to care for themselves (Self Care) was a result of them having to fulfill multiple roles in the home simultaneously: primary caregiver of the child with CHD, adult responsible for managing the household, guardian of the other children.

Despite the above, the analysis of the results suggest that primary caregivers acknowledged the support of the community, family and their partners and found their own coping mechanisms to assist them to navigate the difficult circumstances. It appeared that amongst all of those interviewed there was an immediate sense of relief and joy after the cardiac intervention- more so a sense of hope for the survival and future of their ill child.

As described in this chapter, the 8 primary caregivers that were interviewed identified a number of unmet needs when taking care of their child post-cardiac intervention. The priority ones being a need for obtaining employment as well as some form of counselling to support themselves to assist them to emotionally manage their tasks as the primary caregiver.

In the next chapter, Chapter 5, the researcher will discuss these findings in relation to current literature.

COVID 19 Lock Down Considerations

At the time of the interviews the country went into a National lock down Level 5 in March 2020 and until approximately June 2020, due to the COVID 19 virus. Interviews were conducted in April until June 2020. The following should be considered.

Unemployment

As described in the results section, participants as well as family members were either unemployed or employed on a part time basis and their reasons alluded to the care needs of their child with CHD post-cardiac intervention. However, unemployment opportunities in the informal sector was also influenced by the economic state of businesses as a result of the Level 5 lock down and limited trade during this time. As participant 5 noted, “Generally, the lock down has impacted us, well baby is fine, gaining weight, but because there is a shortage of income, that has impacted on us heavily because now I can’t even go and make some peace job (usually a home based income generation stream) by baking because of lock down” (Participant 5, 37 years with 7 months old son) and the sentiments shared by Participant 8 ,25 years old with 8 month old daughter, “ so we both work (partner and participant) but because of the pandemic, I also lost my job”

Subsequently even though participants cited reasons related to care needs for their child with CHD, unemployment and loss of jobs was significant during this time.

Isolation

Study findings revealed that participants felt isolated from friends, family and neighbours, as a result of the dedicating more time for taking care of the of the needs of their child with CHD post-cardiac intervention. However, yet again, there was also an imposed isolation due to COVID 19 lock down that restricted movement of the public at large. This was justified by the need to curb the spread of the virus. And as quoted, “so now we are struggling, we are struggling cos there is lock down and the child with CHD wanted to go and play outside but we are not allowed to go outside” (Participant 4, 23 years with 3 years old daughter. Thus the study must account for the possibility that social isolation could have been influenced by the country’s lock down.

Food insecurity

During lock down many families especially the vulnerable families faced challenges of securing food due to limited access and supply of food and food outlets. Most participants lived in low cost informal communities where “corner shops” and street vendors had to be shut down in order to adhere to social distancing to curb the spread of the virus. Thus

CHAPTER 5: DISCUSSION

5.1. Introduction

This study aimed to explore and understand the experiences of primary caregivers who were taking care of a child who recently underwent a cardiac intervention at a tertiary level hospital in KZN, South Africa. In the semi-structured interviews, a description of both the positive and negative experiences of primary caregivers was captured. Environmental factors, such as the very basic living conditions of the participants, and the various roles that the primary caregivers played within their home environment - whilst mothering their child who had a cardiac intervention was explored at length. The importance of the psychological and emotional well-being of the primary caregivers whilst taking care of their child in the context of their home environment was highlighted in the interviews. The financial stability of the households, and how this was impacting on the primary caregiver's ability to care for their child was also considered in this study. Included in this study was also an account of the primary caregivers' experiences upon receiving the diagnosis of CHD in relation to their child with CHD. In this chapter, some of these key findings are reflected upon and considered in relation to the existing literature.

5.2. Primary caregivers' experiences at the time of the diagnosis of their child

5.2.1. The timing and misdiagnosis of a congenital heart defect

Correctly and timeously diagnosing a congenital heart defect on a child can have many implications for both the child with CHD and the primary caregiver. In this study, the majority of the participants (5) were informed early in their journey of their child's CHD condition. This early diagnosis translated to a swift intervention – which was experienced as both beneficial to the child with CHD and the primary caregivers. In most cases in this study, primary caregivers were very concerned about the survival of their child at the time of the diagnosis. As one of the participants shared *"(I thought) my baby is going to die"* (Participant 2), months old daughter). This narrative is in keeping with the study by Bruce et al. (2014), where at the time of diagnosis, it was also noted that the focus of the mothers' concern rested on the survival and well-being of their child.

When CHD conditions are detected, diagnosed and subject to interventions as soon as possible, there is decreased morbidity and increased survival (Carvalho, 2016; Yun, 2011). This swift diagnosis was unfortunately not so evident for Participant 7 (a 43 year old mother with 9 years old daughter), as her journey "*all started around when she (the child with CHD) was 5 years"* and *"she (the child with CHD) only got to the tertiary hospital (the study setting) when she was 8 years"* thus describing a long duration of 3 years before a final diagnosis was made. Initially, at the local clinic she was told to give her baby "*vitamin A, vitamin C and if her (the child with CHD) blood is purified and cleaned...then her (the child with CHD) irregular heart beat will be gone*". Further on her child was diagnosed with other conditions such as "*Tuberculosis and lung cancer",* understandably equally life threatening conditions for the child and stressful for the primary caregiver. However, both these diagnoses were eventually ruled out. Congenital heart defects are often assumed uncommon in children and subsequently health care workers do not suspect a heart condition at first, and children are often treated for other conditions (Bode-Thomas, 2012).

Another participant who experienced delays in the CHD diagnosis of their child (Participant 6, 32 years with 1 years old daughter), pointed to the possible lack of adequately trained health personal at the primary care level. This participant had taken her daughter to the local primary health care facility on numerous occasions but was incorrectly advised by the nurses. The primary caregiver noted that the nurses described the hypoxic (darkish, blueish skin colour) presentation of the baby as *"the baby was gonna be like the father so it was a process of transition, he would also (become) dark (in complexion)"*. This misdiagnosis was confirmed as such by the doctor at the same clinic a few months later *"when I told them (the doctors) what the nurses have been saying, then the doctor said they (the nurses) were clearly wrong*". Similarly, the findings by Rashid et al. (2016), also found that the misdiagnosis of children with CHD was largely due to gaps in training of healthcare staff in managing children at the primary healthcare level.

Quite understandably, at the time of diagnosis primary caregivers in this study reported experiencing a significant amount of concern and worry for their child. These concerns can be further amplified when, according to Bruce et al. (2014), mothers felt stressed and helpless when the diagnosis took *too long*. This was certainly the case of the two participants in this study who experienced a significant delay in their child's diagnosis (Participants 6 and 7).

5.2.2. Processing and managing the diagnosis

Participants also reported experiencing a deep sense of sadness, grief and emotional pain when receiving the diagnosis of their child. Being told that your child has a heart condition can be a traumatic experience for many parents as was the case of Participant 3 (21 years with 8 months old son), who was told that *"he had a large PDA- in the heart is a hole"* and her immediate response was "*I was so sad…it was painful*".

The stress that the primary caregivers experienced on receiving their child's diagnosis naturally had an impact on their own well-being. This scenario was illustrated in this study in the case of Participant 2 (23 years with 15 months old daughter) who described in detail her mental state at the time of diagnosis: - "*It (the diagnosis) made me feel stressed*" and "*I was like…losing my mind*". It has been reported that this feeling of stress at the time of diagnosis is common and in keeping with many previous studies conducted amongst parents of children with CHD (Lisanti, 2019; Robyn Smith, 2017; L. M. H. Vivian et al., 2021; Wei et al., 2015).

The sudden and unexpected news of a diagnosis, such as CHD, can leave one feeling emotionally overwhelmed and with a lot of information to process - as was the case in this study with Participant 8 who was asked not to be present at the time of the intervention as she could not stop crying when they told her what was wrong with her child.

Nonetheless, participants shared that when they were informed of their child's cardiac condition, the doctors at the Paediatric Cardiology Clinic where this study was conducted, did offer some support to patients by communicating to them the nature of what was wrong with their baby and how they, at the hospital, would be able to help their child. However, most of the primary caregivers revealed that they were not aware or offered access to counseling for themselves, upon receiving the diagnosis of their ill child. Primary caregivers felt that access to counseling at that critical time (of diagnosis) would have been beneficial for them as they were overwhelmed with worry and concern about the survival of their child. This was illustrated in this study in the case of Participant 6 (a 32 year old mother with 1year old daughter), who described that had she been offered a counsellor:

> *"I will explain to them (counsellor) about how (she) feels and all the problems I am encountering but if it was not provided, I would make means to survive but most importantly I would ask for support".*

This was similar to a study by Arya et al. (2013:78), where parents at the time of diagnosis of a CHD, "would prefer to receive more counseling and education in the prenatal and newborn period than cardiologists perceive is wanted." One primary caregiver though (Participant 2, 23 years with 15 months old daughter) was satisfied with the counseling received as she stated "*well the only counseling I got was from the doctors and they did a great job*".

Primary caregivers in this study were found blaming themselves for the diagnosis of their child's CHD condition. This is in keeping with the findings by Zhi Hong et al. (2019) and Wei et al. (2015), where parents felt responsible for their child's condition. According to Wei et al. (2015) this behavior can be explained by the attribution theory, where people associate cause to try to understand what they are experiencing (Weary et al., 1980; Wei, 2015). In this study this resonated with the primary caregiver (Participant 4, 23 years with 3 years old daughter) who initially was *"asking myself why my baby is like this, what I been done to God"* and eventually after the intervention expressed how *"I'm not blaming myself anymore"*, revealed her feeling guilty for her child with CHD's condition. One primary caregiver (Participant 1 with 10 month old daughter) thought that as a mother she should have known what was wrong with her child, and shared how "*It (the diagnosis) made me feel stressed and terrible as a mother, that my baby was born with this and I didn't even know"* and perhaps could have prevented in some way their child from being diagnosed with CHD.

Unlike in the findings of the Wei et al. (2015) and Vivian et al. (2021) where some parents, at the time of diagnosis, were both sad and fearful and others happy and hopeful, in this study only one primary caregiver (Participant 7) shared how she was *"relieved and happy that they found out what was wrong with her (child with CHD)"*. However, none of the other 7 primary caregivers in this study expressed feelings of hope or relief when receiving the diagnosis of their child. This feeling was expressed only after the intervention.

5.2.3. Primary caregivers understanding of their child's heart condition

Mothers of children who have primary, secondary or higher education have increased health care seeking behaviours (Adedokun & Yaya, 2020). In this study, all the primary caregivers had secondary education ranging from Grade 10 until the completion of school at Grade 12. Notably, not only did the primary caregivers in this study seek out medical care for their child with a CHD, they also did not object to the treatment offered from the Paediatric Cardiology Unit, the setting for this study.

However, whilst the 8 primary caregivers in this study demonstrated positive health seeking behaviour, many of them did not fully understand what was wrong with their child and why their child was experiencing these symptoms. One participant (Participant 6) described how at first she couldn't *"pronounce the term to describe the condition...I can't… factory or…factory"* but later on she understood that there was a heart problem.

This was similar to a study by Cheuk et al. (2004), conducted in Hong Kong where parental education and occupation were significant determinants in understanding heart defects amongst their child with CHD. Furthermore, how parents/ primary caregivers received the diagnosis was also associated with their educational level where primary caregivers with poor educational levels responded with increased stress and anxiety during hospital admission and long term care of children with CHD as reported in a study in South Africa (Vivian et al., 2021). Thus, the increased level of stress amongst the primary caregivers at the time of diagnosis, in this study could possibly be explained by them not completely understanding the nature of their child's heart condition.

As Participant 1 in this study shared:

> *"At first I didn't understand. I was curious. Worried and confused. But then when they explained me like about 2 or 3 times, then I said no, my baby really needs this, I have to go ahead with it"* (Participant 1, 23 years with 10 months old daughter)

Similarly, previous studies reinforce that primary caregivers of a child with CHD have heightened worry and concern when they don't fully understand what is wrong with their child. This was observed in studies conducted by Harvey et al. (2018) and Biber et al. (2019)

conducted in the USA and Germany respectively, and also observed in this study where the primary caregiver referred to above revealed that they felt *"worried, lost and confused"* about what was wrong with their child which stemmed from their lack of understanding of the cardiac condition.

In this study, whilst primary caregivers basic understanding of their child's CHD condition may have brought on increased feelings of stress, it did not create a barrier for coming to terms with the diagnosis or receptiveness of their child's condition. For one participant, she said *"but the doctors tried to comfort me and say the operation is going to help her…we need to do the operation, because we need to…we need to help your baby…yeah, I understand …"* (Participant 4, 23 years with 3 years old daughter). Thus even though some of the primary caregivers were not completely knowledgeable about their child's heart condition, they still accepted what the doctors were saying and more importantly proceeded with the intervention. This was unlike the study by Azhar et al. (2018) conducted in Saudi Arabia amongst 115 primary caregivers, where primary caregivers were more receptive and accepting of their child's condition only when their understanding of the condition improved.

Despite having a limited understanding of the diagnosis and prognosis of their child with CHD and the apparent lack of formal counselling services being provided to the primary caregivers in this study, all the caregivers appeared to "hear" or "accept" what was wrong with their child and agreed to the treatment options offered by the tertiary level hospital, the setting for this study.

5.3. Primary caregivers' financial experiences within their home environments

Participants and their families in this study were living in significant poverty. For example, one of the households in this study (Participant 7) which had the smallest reported monthly income (i.e. R880), meant that the 3 family members had to each survive on R293 per month. At the other end of the income spectrum in this study, Participant 1 (with their 10 other family members in the household), and a reported monthly income of R 4 180 – meant that each family member had to survive on R 380 per month.

The amount in South African Rands per grant benefit in 2020 (the year in which this study was conducted) is tabulated below (Table 6):

Table 6: South African Grants- amounts of grants as at 01 April 2020

Grant type	Amount payable 01 October 2019	Amount payable 01 April 2020	Amount payable 01 October 2020
Older Persons Grant (Old age pension)	R 1 780.00	R 1 860.00	
Older Persons Grant (Old age pension) Beneficiary older than 75 years	R 1 800.00	R1 880.00	
Disability Grant	R 1 780.00	R1 860.00	
War Veteran's Grant	R 1 800.00	R1 880.00	
Grant in aid	R 430.00	R 440.00	R 450.00
Child Support Grant	R 430.00	R 440.00	R 450.00
Foster Child Grant	1000.00	R 1040.00	
Care Dependency Grant	1780.00	R 1860.00	

Adapted from You and Your grants 2020/21 (SASSA, 2020)

In the other 6 households, it was a combination of specific grants like PG or CSG, and generally one or two adult members of the household who were employed – but only on an ad-hoc and part-time basis. These employment opportunities were also within the informal sector such as painting of houses, tiling, construction work as well as being a part time domestic worker.

The total income per month per participant household ranged between R880 - R4180 (see Table 4). When dividing the total monthly income per household by the number of household members, the data revealed that two households had as little as R264 and R 293 per person per month to spend (Participant 6 and 7 respectively), with other households having slightly more i.e. R 660 and R750 per person per month allocation (Participants 5 and 8 respectively).

The monthly amount of money available per person in each of the 8 participant's households' places all of the households in the lowest category of three of the country's national poverty lines (SASSA, 2020), namely:

- the food poverty line, which was set at R585.00 per person per month (in April 2020 prices). This refers to the amount of money that an individual will need to afford the *minimum* required daily energy intake. This is also commonly referred to as the "extreme" poverty line.
- the lower-bound poverty line, set at R840.00 per person per month (April 2020 prices). This refers to the food poverty line *plus* the average amount derived from non-food items of households whose total expenditure is equal to the food poverty line.

- the upper-bound poverty line is set at R1268.00 per person per month (in April 2020 prices). This refers to the food poverty line *plus* the average amount derived from non-food items of households whose food expenditure is equal to the food poverty line. (STATS-SA, 2020).

Whilst the participants were not asked to share all the details of the general household expenses, they were asked how much it cost them to travel to and from the Paediatric Cardiology clinic at the hospital to receive the care that they needed for their child. Seven participants utilized public transport to and from the hospital whilst one participant was reliant on a family car within their broader family group (Table 4).

The hospital transport costs varied amongst all eight participants. For some participants (Participant 4) who lived in close proximity to the hospital (IALCH) they spent approximately R60.00 per hospital visits whilst other participants (Participant 6 and 8) lived at a distance from the hospital and it had cost them as much as R250.00 per visit. In addition, some participants (Participant 1, 2 and 3) lived approximately the same distance from the hospital but because they traveled from different districts thus their travel costs also varied from between R50.00 (Participant 3)- R100.00 (Participant 1) per hospital visit (Table 4). The proportion of hospital transport versus the household income also varied for all eight participants. For example, Participant 8 hospital transport cost is equivalent to 8.3% of their monthly income; Participant 3 hospital transport cost is equivalent to 11.3% of their total monthly income and Participant 7 utilized approximately 20% of their monthly income per hospital visit. Thus for some, transport costs were manageable whilst others had a heavy burden of transport cost. The extent and impact of these meagre earnings will be elaborated on in the sections hereafter.

5.3.1 The financial challenges faced by the primary caregivers

Whilst the reported monthly income of the households of the 8 study participants (as outlined in Table 3), might not be totally accurate: for example, a participant could have easily forgotten to include a source of income, or found it difficult to provide an average monthly income when the ebb and flow of informal employment opportunities is so variable from month to month, this data likely provides one with a reasonable estimate of the depth of financial insecurity and material deprivation that each of the 8 primary caregivers and the members of their household found themselves in. This is also the setting to which the children with CHD were returning post-cardiac intervention.

Whilst poverty has dropped in the post-apartheid period in South Africa, inequality remains significant and unemployment has increased (Isaacs, 2016). South Africa's Census and Economic Information Center (2021) noted that unemployment in South Africa was at 36.989 % in December 2020. As illustrated in Table 3, a number of adults were reported as unemployed in each of the primary care giver's households at the time of the interviews in 2020. Furthermore, participants, their partners and other family members in this study worked in informal jobs that did not guarantee a regular income on a monthly basis.

The interviews also highlighted that the caregiver's need to take care of their child with CHD after the intervention also impacted on their potential to maintain or obtain employment during this time. For example, Participant 6 (a 32 year old with 1 year old daughter) shared her fear of being away from her daughter with CHD and thus did not continue to seek employment opportunities:

> *"for now…for now...it's quite difficult for me to think that I can leave anyone else with child with CHD because child with CHD is on treatment…and some people might not give the treatment accordingly...so therefore in this point in time I would like to take care of child with CHD by myself".*

These findings are similar to the studies by Smith (2017) and Connor et al. (2010) conducted in South Africa and the United States of America, respectively where parents gave up their jobs in order to be more actively involved in taking care of their child post an intervention and where mothers were fearful to leave their child and return to work due their child's heart condition.

Some primary caregivers also reported that their partner's employment was also impacted post the cardiac intervention. A husband and wife in this study (participant 5, 37 years with 7 months old son) reported that post-cardiac intervention, they both faced employment challenges:

> *"it (the operation) impacted on them heavily, because I had to stop doing my normal business of baking because now I have to look after the child, go to the hospital now and again…and my husband as well has lost some opportunity to go and work because he has to support me, to be there at the hospital with me".*

This was also the case for parents of the study by Connor et al. (2010) in the United States, where both parents indicated an immediate loss of their jobs when they brought their child home after the cardiac intervention and to prioritize the care of their child with CHD post-cardiac intervention.

5.3.2. Facing the additional expenses required to support their child with CHD

Parents in a study by Ludomirsky et al. (2020), in the United States of America, described the increased nutritional needs of their child post a CHD intervention as a significant cause of financial hardship and food insecurity. In this study all eight primary caregivers reported that the child with CHD had improved nutritional uptake post the cardiac intervention. This was seen as a positive development but it also meant that families had to increase their spending on food in order to meet the needs of the child with CHD. One participant (Participant 1, 23 years old 1 year old daughter) elaborated on this:

> *"Okay…before the op she was barely eating much food which was different and difficult. Like before she should only eat purity and stuff...now after the op, she's eating normal kind of food which costs more, those things...it changed in a massive way because now the kind of changes we need changes our budget which had to be for her needs because she really really cannot change her options".*

Thus whilst the improved nutritional uptake was a welcomed development for the child with CHD, primary caregivers struggled to meet the needs, in specific, nutritional needs of their baby bringing with it a further dimension of financial difficulty.

As previously discussed in Chapter 4, transport costs to and from the hospital was a significant expense for all the primary caregivers in this study, adding a different but additional dimension to their financial difficulties. This was in keeping with the study by Gerber et al. (2010), where one of the most significant direct non-medical costs was the high transportation cost for the child with CHD to access medical care.

The additional financial burden of transport costs for participants in this study, in a context where their monthly income was very small, placed a heavy toll on the primary caregivers, as is illustrated, for example, by Participant 6 (32 years with a 1 year old daughter) who stated:

> *"So it is quite difficult for me whenever I have to take the R200...to take my baby to hospital or clinic whenever the need arises and again my main challenge is that I am unable to (meet) other needs that baby has to an extent that at some point for most of the time that I take the baby to clinic or hospital, my baby would run out of food before the months end so that's a very big challenge and I don't know where to get the food or the additional money to buy anything that my baby might need especially after I take a trip to take the baby back to the hospital or the clinic".*

This primary caregiver went on to further describe how other children in the household were deprived of scholarly needs in order to ensure that the sick baby received the medical attention needed:

> *"Yes it (money used to travel to and from the hospital) does have an impact…for example the ones that are in school… sometimes when they need things or the school requests for things I am unable to provide or sometimes the school would ask for R20 to contribute towards something I am unable to contribute towards that because I don't have the money or one of them would run out of school shoes and I don't have money because I spent in on (the child with CHD)...I don't have money to replace those shoes...,so yes it does affect the others negatively".*

Sadly, one primary caregiver reported how they could not afford the hospital trip and thus missed their child's appointment at the hospital:

> *"My budget is deeply disrupted, because I have to take out an average of R200 just for transport, for taking her back and forth to hospital, and with what is remaining or is left I have to buy groceries for the house, buy electricity, pay for water and...the price is quite stiff or was quite heavy for me because if I am travelling alone I will be paying R74, but if my daughter is travelling with me, I will be paying R150 or R180 something, so then that was very problematic to the extent, I was meant to go for her appointment on the 28th and then I cancelled because of the money,."* (Participant 7, 43 years old with 9 year old daughter)

These findings was similar to a study by Zhi Hong et al. (2019) where families experienced a high economic burden due to the various hospital visits post-cardiac intervention.

The one financial relief that participants in this study had was the no surgical and/or minimal hospital admission costs that they had to pay when attending the tertiary level hospital given it was a public health facility. This was unlike other studies conducted in Pakistan and China that reported families experienced high cost burdens related to the hospital and surgical interventions for their child with CHD (Mughal et al., 2011 and Zhi Hong et al., 2019).

Participants also reported many other supportive care needs for the child with CHD and other siblings that could not be met due to their limited resources. These supportive care needs included items such as winter clothes, toys for their children as well as personal items for primary caregivers themselves. The primary caregiver's limited ability to provide these material needs was an additional significant stress. Primary caregivers also felt despondent about their inability to provide these items, which they acknowledged was their responsibility to shoulder.

The challenges faced by the primary caregivers in not being able to provide sufficiently for the child with CHD and their siblings ought to be considered in the context have already impoverished households who were unable to meet the basic needs of their families due to the significant presence of poverty. Challenges of these primary caregivers were similar to the challenges of primary caregivers of children with HIV in a study by Mafune et al. (2017), in the Limpopo Province, South Africa. The findings of that study reported that participants i.e. caregivers of children on anti-retroviral therapy, faced similar financial burdens around the cost of transport to their follow-up appointments and similarly having limited financial resources for food as well as clothing for the child with CHD.

The researcher was aware of the constant presence of financial distress amongst primary caregivers interviewed in this study. Their financial distress clearly impacted on aspects of the daily function as a family or household. Ahmed (2018), drawing on the "Family Stress Model" noted that families in poverty often experience high levels of depression and family dysfunction as a result of their poverty. In this study, the financial challenges noted above often tended to increase post the cardiac intervention.

5.3.3. The mechanisms used by primary caregivers to cover their additional expenses

Primary caregivers in this study resorted to short-term loans in cash or borrowing of food from neighbours when faced with food insecurity or financial hardship. One primary caregiver (Participant 1, 23 years with 1 year old daughter) described that this borrowing increased after returning home with their child with CHD post a cardiac intervention:

> *"okay, it (borrowing from neighbours) does happen more after the operation because errr….she (the child with CHD) really needs this and that stuff, and err…she (the child with CHD) likes really run short of medication. We have to go back to the hospital to get medication, so we have to use up that money to go to the hospital, so it's like more borrowing, now than before"*

Similarly studies by Raj et al. (2015) and Zhi Hong et al. (2019) in India and China respectively describe the primary caregivers borrowing money in order to meet the needs of their household post a cardiac intervention. However, unlike the study by Raj et al. (2015), where parents mortgaged their homes or sold their valuables in order to meet the financial needs of the home, in this study none of the participants claimed to have resorted to these measures. Part of this difference can be explained by the fact that none of the families in this study owned their homes and given their poor socio-economic status are unlikely to have had in their possession many valuables that they could have been redeemed for cash in order to assist them.

5.4. The familial and relationship challenges experienced by the primary caregivers

In considering this issue, it is important to bear in mind that the data offers only one perspective of the challenges within the families – as they the experiences as reported by the primary caregivers and not the perspectives of the other family members.

A number of authors (Almesned et al., 2013; Azhar et al., 2016; Lemacks et al., 2013), have reported that siblings felt neglected by their parents and often jealousy towards a child with CHD. Similar findings were reported in the accounts of Participant 1 in this study, her 7 year old son *"gets all emotional and says you (primary caregiver) only care about her (child with CHD)"* as well as Participant 4 stated that *"she (sibling) even complain that I don't love her like the other child [child with CHD]".*

Besides not only feeling jealous, primary caregivers also described how their other child would feel *"anger"* towards their ill brother/ sister and would throw a *"tantrum"* when feeling this way (Participant 1 and 7 respectively). This was similar to a study by Wray & Maynard, (2005), where siblings of children with CHD expressed anger and intolerance towards their ill sibling.

Furthermore, siblings also experienced anxiety, when, for example, Participant 4 shared how her 4 year old daughter became *"anxious"* when primary caregiver had to travel to the hospital with her 3 year old child with CHD. Notably, her 4 year old had a shift in behaviour where she withdrew by *"even refuse(ing) to go to school"* during these hospital trips. Similarly, a literature review by Parker et al. (2020), shared how siblings of children with CHD or other chronic condition, like cancer, experienced more changes in behaviour as well as internalizing problematic situations like being left behind as compared to siblings of children with for example less apparent life threatening illnesses like cystic fibrosis and diabetes (Havermans et al., 2015).

One participant also shared how her 7 year old son (sibling to a child with CHD) felt *"terrible and... you can say like he feels her emotions"* (Participant 1) when learning about something being *"wrong"* with their sibling. Similarly, siblings of life threatening cancer patients, were also concerned about the survival of their sick brother or sister and felt emotional when they observed the physical changes that occurred with the sick sibling (Dinleyici & Şahin Dağlı, 2018).

Primary care-givers also reported that they relied on the siblings at times to take care of the child with CHD whilst they attended to chores around the house. Some of these chores were a distance away from the home, like *"fetching water from the communal taps"* (Participant 1). Participant 1 also added that her 7 year old son (sibling to the child with CHD) would also *"partake in giving her(child with CHD) meds, and help to feed her (child with CHD)"*, similar to a study by Connor et al. (2010), where sibling were taking on responsibility for their ill brother or sister, by learning about their brother's medication, doctor's name as well as the phone numbers as forms assistance to primary caregivers.

Another issue raised by one of the primary caregivers in her interview was that the intimacy she shared with her husband had altered since bringing the child with CHD home. The responsibilities associated with caring for the child with CHD translated to a reduced amount of time for her spouse and in her own words *"the quality of intimacy"* with her spouse had decreased. Not many studies report on the quality of intimacy between parents with a child with CHD, however a study by Golics et al. (2013), reported that the impact of a family member's illness or disease can also affect the sex life of the parents of the child with CHD due to lack of time to spend with each other. This can potentially lead to marital dissatisfaction as discussed by Leon et al. (2013) where parents of a child with CHD described that the lack of intimacy as a cause for marital dissatisfaction.

In contrast to this, another participant (Participant5) described that her marital relations had improved and that she and her husband seemed to have more time for each other post the cardiac intervention. This was similar to a study by Wray & Maynard (2005) where they reported that 43% of families experienced a feeling of togetherness after the cardiac intervention.

The mixed experiences reported by the different primary caregivers regarding the positive and negative changes within their family relationships finding is similar to the results in a relationship satisfaction study by Dale et al. (2013), where a large number of mothers of children with CHD were satisfied with their marital relations and a significant percentage (12%) of mothers were not satisfied with their marital relationships and thus experienced marital dissatisfaction. Furthermore, a study by Gaskin (2018), found that the participants of a child with CHD in that study revealed that their marital relations had taken a strain during the hospitilisation period and for some even immediately after returning home, however, over time the relationships improved as the health of the child with CHD improved.

5.5. The challenges of providing care in poor living conditions

Parental stress was one of the keys theme that emerged from the interviews. A number of factors contributed to this – some of which have been described above. Another stressor was that of the physical environment in which the primary caregivers was having to care for their child with CHD. A recent study by Vivian et al. (2021) in South Africa, revealed that parental stress was significantly influenced by the socioeconomic factors like poor education, ethnic and language differences, community disempowerment and poverty. The consequential effects of poverty and their impact on the participants in this study is explored further below, specifically in relation to the physical environment in which the caregivers were providing care for the child with a CHD.

As mentioned previously, the majority of the participants lived in informal settlements which are commonly referred to as "shacks" by the locals. These shacks are make-shift homes built from cheap unapproved building material. This type of informal settlement obviously has a range of negative impacts on parents providing care to their children (Meth, 2013).

Therefore, unique to this study, was the revelation of the impact of such living conditions, like shacks or tin houses, on the primary caregiver and inadvertently on the care of the child with CHD with reference to CHD. Not many studies discuss poor living conditions and CHD, however, there is vast literature that present the effects of poor living conditions and other health outcomes amongst primary caregivers and children in general and these will be considered given the paucity of literature specifically related to CHD. According to Clair (2019) living conditions may influence the care of children through a number of processes.

For example, the building materials of the home contributed greatly towards the constant concern and worry that primary caregivers experienced whilst taking care of their child post-cardiac intervention. This was mentioned by 5 participants (Participant 1,2,3,4 and 6). They had fears around the possible *"collapse"* of the home that could cause injury to their families. This was similar to the study by Meth (2013), conducted in an informal settlement in Durban, KZN, South Africa, where poor structural material was a cause of parental anxiety. In addition, primary caregivers were also stressed about the poor ventilation, damp surroundings and unhygienic neighborhoods that could affect again the health of their already vulnerable child with CHD. This was in keeping with the findings by Beasley et al. (2015) where dampness in the home affected the respiratory condition of both adults and children in the household thus bringing about added stress.

Understandably, the limited sleeping and living areas in a one bedroom *"shack"* for a number of participants led to significant overcrowding within the household (Table 5). For example, Participant 3,4 and 6 only had one bedroom with no kitchen or living area with an average of 3-4 people per household. Another participant (Participant1), whose family consisted of 11 family members, had a tin house with 3 bedrooms and a kitchen. The lack of space within the home and the poor hygiene outside the home meant that children with CHD were confined to small spaces within the home during recovery period. Participants described how uncomfortable it became for their child with CHD when for example, *"cooking inside here while the baby is sleeping and then the baby starts sweating and then it just becomes difficult for everyone"* (Participant 6). In addition, Participant 1 described how her marital relations with her husband had suffered as she had to *"share the bedroom with both her kids"* and this meant she had minimal privacy. Thus the overcrowding in the small, informal homes no doubt increased the parental anxiety amongst many of the primary caregivers.

These challenges can be confirmed by Meth (2013), where the direct source of parental anxiety was traced to the size of the house, the number of people living in the home, the lack of room boundaries within the home, shared spaces such as kitchen and bedrooms as well as minimal privacy for parents to enjoy their sexual life.

Nearly all the participants in this study reported how the lack of basic amenities like access to water, sanitation and electricity was a major challenge that impacted on how they took care of their families and implementation of their daily routines. These challenges were reported as being exacerbated post-cardiac intervention due to the additional care needs of the child with CHD.

The act of collecting water for household use, for some participants (Participant1, 3 and 4) posed both a danger and a source of possible infection for the child with CHD due to the source of the water supply (a communal tap or a river) as well as the distance of the water supply away from the home. One primary caregiver (Participant 1) detailed how psychologically and physically challenging it was to carry her 10-month old child with CHD and buckets of water simultaneously from the communal tap to her home. She was in constant fear of either *"letting go of her child or the water"* and it became an internal mind game of balance and motivation until she finally reached home. Another participant (Participant 4) who also resided in an informal settlement, stated that due to the high occurrence of rape in the informal settlement, she would *"lock her 4 year and 3-year old daughters in her room"* as there was no one else to care of them whilst she collected water. Thus fetching water for household needs was mentally traumatizing for the participants in the current study.

Similarly, illegal electrical connections were a hazardous situation that primary caregivers recognized for both the child with CHD and any other siblings in the family. These illegal connections meant that when children were unsupervised for a considerable amount of time, they may *"touch the exposed electrical wires"* making them vulnerable to electrocution and bodily burns. In this study, primary caregivers who connected with electricity illegally, expressed fear and anxiety "*because people are dying because of this electricity"* (Participant 4).

Furthermore, lack of electricity meant that primary caregivers resorted to various unsafe and unhealthy cooking methods like outside fires (Participant 1) or paraffin stoves. Here too, primary caregivers were concerned about their child being burnt by the open fires as well as the health risks to paraffin stoves and smoke inhalation.

Another hygiene concern was the lack of flush toilets within the parameters of the home that added to the difficulties in the care routines of primary caregivers. Utilising the pit latrine system, a non-functional flush system or a communal toilet for many individuals meant fear of increased risk of health issues for the primary caregivers and their families. This risk was even more concerning for their child with CHD who only recently had a cardiac intervention and whether the utmost care is needed to ensure that the child with CHD does not contract any infections.

Managing the care of their child with CHD and the household needs in impoverished neighbourhood and unsafe surroundings is a considerable source of stress for most of the primary caregivers in this study. This echoed the findings by Gee & Payne–Sturges, (2004), where communities with poor resources amongst issues like violence, crime and pollution produce an added challenge for parents. Again, these can be connected to the findings by Jones-Rounds et al. (2014), a study conducted in various cities in Europe, where the physical structures of the home and the poverty of communities impact heavily on the mental health of the inhabitants of the home.

The above findings where there is a significant lack of basic services and its impact on primary caregivers, are similar to the study conducted by Meth (2013) in KZN, South Africa, where parents in informal settlements expressed feelings of fear and anxiety when taking care of their children in a poor environment. Parents in that study witnessed the death of children due to electrocution and also revealed how unhygienic water and sanitation posed major health risks for their children thereby creating heightened levels of anxiety and fear for parents (Meth 2013).

Another concern raised by the primary caregivers was the lack of access that they and their children had to recreational facilities. All the participants reported that there were no recreational facilities nearby in their communities. Within the confines of the home, participants felt that children had *"no space for (the child with CHD) to play and her (child with CHD) sister to play"* (Participant 4). Post-cardiac intervention, one participant (Participant 2) shared how her *"baby was so active and she's (child with CHD) got a lot of energy"* and thus limited spaces did not cater for the needs of the child with CHD. This was in conjunction with not having access to play areas within the community as well as living in a community that was generally unsafe for children to play in. This left many of the participants feeling stressed and a sense of sadness for themselves and their child with CHD due to not having access to recreational facilities. Thus, primary caregivers felt almost like there was no reprieve from the poor homes as there was *"there's no swings or any other play facilities around"* (Participant 1) that they lived in where recreational facilities can be a means to decrease stress levels associated with poor living conditions. This was similar to the study by Jones-Rounds et al. (2014), where impoverished neighbourhoods and houses were a source of depression and stress for the inhabitants of that community. However, community facilities could serve as environments of restoration and relief for persons residing in low cost housing. If the home is not a place of comfort, then perhaps nearby facilities like parks and play areas could help lessen adversarial impacts.

Whilst many of the environmental challenges were always present in the lives of the primary caregivers prior to the intervention, they had a greater impact on the primary caregivers after the intervention of child with CHD. Post the cardiac intervention, primary caregivers experienced more than the usual stress, fear and anxiety associated with poor living conditions due to the constant increased concern of how their environmental constraints influenced the care processes and recovery of their ill child. The findings in this study were similar to Sandel & Wright (2006), who reported that housing problems in their study in the USA affected the care processes of children due to the stress and impaired functioning amongst the adults taking care of the children. In addition, Jones-Rounds et al. (2014), in their study in Europe found that the physical characteristics and neighbourhood quality affected the mental health of the individuals within the household.

5.6. The challenges of multiple roles of primary caregivers within their household

Whilst the environmental challenges created a significant amount of stress, a few primary caregivers also expressed how on top of all their routine tasks and household chores they had to manage within and for the household – they also had to keep a watchful eye out for any health changes within the child with CHD, and this impacted heavily on primary caregivers mental and emotional well-being. For example, *"when doing the laundry, suddenly child with CHD doesn't look okay and I have to leave whatever I am doing and do it later"* (Participant 6) or "*now that baby is at home, especially after the operation, I have to take her and give her meds and things, I actually get delayed doing the housework"* (Participant 1). Similarly a study by Gaskin, (2018) in the United Kingdom, found the mothers also felt the need to constantly watch over their child both at the hospital and when returning home after intervention.

As previously discussed, primary caregivers also had the role of mothering other children under their care whilst attending to the household needs and needs of the child with CHD. They sometimes *"focused all their time on (the child with CHD)"* (Participant 6) and often felt guilty and like they neglected their other children, similar to the findings by Lemacks et al. (2013) where mothers experienced guilt due to their perceived neglect to their other children and not having time or energy to address these issues. Parental guilt amongst parents of children with CHD was a significant emotion experienced by primary caregivers in studies conducted by Gaskin, (2018) & Lantin-Hermoso et al., (2017).

In addition, not living within an environment with nearby recreational facilities, also meant that in the home environment primary caregivers had to also make time for entertaining their children and offer "play" time thereby further diminishing time for themselves.

Understandably, the many roles of the primary caregivers has the potential to leave them experiencing physical strain and fatigue, which is keeping with the study by Simeone et al. (2018) conducted in the cities of Naples and Massa, Italy, found that in their study mothers were also exhausted and were suffering from psychophysical fatigue when they returned home with their child post-cardiac intervention.

5.7. The social isolation of the primary caregivers

In juggling the needs of the child with CHD post-cardiac intervention and the numerous tasks they needed to complete within the household, one of the primary caregivers shared how *"I have no time for myself"* (Participant 1). The lack of time for oneself was similar to the study by Zhi Hong et al. (2019), conducted in China where it was found mothers had very little time for themselves due to the constant burden of care for child with CHD and other household routines.

Another participant also shared *"I don't have time…baby is enough time"* (Participant 3) post-cardiac intervention of their child with CHD, also translated to decreased social activities. Participants no longer had time to keep up with friends and family as well as attending church for example since bringing their child home after the cardiac intervention. Personal care and a leisure activity like *"visits to the salon"* (Participant 1) was also not possible for some primary caregivers' post-cardiac intervention. Decreased leisure activities was similar to a study by Kiernozek, (2015), where parents of children with disabilities reported a significant lack of time for themselves due to the care needs of their disabled child.

A study by Jo Wray et al. (2018), in the United Kingdom, found that many CHD parents reported social as well as physical isolation when caring for child with CHD post a cardiac intervention which can lead to long term psychosocial issues. Similarly, in this study, being confined to the home because "*I have a baby that is not well so I cannot be roaming around the place"* (Participant 6) can leave primary caregivers sometimes feeling "*pathetic and lonely"* (Participant 1) is indicating that primary caregivers in this study are possibly also at risk of long term psychosocial issues. A concern that most certainly cannot be ignored.

5.8. The emotional health of the primary caregivers

Primary caregivers in this study were experiencing great sadness and hurt especially at the time of the cardiac intervention. As shared by Participant 2 *"every time I was sad and crying, crying"* or as Participant 6 described that *"I was hurt, it (the diagnosis) was very painful and scary"*. Authors have found that parental sadness and sorrow at the time of diagnosis and/ or intervention is commonly found amongst mothers of children with CHD (Vainberg et al., 2019; Leon et al., 2013). Other authors also describe how fear together with shock were also significantly present amongst primary caregivers (Vainberg et al., 2019; Lumsden et al., 2019), similar to this study.

A number of participants were still concerned about the health of their child like, *"if she (child with CHD) is going to get another operation"* (Participant 2) or uncertain about their dietary requirements post-cardiac intervention or as Participant 7 shared that her future concerns are how child with CHD will cope at school *"where there is overcrowding, and they running all over, pushing one another"*. This was also in keeping with a study by Amakali & Small (2013) where parents also expressed anxiety that the child with CHD will experience delays in their educational milestones. This emerged as a result of their fears of the child's inability to attend school or complete school due to ill health and regular hospital visits which could give rise to child with CHD social isolation due to their poor health and low education levels (Amakali & Small, 2013).

Primary caregivers in this study also mentioned how upon discharge they were not fully aware on *"how to care for the surgical area"* (Participant 3) but also other matters like appropriate nutrition for their child. This created an additional layer of fear for the primary caregivers similar to the study by Gaskin (2018), where parents were also concerned about not receiving adequate care information when transitioning from hospital to home.

The emotional and physical well-being of the participants in this study was often compromised due to various care taking and household challenges that primary caregivers in this study are faced with. Connor et al. (2010), described the meaning of cost when taking care of a child with CHD. More than 50% of the participants who were from a low to middle socioeconomic status group, stated that cost burdens were beyond monetary terms and included emotional well-being and overall family burdens that were life changing and uncertain giving rise to increased stress levels financially and emotionally.

Undoubtedly, the dominant source of emotional distress and concern for all primary caregivers in this study was related to their unemployment status at the time of interviews and "the fact that I am not working and it's a challenge" (Participant 5), with the challenges described in detail in sections 5.3, 5.4 and 5.5 above. The effect of this impact can be correlated with study by Lawoko & Soares(2006), where participants who were caring for an infant with CHD, found that financial difficulties were two to three times more likely associated with the experience of psychiatric stress. According to a review of the mental health problems in parents of children with CHD, in the United States, stress and fear amongst parents make them vulnerable to acute stress disorder (ASD) as well as post-traumatic stress disorder (PTSD)(Kolaitis et al., 2017). Poverty and reduced income/no income are leading causes of parental stress which is echoed in this study. It is similar to the study by da Silva et al. (2019) where components linked to poverty led to increased levels of distress or parental stress.

Understandably, the number of financial, familial and household challenges post-cardiac intervention, brought about significant amounts of stress for many of the primary caregivers in the current study. Kaugars et al. (2018) found in their study that 43% of parents of CHD had clinically significant stress when taking care of their child immediately after the cardiac intervention.

Despite experiencing a range of financial, familial and psychosocial challenges, primary caregivers in this study were optimistic for their child with CHD as they described the number of benefits for their child with CHD after the cardiac intervention. These will be discussed in the last section of this chapter.

5.9. Counselling services available to the primary caregiver

Psychosocial therapies have significant potential to decrease ongoing stress and emotional tension in caregivers of infants with CHD (Lazar & Hylarides, 2017). Furthermore, findings by Kolaitis et al. (2017), revealed that the need for this therapy was greatest in parents of children with CHD between the ages of 0-12 years, similar to the primary caregivers in this study. Parents cited that they would like to be referred to mental health professionals when faced with challenges like physical, emotional and social challenges.

However, primary caregivers in the study expressed that there was *"no counselling offered"* (Participant 6) from the healthcare providers either in the form of a social worker or a psychologist and *"they just told me the diagnosis and let it be"*. Primary caregivers expressed that access to a counsellor at the time of diagnosis for example, *"will be good because sometimes I can say I have anger"* (Participant 4) or as another primary caregiver shared that post the intervention, it will offer me an opportunity *"to talk about it (challenges post-cardiac intervention), actually it might be much easier and lighter"* (Participant 1).

Only one primary caregiver (Participant 3) seemed satisfied with the counselling offered as she shared that she *"only got counselling from the doctors and it was good"*. The remainder of the primary caregivers shared how they thought counselling will be valuable as they felt they *"still need counselling"* especially after *"everything I have been through"* (Participant 4). Surprisingly, she expressed that she was *"very scared"* to ask for counselling. Furthermore, one primary caregiver (Participant 5) thought the hospital would *"offer"* it and then she continued to share in interview that *"she would love it"* as it would have been a platform for her to ask questions and meet other mums in a similar situation where she could learn more about how to take care of her child post-cardiac intervention.

Besides the lack of counselling, primary caregivers also expressed how very little information regarding post op care like nursing the site of where the operation was performed (usually at the groin area for catheterisation interventions), or specific dietary requirements for the child with CHD, was offered from the health care facility. One primary caregiver (Participant 3) shared that the hospital staff said *"nothing"* about post op care and that she *"had to ask"* and the most that the hospital staff offered was that she *"must no put water on the operation".* Importantly one primary caregiver (Participant 6) requested the assistance from the hospital in *"applying for a disability grant"* for her child with CHD.

Thus, many of the participants described that referral to a counsellor or social worker for that matter would prove beneficial both for them and for child with CHD. It is something that they will look forward to requesting in their upcoming appointment and hopefully have access to.

5.10. Reported benefits of the cardiac intervention

Despite the numerous challenges, primary caregivers reported that there were numerous benefits derived from the intervention. Participants described that their child with CHD wanted *"more food"* and thus they were *"growing and gaining weight"* immediately attributing positive outcomes for their child with CHD post-cardiac intervention. Furthermore, many primary caregivers were *"happy"* to observe the *"increased energy levels"* of child with CHD translating to them *"playing for longer hours",* the child with CHD was also reaching other milestones like *"sitting up*" on their own and generally appearing to be *"breathing better"* and *"happy".* One participant (Participant 6) described how the physical symptoms like *"difficulty in breathing and blue in the lips, hand and mouth*", had subsided and sometimes altogether disappeared post-cardiac intervention. A study by Simeone et al. (2018), found that mothers of children with CHD in their study experienced both happiness and uncertainty when returning home after their child underwent a cardiac intervention. Similarly, in the current study, primary caregivers felt a great sense of *"joy and relief"* that their ill child was getting better as one participant shared, *"I see her (growing) and I can take care of her"* (Participant 6) after her child's cardiac condition.

In addition, siblings of children with CHD were also positively impacted by the intervention. According to one primary caregiver (Participant 4) her other child (4 year old daughter) who used to be *"anxious"* is now happy and "not worried" anymore. Another participant (Participant 6) shared that when her child with CHD is doing well, her other child *"looks relieved or feels relieved because they can play together again"*.

Whilst many members of the families endured difficult sacrifices like school items and going without food at times, the return home post-cardiac intervention created a sense of family togetherness and stronger family bonds for the participants who had other family members and siblings residing with them. This was similar to the Gaskin, (2018), where family togetherness after being separated due to hospital admission was evident upon transition from hospital to home.

The culmination of these benefits manifested itself as feelings of joy, short- term relief and hope for the primary caregivers. They were grateful for having had access to the medical interventions and the care that they received from the medical fraternity. This was similar to the study by Bruce et al. (2014), where parents were also grateful for the access to specialized care and professional healthcare providers. Primary caregivers were relieved that their child had underwent the intervention that will improve their child's overall health. This was similar to the study by Simeone et al. (2018), where parents felt an immediate sense of relief and joy upon returning home. In the current study, the improvement in the child with CHD brought them hope for the future of their child, even in the midst of their many challenges.

5.11. Coping mechanisms used by the primary caregivers

Navigating their way through the ordeal of having a child with CHD, participants in this study cited various methods and ways that helped them cope with everyday life and caring for their child post-cardiac intervention. These were both extrinsic and intrinsic. Intrinsically, primary caregivers coping commenced at the point where they accepted their child's condition for what it is, after the initial shock of the diagnosis. This is in keeping with the study by Dalir et al. (2020), where the first signs of coping amongst mothers of children with CHD was accepting and adjusting to the needs of their child with CHD.

Another way of coping was being able to rely on the support they received from within their family. Family members like aunts or grannies, and sometimes partners/husbands assisted with daily routines and household chores. Some participants received support from their partners, *"Thank god I have my husband to help when I need!"* (Participant 1) or Participant 3 who shared how her partner helps by "*changing the nappy, bathing the baby, feeding the baby, carrying the baby"* and other family members like "*my mother on the other side, She's helping me to give them (child with CHD and sibling) love"* (Participant 4), whilst others did not receive any support. This was in keeping with the study by Lumsden et al. (2019), where the meta-analysis study of how parents coped found that there was definitely a supportive system in the form of family and couples support.

Family support was a key coping mechanism in this study. This is in keeping with a study by Toledano-Toledano & Domínguez-Guedea, (2019) where mothers of chronically ill children benefited most from the support they received from families. An additional extrinsic support was the presence of *"neighbours"* and friends for both financial and nutritional support. In as much as it incurred short-term debt at the end of the month, it was a huge support that avoided starvation and other basic needs at the time of need. Thus to some extent, where possible, primary caregivers had the support of the community.

Primary caregivers experienced personal sacrifices that helped them cope with taking care of their child post-cardiac intervention. Primary caregivers focused on the *"survival"* and thriving of their ill child by removing any need of their own and putting the needs of their child with CHD before all. This was similar to the study by Gaskin, (2018), where parents reported how unselfishly they prioritized their infants' survival ahead of their own needs or health and wellbeing. They were resilient and relied on inner coping mechanism like *"well I read, sometimes at times maybe I write about my feelings down, that helps me a lot"* (Participant 2).

Spirituality and being *“hopeful”* are also ways that primary caregivers adopted as part of their coping strategy. Participants visits to the church and their trust in God helped them to cope and manage their emotions during trying times. This act of trusting God brought with it renewed hope and optimism for themselves and more so their ill child. These findings also echoed in the study by Dalir et al. (2020), where mothers in the study regularly prayed and remained hopeful for the future of their ill child. It proved to be a much accessed coping mechanism for the participants in that study.

Lastly, primary caregivers in the study remained hopeful and optimistic about the survival and health of child with CHD post-cardiac intervention. The mere survival of their child post-cardiac intervention brought with it renewed hope and a possibility of positive outcomes for their child with CHD and families. This was very similar to the study by Dalir et al. (2020) where optimism and hopefulness were key findings in the coping mechanisms of mothers of children with CHD. Primary caregivers also revealed gratitude for the care that their child with CHD received and were grateful to take their baby back home *“alive”* post-cardiac intervention like the study by Jo Wray et al. (2018) where parents of children with CHD felt a sense of gratitude for their child surviving the intervention and returning home with them upon hospital discharge.

In summary, whilst primary caregivers described varying coping mechanisms, the access to formal counseling and therapy as described in the section above (5.9) is still very much needed and will help improve their current coping strategies. This type of support and other recommendations will be put forward in the concluding chapter below.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1. Conclusion

This study concludes that there are several significant challenges experienced by primary caregivers living in low-income communities and taking care of their child with CHD post-cardiac intervention in this study setting in South Africa.

Caring for a child with a life threating heart condition within the home environment in this context is difficult for primary caregivers and without a doubt requires continuous support to ease the primary caregiver’s multiple burdens. One of the key challenges faced by primary caregivers is maintaining their emotional well-being across different stressful or even traumatic periods i.e. at the time of diagnosis as well as post the cardiac intervention. Many of the primary caregivers who were interviewed as part of this study commented on their lack of understanding of basic information related to their child’s heart condition and how this affected them mentally. Gaps in understanding between the healthcare providers and the primary caregivers can be a significant source of anxiety (Lazar & Hylarides, 2017). Understandably, this gap in information will impact on how confident and skilled they feel in caring for their ill child.

Caregiving also places a substantial emotional burden on the primary caregiver – especially within the context where the socio-economic status and living conditions are poor and the patient is a young child in need of so much support from their primary caregiver. Many of the primary caregivers interviewed lived and cared for their sick child along with their other children, their partners and extended family members such as sisters and aunts. Whilst they sometimes got assistance from other adult members of their household with, for example, some of the domestic chores, they could not share the emotional burden of caregiving with them – and, for example, share how anxious and distressed they felt. Many of the primary caregivers shared how alone they felt when taking on the multiple roles they did in running the home, attending to the needs of their ill child as well as managing the finances of their home - something that was a major challenge for all primary caregivers. Within the context it is understandable that the primary caregivers are undoubtedly at risk to psychological distress, anxiety, depression and post-traumatic stress symptoms, which in turn may influence their ability to provide care. As a result of this burden, primary caregivers require referral for counselling, support and psychosocial care from medical professionals (Kolaitis et al., 2017). However, there appeared to be little counselling support that had been made available to those who were interviewed in this study.

Primary caregivers also commented on the increasing nutritional needs of their ill child and their difficulty in meeting these needs due to their financial constraints. None of the primary caregivers were employed at the time of the interview, largely due to the care needs of their ill child, and despite some of the primary caregivers receiving some income from other family members and a small grant from the South African government, this small income was not adequate to cover the basic needs (like food and clothing) for their sick child and their other children. Thus, many of the caregivers live under the constant worry about the day to day as well as the future well-being of their loved one and other children who are under their care.

In a number of the interviews, a rather concerning account emerged of the partners, often the biological fathers of the child with CHD, being noticeably absent or minimally involved in providing support to the primary caregiver. Remarks about how one of the fathers was “no longer living” (Participant 6) or how another father “don’t ever contribute or communicate” (Participant 7) was obviously very painful to witness. The heaviness of having to take on a large proportion of the burden of care themselves - and, on top of that, feeling psychologically alone in doing this was visible in many of the interviews with primary caregivers. In contrast, it was comforting to hear of some of the accounts of how community support was given to the primary caregivers in the form of food items or financial assistance – especially in situations where the primary caregivers had no one else to turn to for help.

Caregiving activities like “giving medication” (Participant 1), compounded with regular household activities result in the primary caregivers having to manage a significant amount of physical strain as well as personal sacrifices. The concern about the survival of their sick child and ensuring that “somebody must be around her (child with CHD) all the time” (Participant 8) left little or no time for self-care. They were thus at risk of neglecting their own health and general well-being as they began to increasingly withdraw from social activities like meeting with friends or going to church regularly. The absence of nearby safe recreational facilities shared by all primary caregivers was also discouraging to learn of as such facilities can be a positive environment for children and a much needed break away from the routines and chores within the home for the primary caregivers.

A significant number of the primary caregivers also seem to experience a challenge in engaging with healthcare professionals at their local health facility and at the hospital. Often, the healthcare professionals were unable to immediately identify the cardiac condition of the child and provided and incorrect interpretation of the child's symptoms. Thus some of the primary caregivers (Participant 6 and Participant 7) went back and forth several times before eventually being referred for the appropriate medical care. As a result, the many trips were made to a health facility in their search for an explanation or a diagnosis – all of which added transport costs on to an already stretched monthly household budgets. In one case (Participant 7), it was as much as 3 years before a final confirmed diagnosis was made at the tertiary level hospital. Besides the cost burden, understandably, not knowing what is wrong with your child for such an extended period of time can be traumatising and unsettling for a primary caregiver.

The study concludes that providing ongoing care for a child with a heart condition, pre and post intervention, is taxing on the primary caregivers and should not be a responsibility that is shouldered by a primary caregiver alone. Section 28 of the Bill of Rights states that "Children have a right to family care or parental care" as well as "basic nutrition, shelter, basic health care services and social services" (Children's Bill [B70 – 2003], 2003) and thus our health services – and all whom work within them, need to consider creative and strategic ways of helping the primary caregivers of children who are going to extraordinary lengths, despite their lack of resources, in taking care of their child pre and post-cardiac intervention.

6.2. Recommendations

Based on the findings of this study, the following key recommendations are made. It ought to be noted that whilst these recommendations are not extensive, they are offered as a set of preliminary proposals as to how local and regional or national health facilities and specifically the Department of Health, KZN, can start to address (or perhaps decrease) some of the challenges identified by primary caregivers within the context of their household in Kwa-Zulu Natal.

1. Healthcare professionals, particularly nurses working at a primary level of care in, for example, a clinic should be trained more thoroughly about how to identify and screen children with a potential heart condition and how to alert other members of the health

team (for example, the doctor or sister-in-charge), that a further assessment and referral is necessary.

2. Healthcare professionals working at a tertiary level hospital should consider strengthening the content and their methods of communication with the primary caregivers – both at the point of diagnosis and as part of their regular, on-going management of the child within their care. This is particularly important in communicating the diagnosis, the prognosis and the proposed treatment plan to the primary caregiver. Such information could also be reiterated by a social worker or counsellor. The latter (or another member of the health team) could, working together with the primary caregiver, develop a realistic and appropriate strategy of how the primary caregiver could feasibly provide their child with the care that was needed post-cardiac intervention. Some of the challenges identified in this study could be considered, and practical ways of over-coming them considered. Ways in which the primary care giver could access emotional support would be an essential component of this strategy.
3. Healthcare professionals at the tertiary level hospital should consider referring the primary caregivers to a dietician prior to discharge where more affordable nutritional supplements and healthy food options for the child with CHD and other members of the household could be discussed. This would be particularly important in instances where a family or household is identified as financially and/or food insecure.

4. Home-based care visits by a professional nurse, perhaps from a local clinic at primary level should be considered at appropriate times after the intervention- and this should be part of an integrated package of continuum of care offered by the Department of Health to primary caregivers of children with cardiac conditions.

5. The provision of support by Lay Counsellors (and where available, Social Workers) should be seen as an essential part of the service that is provided to primary caregivers of children with cardiac conditions at a local primary care level. Counsellors/ Social workers should ensure that primary caregivers are offered ongoing psychosocial support and assist in referring primary caregivers to the appropriate social welfare departments, like grants, so that application for grants are correctly followed so as to receive grants as

soon as possible- psychosocial therapies are effective ways of reducing chronic stress and emotional pain among caretakers of children with CHD (Lazar & Hylarides, 2017).

6. Recommend the use of the newly created Parental Stress and Resilience in CHD Model (Lisanti, 2019), will provide a helpful foundation for clinicians and researchers to develop interventions in an effort to decrease stress and the subsequent impact of stress for parents of children with CHD and improve overall family well-being, quality of life, and child development. This should include early, regular and continuous screening for mental health problems in parents of children with CHD for prompt referral to psychologist or social workers. In addition “routine screening should include assessment of social risk, prior trauma, and other risk factors for parental stress and negative mental health outcomes identified by the Parental Stress and Resilience in CHD Model” (Lisanti, 2019:8).

Finally, whilst the financial plight and the poor living conditions of the primary caregivers cannot be ignored, the above proposals are hopefully appropriate interventions that can build the coping capacity of the primary caregivers and inadvertently alleviate some of the stress and anxiety that many of them face on a daily basis. This ultimately will impact positively on the care and recovery period of their child with a cardiac condition, a long term defect that will sometimes require ongoing medical attention and continued care from primary caregivers.

Furthermore, the connection between parental stress and how this impacts the development of the child emotionally, behaviourally, and neurodevelopmental outcomes in the South African context should be prioritized for future research.

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APPENDIX 1: Participant Information Sheet (English)

UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21 959 2809 Fax: 27 21 959 2872
E-mail: soph-comm@uwc.ac.za

PARTICIPANT INFORMATION SHEET

Project Title:

Primary care-givers experiences of caring for their children post cardiac intervention: An exploratory study.

What is this study about?

This is a research project being conducted by myself, Fathima BR Ennos. I am inviting you to participate in this research project because you are a guardian or parent to a child who had a heart procedure. The purpose of this research project is to fulfill the requirements for my Masters Degree in Public Health at the School of Public Health, University of the Western Cape. In addition to fulfilling these requirements, the research also aims to understand what guardians or parents experience when taking care of their child who has had a cardiac interventional procedure. It is believed that with your participation, a better understanding of the needs and challenges that you experience when taking care of your child at home, will be communicated to the cardiac team at Inkosi Albert Luthuli Central Hospital. This will assist the team in their future planning of support to their patients and their families.

What will I be asked to do if I agree to participate?

In this study I will ask you some questions regarding the various experiences that you have in taking care of your child who underwent a heart procedure. I would like you to discuss them with me in an interview. This will take about an hour of your time. The interview will be done at the outpatient Paediatric Clinic, at Inkosi Albert Luthuli Central Hospital, when you come for your follow-up visit to the hospital or at the mothers lodge whilst you stay with your child at the hospital when they get admitted again If you agree to participate, I would like to request you to allow me to tape-record the interview.

Would my participation in this study be kept confidential?

As the researcher, I will undertake to protect your identity and the nature of your contribution. To ensure your anonymity, at all times I will keep the information you share with me confidential and refer to you or your child by a pseudonym or invented name which I would like you to choose. I shall keep all other records of your participation locked away at all times, and destroy them 5 years after the completion of the research project.

To ensure your confidentiality, I will store your data on a computer using a password protected file which only I will have access to. If I write a report or article about this research project, your identity – and that of your child - will be protected.

In accordance with legal requirements and/or professional standards, we will disclose to the appropriate individuals and/or authorities' information that comes to our attention concerning child abuse or neglect or potential harm to you or others. In this event, we will inform you that we have to break confidentiality to fulfill our legal responsibility to report to the designated authorities.

What are the risks of this research?

There may be some risks from participating in this research study as all human interactions and talking about oneself or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. If you require immediate counseling, the Paediatric Cardiologist at the clinic will be available to assist you. If necessary, the Paediatric Cardiologist will then make an appropriate referral to a suitable counseling professional within the Hospital to support you further.

What are the benefits of this research?

There is no direct benefit to you in participating in this study. However, the results of the study may help us to identify the challenges parents or guardians like yourself face in looking after a child in their home after a heart operation. On the basis of this, we will share some of our recommendations with the cardiac team at the at Inkosi Albert Luthuli Hospital, about the possible ways they might be able to better help and support parents and guardians in similar situations in the future.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may also withdraw any time from the interview and the study, if you wish to do so. You may also refuse to answer any or all the questions if you don't feel comfortable with the questions. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify- especially in relation to the service and treatment that your child is provided at this hospital.

Do I have to sign a consent form if I participate in this study?

As I mentioned earlier, you are required to give your consent before I conduct the interview with you. I have included the consent form with this information sheet so that you will be able to review it in your own time and, along with this information, consider whether to participate in this study or not.

What if I have questions?

This research is being conducted by Fathima BR Ennos, SOPH, at the University of the Western Cape. If you have any questions about the research study itself, please contact me at:

Tel: 079 0792056 or by email: fathimaennos@gmail.com

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof U Lehmann

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This research has been approved by the University of the Western Cape's Biomedical Research Ethics Committee:

Biomedical Research Ethics Committee

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REFERENCE NUMBER:

BM19/10/15

APPENDIX 2: Informed Consent Sheet (English)

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21 959 2809 Fax: 27 21 959 2872
E-mail: soph-comm@uwc.ac.za

INFORMED CONSENT FORM

Title of Research Project: Primary caregivers experiences of caring for their children post cardiac intervention: An exploratory study.

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

___ I agree to be audio taped during my participation in this study.
___ I do not agree to be audio taped during my participation in this study.

Participant's name……………………….

Participant's signature……………………………….

Date………………………

This research has been approved by the University of the Western Cape's Biomedical Research Ethics Committee:

Biomedical Research Ethics Committee
University of the Western Cape
Private Bag X17, Bellville
7535
Tel: 021 959 4111
e-mail: research-ethics@uwc.ac.za

APPENDIX 3: Interview Guide (English)

I would like to start off by finding out a little more about your child (name) and yourself and your family.

Male/Female	
Age of child	
The interviewee's relationship to the child with CHD: Biological child / adopted or foster child / child of family member	

Now I would like to ask a few questions about you, your family and household.

1. Are you married or do you have a partner?
   - Check: if yes, do they live in the same household – or not with the interviewee and the child?

2. What is their (partner's) relationship to the (Index) child eg. biological parent / adoptive or foster parent / child of their family member / considered father/mother as a result of relationship?
3. Who else lives in the household?

   Researcher to:

   - Record the relationship of each household member to the (index) child
   - Record the sex and age of each household member
   - Enquire about the basic circumstances of each other household member eg. at school /unemployed/ employed full or part-time /pensioner. Record which of the above household members are reliant or dependent on the interviewee (eg. in terms of child care and/or financial support).
4. Can you describe the living conditions that you and your child reside in?
   - Enquire about access to water and electricity, sanitation, living spaces for the entire family, cooking methods and nearby recreational facilities

5. Can you describe how you get money to support your household?
   - From the salaries and income of household members? And who in particular?
   - Grants? What type(s) of grant (s)? Other family members providing support?

If not elaborated above:

- Are you currently employed or self-employed?

If they are employed, clarify if this is:

- Full or part-time / formal or informal or ad hoc income generation?

- Has this income generation activity / work presented any challenges for you in relation to caring for your child after the operation? (Explore what these challenges are, where appropriate).
- Enquire about whether the members of the household observe a faith/religion, and if so – what that is.

If interviewee is <u>*not*</u> *currently employed, explore whether s/he was employed before the (child with CHD's) operation?*

- Has the operation and child caring impacted on your ability (or your partner's ability) to work and earn an income?

6. Finally,has the operation and additional child caring responsibilities after the operation impacted on the way you spend your household income? (If it has, get details of how / what type of expenses have increased).

2.0 Guiding questions - Information to primary caregivers/parents about experiences when taking care of the (index) child

Now that we have information about you and your child, I would like to continue to ask some questions about how you and your family are doing whilst taking care of your child.

1. What were the first things that you noticed about your child that made you go to a hospital or a doctor?

2. When was the first time you decided to see a doctor?

   - How did you get referred to Inkosi Albert Luthuli Central Hospital? What were some of the suggestions made by the doctors at the cardiology clinic at Albert Luthuli to help your child? According to the doctor, and your understanding, how would these options help your child

3. Now that the procedure is done, how long has the child been at home after the procedure/operation? How would you say your child is doing since you brought him/her home?

4. How did you feel when you found out about your child having a heart problem?

5. Now that the doctors have done an operation/procedure how are you feeling about your child's heart problem? What concerns do you have?

6. What is it like being a parent/caregiver to your other children whilst taking care of your child who had a heart operation?

7. How have you arranged your daily life since bringing your child home after the operation? (Explore whether there are key things in their routine that they have had to change).

8. How have other family members supported you during this time?

9. How do the other children feel about their brother/sister who is sick?

10. And how are you personally feeling about taking care of your child during their recovery period?
    - Probes:
        - How has your health been during this time that you are taking care of your child?
        - Health related quality of life for other members of the household?
11. What are some of the most difficult problems that you experience whilst taking of your child?

12. *If the interviewee highlights specific difficulties:* How do you go about managing these difficulties?

13. What is the most significant help that you require during this time?

14. Is there any help that you would have found valuable to receive from the hospital during this time (ie. after the operation/procedure and the discharge from the hospital and before your next 6 weekly follow up visit)?
    - Explore what this would be if they feel it would be helpful.
    - Clarify what help they did receive from the hospital in preparation for this period (ie. after the operation/procedure and you returning home with your child

15. We have talked about a range of issues during this interview, and I would just like to check in with you and ask you if there is anything else you would like to add or share with me about caring for your child during this period?

16. I also would like to find out if you have any questions for me?

Thank the interviewee for participating in the interview, and make sure – if they had queries or concerns that they felt would be important to talk about more – they are comfortable with the plans that have been put in place for (eg. counselling, meeting with one of the clinical team).

APPENDIX 4: Letter of Request to the Provincial Health and Research Ethics Committee, Kwa-Zulu Natal

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21 959 2809 Fax: 27 21 959 2872
E-mail: soph-comm@uwc.ac.za

17 February 2020

Department of Health: KZN Health Research & Knowledge Management
Natalia Building 10 - 102 South Tower
330 Langalibalele Street Pietermaritzburg,
3201
E-mail Address: hrkm@kznhealth.gov.za

Dear Sir/Madam

RE: Application to conduct a research project: *"Primary care-givers experiences of caring for their children post cardiac intervention: An exploratory study."*

Ms Fathima BR Ennos, a Master of Public Health student (MPH) (Student Number:3610434), at the School of Public Health at the University of Western Cape would like to request the Department's approval for me to conduct a research study regarding the experiences and challenges of primary caregivers who are taking care of their child who underwent a cardiac intervention. The study will be conducted at a tertiary level hospital; Inkosi Albert Luthuli Central Hospital (IALCH) situated in Durban, a city in Kwa Zulu-Natal and will look at what primary caregivers are experiencing once they take their child home within the first 6 weeks to 18 months after their discharge.

The study will focus on primary caregivers and/or parents of young children who are currently still receiving treatment and require follow up visits at IALCH. A study sample of 8-12 parents and/or primary caregivers will be recruited for the study. Qualitative research methods using a semi-structured interview guide will be employed for collecting data about what primary caregivers are experiencing and what these experiences mean to them in the context of their setting and lifestyles.

Confidentiality, anonymity and voluntariness of information and/or participation in the study will be assured throughout the study and a Participant Information Sheet and Consent Form will be given to all potential participants for their perusal prior to them deciding on whether to voluntarily participate in the study or not.

I kindly request permission to carry out this study. The study should run from February 2019 to March 2020. I also attach with this letter the ethical clearance I have received from the University of the Western Cape's Biomedical Research Ethics Committee.

Should you require further information, feel free to contact me at (Cell: 0790792056) or (Email:fathimaennos@gmail.com).

Sincerely,

Fathima BR Ennos
Attachments:

1. Participant Information Sheet (English and isiZulu)
2. Consent Form (English and isiZulu)
3. Ethical approval letter from the University of the Western Cape's Biomedical Research Ethics Committee.

APPENDIX 5: Letter of Request to the Hospital Manager of the Inkosi Albert Luthuli Central Hospital

UNIVERSITY OF THE WESTERN CAPE
Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21 959 2809 Fax: 27 21 959 2872
E-mail: soph-comm@uwc.ac.za

10 February 2020

Inkosi Albert Luthuli Central Hospital
Hospital CEO/Manager Dr T.T. Khanyile
800 Vusi Mzimela Road
Mary Thiphe St
Durban

Dear Sir/Madam

RE: Application to conduct a research project: “*Primary caregivers experiences of caring for their children post cardiac intervention: An exploratory study*.”

I, Ms Fathima BR Ennos, a Master of Public Health student (MPH) (Student Number: 3610434), at the School of Public Health at the University of Western Cape, would like to request the hospitals approval for me to your approval conduct a research regarding the experiences and challenges of primary caregivers who are taking care of their child who underwent a cardiac intervention. I hereby seek permission to conduct a study at Inkosi Albert Luthuli Central Hospital (IALCH). This proposed study will attempt to explore and describe primary caregivers/and or parents experiences of taking care of their child post cardiac intervention, with the intention of providing the cardiac team at the tertiary level hospital with a set of suggestions and recommendations of how they might be able to recommend additional support for the primary care givers on their child’s discharge from the hospital post a cardiac intervention.

The study will on primary caregivers and/or parents of young children who are currently still receiving treatment and require follow up visits at IALCH. A study sample of 8-12 parents and/or primary caregivers will be recruited for the study. Qualitative research methods using a semi-structured interview guide will be employed for collecting data about what primary caregivers are experiencing and what these experiences mean to them in the context of their setting and lifestyles.

Confidentiality, anonymity and voluntariness of information and/or participation in the study will be assured throughout the study and a Participant Information Sheet and Consent form will be given to all potential participants for their perusal prior to deciding on whether to voluntarily participate in the study or not.

I kindly request permission to carry out this study. The study should run from February to March 2020. I also attach with this letter the ethical clearance that I have received from the University of the Western Cape's Biomedical Research Ethics Committee.

Should you require further information, feel free to contact me at (Cell: 0790792056) or (Email:fathimaennos@gmail.com).
Sincerely
Fathima BR Ennos

Attachments:

1. Participant Information Sheet (English and isiZulu)
2. Consent Form (English and isiZulu)
3. Ethical approval letter from the University of the Western Cape's Biomedical Research Ethics Committee.

APPENDIX 6: Participant Information Sheet (isiZulu)

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21 959 2809 Fax: 27 21 959 2872
E-mail: soph-comm@uwc.ac.za

IQEQEBA LOLWAZI

Izingqinamba ababhekana nazo abanakekelingqangi ekunakekeleni umntwana wabo emva kokuxilongwa enhliziyweni: ucwaningo oluphenyayo.

Lolu cwaningo lungani?

Lolu cwaningo ludidiyelwa yimi uFathima BR Ennos. Ngiyakumema ukuthi uhlanganyele kulolu cwaningo ngoba ungumzali ogada ingane exilongwe enhliziyweni. Inhloso yalolu cwaningo ukufeza imigomo ye Masters Degree yezempilo zomphakathi yami, Enyuvesi yaseNtshonalanga Kapa. Okungaphezulu kokufeza le migomo, ucwaningo luhlose ukuqonda ukuthi abazali nabaqaphi bahlangabezana nani ngalesi sikhathi benakekela umntwana wabo oxilongwe enhliziyweni. Kukholakala ukuthi ngokuhlanganyela kwakho zingaqondakala kangcono izingqinamba ohlangabezana nazo ngalesi sikhathi unakekela umntwana wakho ekhaya futhi zizodluliseleka kwithimba lezenhliziyo lasesibhedlela saseNkosi Albert Luthuli. Lokhu kuzosiza ithimba ngekusasa lokuhlela ukweseka iziguli zabo nemindeni yazo.

Ikuphi engizocelwa ukuthi ngikwenze uma ngivuma ukuhlanganyela?

Kulolu cwaningo ngizokubuza imibuzo mayelana nezimo ohlangabezana nazo ekunakekeleni umntwana wakho oxilongwe enhliziyweni. Ngizothanda sikudingide kwinkulumo mpendulwano. Lokhu kuzothatha okuthi akube yihora lesikhathi sakho. Le ngxoxo izokwenzelwa emtholampilo wabantwana wase sibhedlela Inkosi Albert Luthuli Central Hospital, ngalesi sikhathi uza esibhedlela ukuzohlolwa. Uma uvuma ukuhlanganyela ngingathanda ukucela ukuba ungivumele ngiqophe ingxoxo yethu.

Kungabe ukuhlanganyela kwami kuzogcinwa kuyimfihlo?

Njengo mcwaningi ngizoqinisekisa ukuvikela imininingwane yakho kanye nobunjalo bokuhlanganyela kwakho. Ukuqinisekisa ukungavezwa kwegama lakho, ngaso sonke isikhathi ngizogcina ulwazi onginika lona luyimfihlo ngikhulume ngawe noma ngomntwana wakho ngelinye igama lokuziqambela engizocela likhethwe nguwe. Konke okuqondene nawe mayelana nalokhu kuhlanganyela ngizokugcina kuvalelekile ngaso sonke isikhathi, kuzoshabalaliswa emva kweminyaka emihlanu luphothuliwe lolu cwaningo.

Ukuqinisekisa ukuphepha kwemininingwane yakho, Ngizogcina imininingwane yakho ivalelwe kwikhompyutha ngisebenzise amagama ayimfihlo okuyivula, yimi kuphela ozokwazi ukuyivula. Uma ngizobhala imiphumela ngalolu cwaningo, imininingwane yakho kanye neyomntwana izovikelwa.

Maqondana nemigomo yezomthetho noma yezinga lobuchwepheshe, kuzodalulwa lawo malunga avelayo aqondene nokuhlukumezeka noma noku yekelelwa kwakho noma umntwana wakho okungadala ukulimala kwakho noma komntwana noma imuphi omunye umuntu. Kulesi sehlo, sizokuchazela ukuthi kumele sophule isivikelo semfihlo ukuze sifeze umsebenzi wethu wokubika kulabo abaphethe kulowo mkhakha.

Buyini ubungozi balolu cwaningo?

Kukhona ubungozi obungaba khona ngokuhlanganyela kulolu cwaningo ngoba konke ukuzimbandakanya nabanye abantu noma ukhuluma ngawe noma ngabanye kuba nabo ubungozi obuthize. Uma udinga usizo oluphuthumayo lomuntu ongakhuluma naye, udokotela wenhliziyo yengane onguchwepheshe uzobe ekhona ukukusiza. Uma kunesidingo udokotela wenhliziyo yengane uzokudlulisela kuchwepheshe ofanelekile ukuze akusize noma angenelele.

Iyini inzuzo yalolu cwaningo?

Ayikho inzuzo eza ngqo kuwe ngokuhlanganyela kulolo cwaningo. Kodwa, imiphumela yocwaningo ingasisiza ukuthi sibone izingqinamba abazali nabaqaphi abanjengawe abahlangabezana nazo uma benakekela umntwana ngemumva kokuhlinzwa enhliziyweni. Ekusukeni lana sizocobelela imibono yethu laba abayithimba lezenhliziyo esibhedlela saseNkosi Albert Luthuli ngezindlela ezahlukene zokuthuthukisa usizo kulaba abangabazali noma abaqaphi ezimweni esifana nalesi kusasa.

Ngiphoqelekile yini ukuba kulolu cwaningo futhi ngingayeka noma yinini na?

Ukuhlanganyela kulolu cwaningo kukuwena. Ungahoxa futhi noma yinini engxoxweni uma ufisa ukwenze njalo. Ungakhetha futhi ukungayiphenduli eminye yemibuzo uma uzizwa ungakhululeki ngayo. Uma ukhetha ukuhlanganyela kulolo cwaningo, ungakhetha futhi ukuphuma noma yinini, angeke ujeze noma ulahlekelwe inzuzo ekufanele njengempatho etholwa yingane yakho kulesi sibhedlela.

Kumele ngisayine imvume yini uma ngihlanganyela kulolu cwaningo?

Njengoba kubaluliwe ekuqaleni udingeka ukuba unginike imvume yakho ngaphambi kokuba ngididiyele le ngxoxo nawe. Ngifake ifomu lenvume kuleli qeqeba lolwazi khona uzolubukeza ngesakho isikhathi kanye nale mininingwane, ucabangisise ukuthi uhlanganyele noma cha.

Uma nginemibuzo?

Lolu cwaningo ludidiyelwa uFathima BR Ennos, SOPH, eNyuvesi yaseNtshonalanga Kapa. Uma unemibuzo ngalolu cwaningo ngicela ungithinte la:

ucingo: 079 0792056 noma ngemeyili: fathimaennos@gmail.com

Uma unemibuzo mayelana nalolu cwaningo kanye namalungelo akho njengomhlanganyeli wocwaningo noma udinga ukubika inkinga ethize ohlangabezane nayo kulolu cwaningo ngicela uthinte u:

Prof U Lehmann

Head of Department: School of Public Health

University of the Western Cape

Private Bag X17

Bellville 7535

ulehmann@uwc.ac.za

Prof Anthea Rhoda

Dean: Faculty of Community and Health Sciences

University of the Western Cape

Private Bag X17

Bellville 7535

chs-deansoffice@uwc.ac.za

Lolu cwaningo luvunyelwe yi-University of the Western Cape's Biomedical Research Ethics Committee:

Biomedical Research Ethics Committee

University of the Western Cape

Private Bag X17

Bellville

7535

Tel: 021 959 4111

e-mail: research-ethics@uwc.ac.za

REFERENCE NUMBER:

BM19/10/15

UNIVERSITY OF THE WESTERN CAPE

Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21 959 2809 Fax: 27 21 959 2872

E-mail: soph-comm@uwc.ac.za

APPENDIX 7: Informed Consent Sheet (isiZulu)

IFOMU LEMVUME

Isihloko salolu cwaningo: **Izingqinamba ababhekana nazo abanakekelingqangi ekunakekeleni umntwana wabo emva kokuxilongwa enhliziyweni: ucwaningo oluphenyayo.**

Lolu cwaningo luchaziwe kimi ngolimi engiliqondayo. Imibuzo yami ngocwaningo iphendulekile. Ngiyaqonda ukuthi ukuhlanganyela kwami kuquketheni futhi ngiyavuma ukuhlanganyela ngokwesinqumo sami nentando yami. Ngiyaqonda ukuthi imininingwane yami angeke idalulwe kumuntu. Ngiyaqonda ukuthi ngingahoxa kulolu cwaningo noma ingasiphi isikhathi ngale kokunika isizathu nangale kovalo kokubi okungenzeka nokulahleka kwamalungelo.

___ Ngiyavuma ukuqoshwa ngesikhathi sokuhlanganyela kwami kulolu cwaningo.

___ Angivumi ukuqoshwa ngesikhathi sokuhlanganyela kwami kulolu cwaningo.

Igama lomhlanganyeli………………………..

Ukusayina komhlanganyeli……………………………….

Usuku………………………

Biomedical Research Ethics Committee

University of the Western Cape

Private Bag X17

Bellville

7535

Tel: 021 959 4111

e-mail: research-ethics@uwc.ac.za

APPENDIX 8: Interview Guide (isiZulu)

UMHLAHLANDLELA WENKULUMO MPENDULWANO – ISIZULU

Imibuzo – imnningwane emayelana nomntwana (Inkomba)

Ngifisa ukuqala ngokwazi kabanzana ngomntwana wakho(uSbanibani) nawe nomndeni wakho.	
Owesilisa/Owesifazane	
Iminyaka	
Ubudlelwane babo nomntwana esingaye: Umntwana wangokwemvelo / ngokuqokwa noma ongeyena owakho /umntwana welunga lomndeni	

- Iziphi izinto zokuqala owazinaka ngomntwana wakho ezakwenza wamuhambisa esibhedlela noma kudokotela?
- Wasithatha nini isinqumo sokubona udokotela?
- Wadluliselwa kanjani esibhedlela saseNkosi Albert Luthuli? Imiphi eminye yemibono eyenziwa odokotela besemtholampilo wezenhliziyo yaseAlbert Luthuli eyokusiza umntwana wakho?
- Ngokukadokotela, nokuqonda kwakho, le mibono ingamusiza kanjani umntwana wakho?
- Njengoba ukuxilonga sekwenziwe, sekuyisikhathi esingakanani umntwana esekhaya ngemumva kokuxilongwa/kokuhlinzwa? Ungathi uqhuba kanjani umntwana selokhu wamuletha ekhaya?

Imibuzo ewumhlahlandlela – Imininingwane ngabanakekeli ngqangi/ umzali nabomuzi

02

Manje ngingathanda ukubuza imibuzo mayelana nawe, umndeni wakho nabomuzi.

Ushadile noma unaye umuntu obambisene naye? Hlola ukuthi bahlala ndawonye yini umhlanganyeli nomntwana: kunjalo noma akunjalo?

Uhlobene ngani yena nomntwana? isibonelo: Umzali ngokwemvelo / ngokuqokwa noma umzali womntwana okungesiye owakhe / umntwana welunga lomndeni / ubaba ngokokubona kwakho / ubaba ngenxa yobudlelwane benu?

Ubani omunye ohlala endlini ?

- Qopha ubudlelwano balowo nalowo uyilunga lomndeni nomntwana Record the sex and age of each household member
- Buza ngezimo zempilo zalabo abayilunga lomndeni , isibonelo: eskoleni /ongasebenzi/ osebenza ngokuphelele noma obamba amatoho/ ohola impesheni. Qopha ukuthi iliphi kulawa malunga elithembele kulowo obuzwayo kule nkulumo mpendulwano (isibonelo. Ngokokunakekelwa komntwana kanye nosizo lwezezimali).

Ungachaza kabanzana ngesimo sendawo sempilo wena nomntwana enihlala kuso?

- Buza ngokutholakala kwamanzi nogesi ukuchithwa kwendle , indawo yokuhlala yomndeni wonke ,indlela okuphekwa ngayo kanye nezindawo eziseduze zokujabula okulula umqondo.

Ungachaza kabanzana ngokuthi uyithola kanjani imali yokweseka umndeni ? From the salaries and income of household members? And who in particular?

- Imali yokubhekelelwa? Enhloboni(Ezinhloboni) imali mbekelelo(noma izimali)? Amanye amalunga omndeni ahlinzeka ngosizo lokweseka umndeni?

Uma kungachazisisekanga ngenhla:

- Okwamanje uqashiwe noma uyazisebenza?

Uma beqashiwe, chaza ukuthi lokho ku:

Ukuqashwa okuphelele noma kwetoho / okuhlelekile noma okungahlelekile noma iholo elifika ngaleso sikhathi?

- Kungabe le ndlela othola ngayo imali / umsebenzi uke wakuhlangabezisa nezingqinamba ezithize mayelana nokunakekelwa komntwana wakho ngemumva kokuhlinzwa (Bhekisisa ukuthi lezi zingqinamba ziyini lapho kunesidingo khona).

Uma lowo obuzwayo engaqashiwei, bhekisisa ukuthi uke waqashwa ngaphambi kokuhlinzwa komntwana?

- Kungabe ukuhlinzwa nokunakekelwa komntwana kube nawo umthelela ekukwazini ukusebenza uhole?

Okokugcina,

- Kungabe ukuhlinzwa nokunakekelwa komntwana ngokwengezekile ngemva kokuhlinzwa kube nawo yini umthelela endleleni osebenzisa ngayo imali yomndeni? (Uma ube khona, thola imininingwane yokuthi kanjani / iziphi izindleko ezikhuphukile?).

Imibuzo ewumhlahlandlela – Imininingwane yabanakekeli ngqangi /abazali ngabahlangabezana nakho uma benakekela umntwana.

Manje njengoba sesinayo imininingwane ngawe nomntwana wakho, ngingathanda ukukubuza imibuzo embalwa ngokuthi wena nomndeni wakho ninjani ngalesi sikhathi ninakekela umntwana wenu.

- Wazizwa kanjani ngalesi sikhathi uthola ukuthi umntwana wakho unenkinga yenhliziyo?
- Njengoba manje odokotela sebemhlinzile/sebemxilongile umntwana uzizwa kanjani ngenkinga yenhliziyo yomntwana wakho? Iziphi izinto okhathazeke ngazo?

- Kunjani ukuba umzali/ umnakekeli kulezi ezinye izingane ngalesi sikhathi unakekela umntwana wakho ohlinziwe enhliziyweni?
- Uhlele kanjani izinsuku zonke zakho kusukela wabuya nomntwana ekhaya emva kokuhlinzwa kwakhe? (Bhekisisa ukuthi kukhona yini abadinge ukukushintsha ekuqhubeni kosuku).

- Akwesekele kanjani amanye amalunga omndeni kulesi sikhathi?
- Bazizwa kanjani abanye abantwana ngo dadewabo/ngomfowabo ogulayo?

- Wena uzizwa kanjani ngesingawe ngokunakekela umntwana kulesi sikhathi sakhe sokululama?
  Uphenyo:
  - Sinjani isimo sakho sempilo kulesi sikhathi unakekela umntwana wakho?
  - Isimo sezempilo kwamanye amalunga omndeni?

- Iziphi ezinye zezinto ezinzima ohlangabezana nazo ngalesi sikhathi unakekela umntwana wakho?

- *Uma lowo obuzwayo eqhakambisa izingqinamba ezithize:*
  Uzixazulula kanjani lezi zingqinamba?
- Ikuphi okungaba usizo kakhulu kuwe okudingayo ngalesi sikhathi?

- Lukhona usizo obungafisa ukube ulutholile esibhedlela ngalesi sikhathi (lokhu kusho: ngemva kokuhlinzwa/kokuxilongwa nangesikhathi sokukhululwa esbhedlela nangaphambi kokubuyela kwakho ukuyohlola emasontweni ayisithupaha alandelayo?

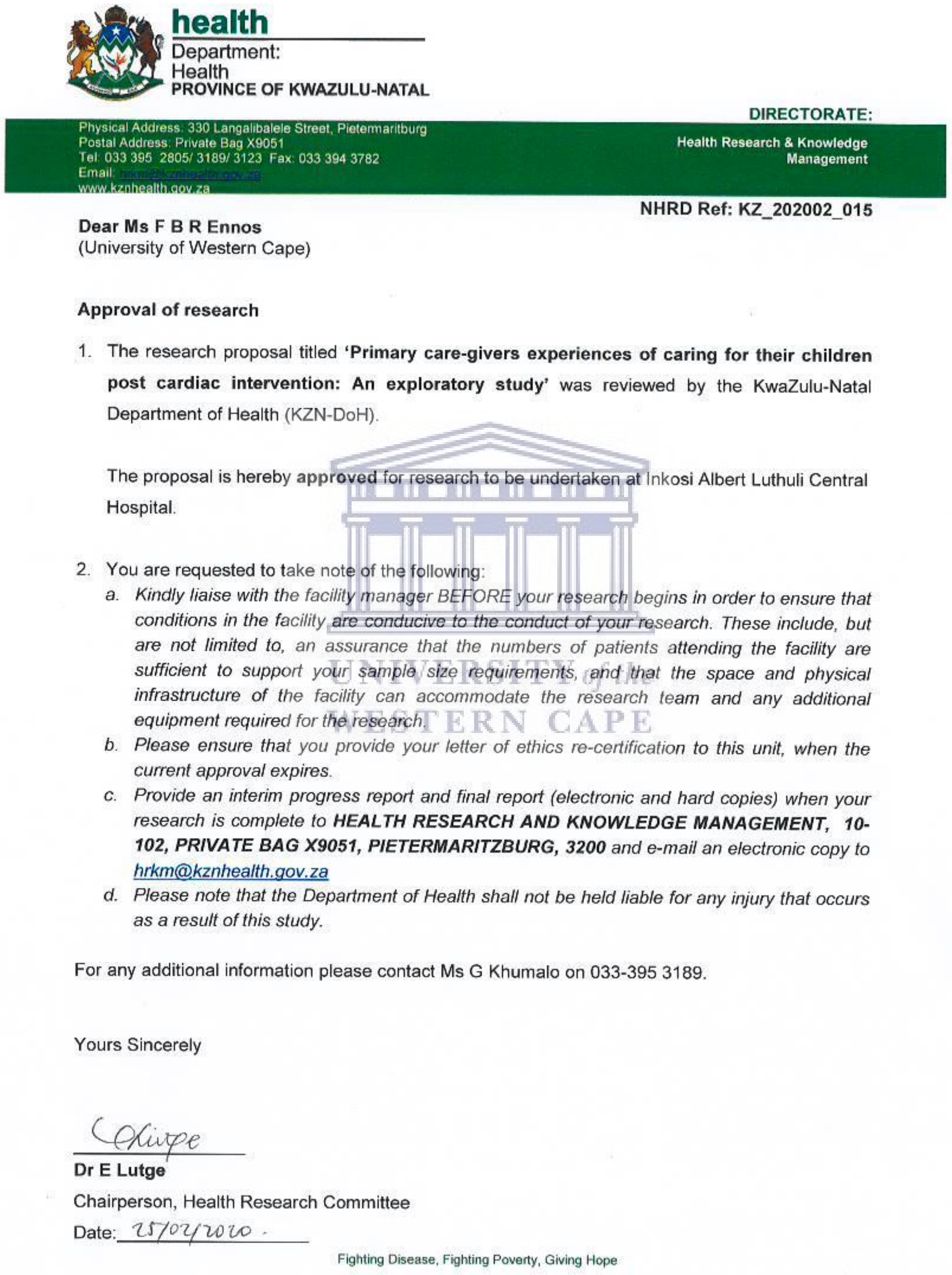
- Bhekisisa ukuthi yini leyo uma ingaba nosizo.

- Chazisisa ukuthi iluphi usizo olutholile esibhedlela elikulungisisele lesi sikhathi (lokhu kusho: emva kokuhlinzwa/kokuxilongwa nokubuyela kwakho ekhaya nomntwana?

- Sesikhulume ngokuthinta okuningi kulesi sikhathi senkulumo mpendulwano , ngingathandake ukuzwa kuwe ukuthi kukhona yini okunye ongathanda ukukunenezela noma ukungicobelela ngakho mayelana nokunakekeleka komntwana wakho kulesi sikhathi?
- Ngingathanda futhi ukuzwa ukuthi ikhona yini imibuzo ofisa ukungibuza yona?

Bonga lowo obuzwayo ngokuhlanganyela kule nkulumo mpendulwano, uqinisekise – uma kade ikhona imibuzo noma izinkalazo abazibone zifanelekile ukuthi bakhulume ngazo kabanzi – bazizwa bekhululekile ngezinhlelo ezibekiwe (lokhu kusho: ukwalulekwa, ukuhlangana nomunye wabezempilo).

APPENDIX 9: Permission letter to conduct study (DOH-Kwa-Zulu Natal)



health
Department:
Health
PROVINCE OF KWAZULU-NATAL

Physical Address: 330 Langalibalele Street, Pietermaritburg
Postal Address: Private Bag X9051
Tel: 033 395 2805/ 3189/ 3123 Fax: 033 394 3782
Email: hrkm@kznhealth.gov.za
www.kznhealth.gov.za

DIRECTORATE:
Health Research & Knowledge Management

NHRD Ref: KZ_202002_015

Dear Ms F B R Ennos
(University of Western Cape)

Approval of research

1. The research proposal titled **'Primary care-givers experiences of caring for their children post cardiac intervention: An exploratory study'** was reviewed by the KwaZulu-Natal Department of Health (KZN-DoH).

   The proposal is hereby approved for research to be undertaken at Inkosi Albert Luthuli Central Hospital.

2. You are requested to take note of the following:
   a. *Kindly liaise with the facility manager BEFORE your research begins in order to ensure that conditions in the facility are conducive to the conduct of your research. These include, but are not limited to, an assurance that the numbers of patients attending the facility are sufficient to support your sample size requirements, and that the space and physical infrastructure of the facility can accommodate the research team and any additional equipment required for the research.*
   b. *Please ensure that you provide your letter of ethics re-certification to this unit, when the current approval expires.*
   c. *Provide an interim progress report and final report (electronic and hard copies) when your research is complete to **HEALTH RESEARCH AND KNOWLEDGE MANAGEMENT, 10-102, PRIVATE BAG X9051, PIETERMARITZBURG, 3200** and e-mail an electronic copy to* hrkm@kznhealth.gov.za
   d. *Please note that the Department of Health shall not be held liable for any injury that occurs as a result of this study.*

For any additional information please contact Ms G Khumalo on 033-395 3189.

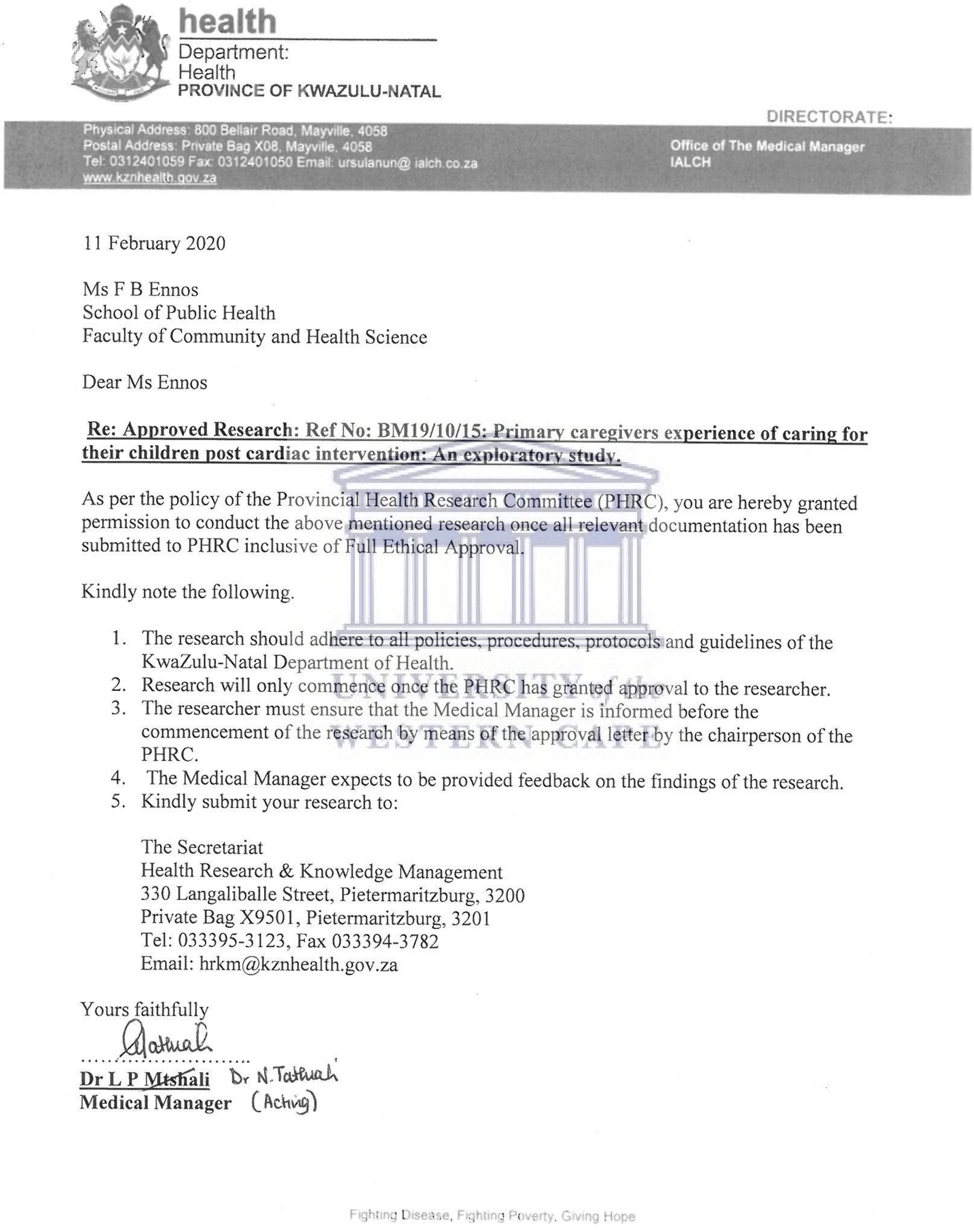
Yours Sincerely

ELutge

Dr E Lutge
Chairperson, Health Research Committee
Date: 25/02/2020.

Fighting Disease, Fighting Poverty, Giving Hope

APPENDIX 10: Permission letter to conduct study (PHRC)



health
Department:
Health
PROVINCE OF KWAZULU-NATAL

DIRECTORATE:

Physical Address: 800 Bellair Road, Mayville, 4058
Postal Address: Private Bag X08, Mayville, 4058
Tel: 0312401059 Fax: 0312401050 Email: ursulanun@ ialch.co.za
www.kznhealth.gov.za

Office of The Medical Manager
IALCH

11 February 2020

Ms F B Ennos
School of Public Health
Faculty of Community and Health Science

Dear Ms Ennos

Re: Approved Research: Ref No: BM19/10/15: Primary caregivers experience of caring for their children post cardiac intervention: An exploratory study.

As per the policy of the Provincial Health Research Committee (PHRC), you are hereby granted permission to conduct the above mentioned research once all relevant documentation has been submitted to PHRC inclusive of Full Ethical Approval.

Kindly note the following.

1. The research should adhere to all policies, procedures, protocols and guidelines of the KwaZulu-Natal Department of Health.
2. Research will only commence once the PHRC has granted approval to the researcher.
3. The researcher must ensure that the Medical Manager is informed before the commencement of the research by means of the approval letter by the chairperson of the PHRC.
4. The Medical Manager expects to be provided feedback on the findings of the research.
5. Kindly submit your research to:

    The Secretariat
    Health Research & Knowledge Management
    330 Langaliballe Street, Pietermaritzburg, 3200
    Private Bag X9501, Pietermaritzburg, 3201
    Tel: 033395-3123, Fax 033394-3782
    Email: hrkm@kznhealth.gov.za

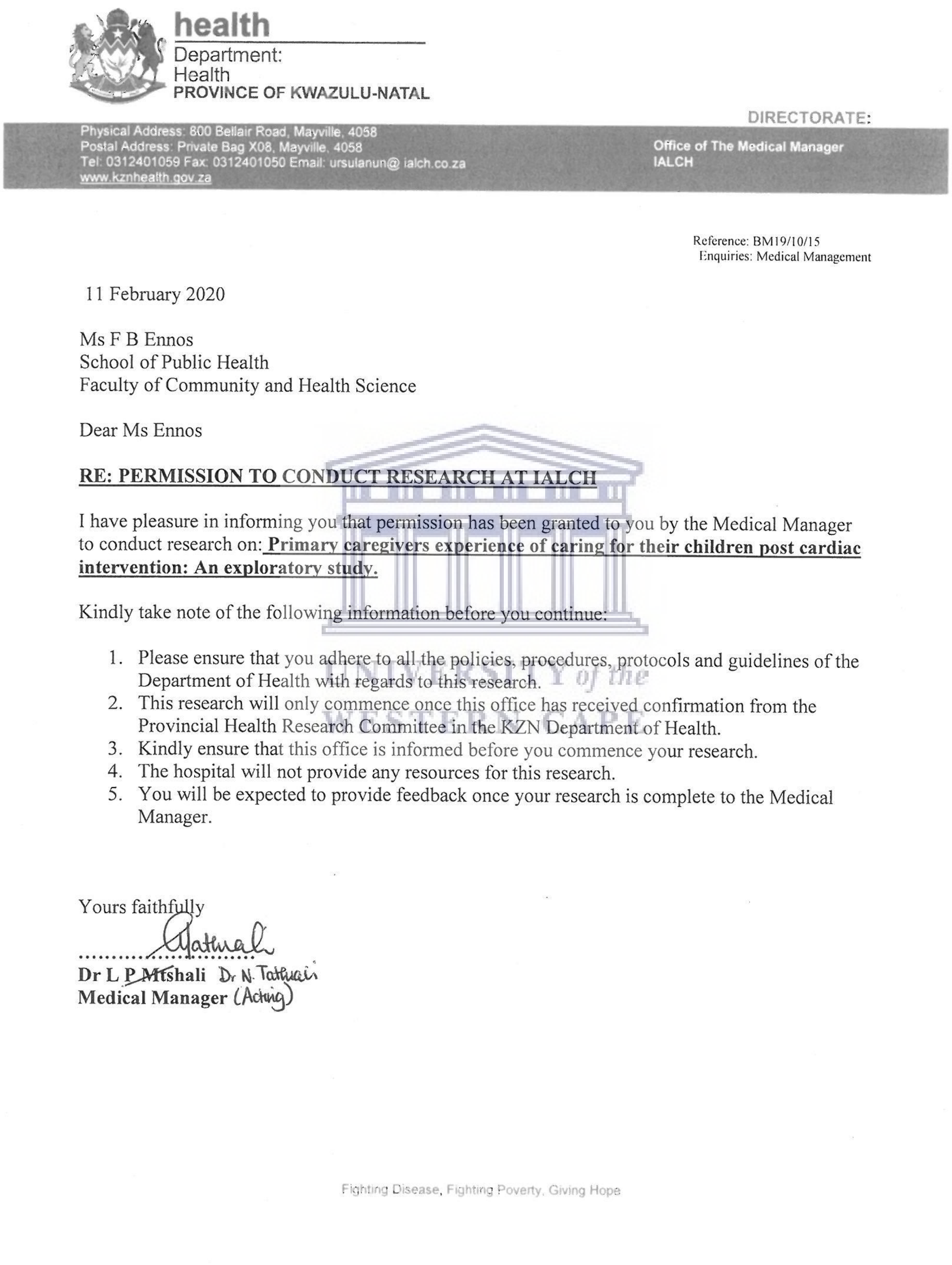
Yours faithfully

……………………………

Dr L P ~~Mtshali~~ Dr N. Tathiah
Medical Manager (Acting)

Fighting Disease, Fighting Poverty, Giving Hope

APPENDIX 11: Permission letter to conduct study (IALCH)



health
Department:
Health
PROVINCE OF KWAZULU-NATAL

DIRECTORATE:

Physical Address: 800 Bellair Road, Mayville, 4058
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Tel: 0312401059 Fax: 0312401050 Email: ursulanun@ ialch.co.za
www.kznhealth.gov.za

Office of The Medical Manager
IALCH

Reference: BM19/10/15
Enquiries: Medical Management

11 February 2020

Ms F B Ennos
School of Public Health
Faculty of Community and Health Science

Dear Ms Ennos

RE: PERMISSION TO CONDUCT RESEARCH AT IALCH

I have pleasure in informing you that permission has been granted to you by the Medical Manager to conduct research on: **Primary caregivers experience of caring for their children post cardiac intervention: An exploratory study.**

Kindly take note of the following information before you continue:

1. Please ensure that you adhere to all the policies, procedures, protocols and guidelines of the Department of Health with regards to this research.
2. This research will only commence once this office has received confirmation from the Provincial Health Research Committee in the KZN Department of Health.
3. Kindly ensure that this office is informed before you commence your research.
4. The hospital will not provide any resources for this research.
5. You will be expected to provide feedback once your research is complete to the Medical Manager.

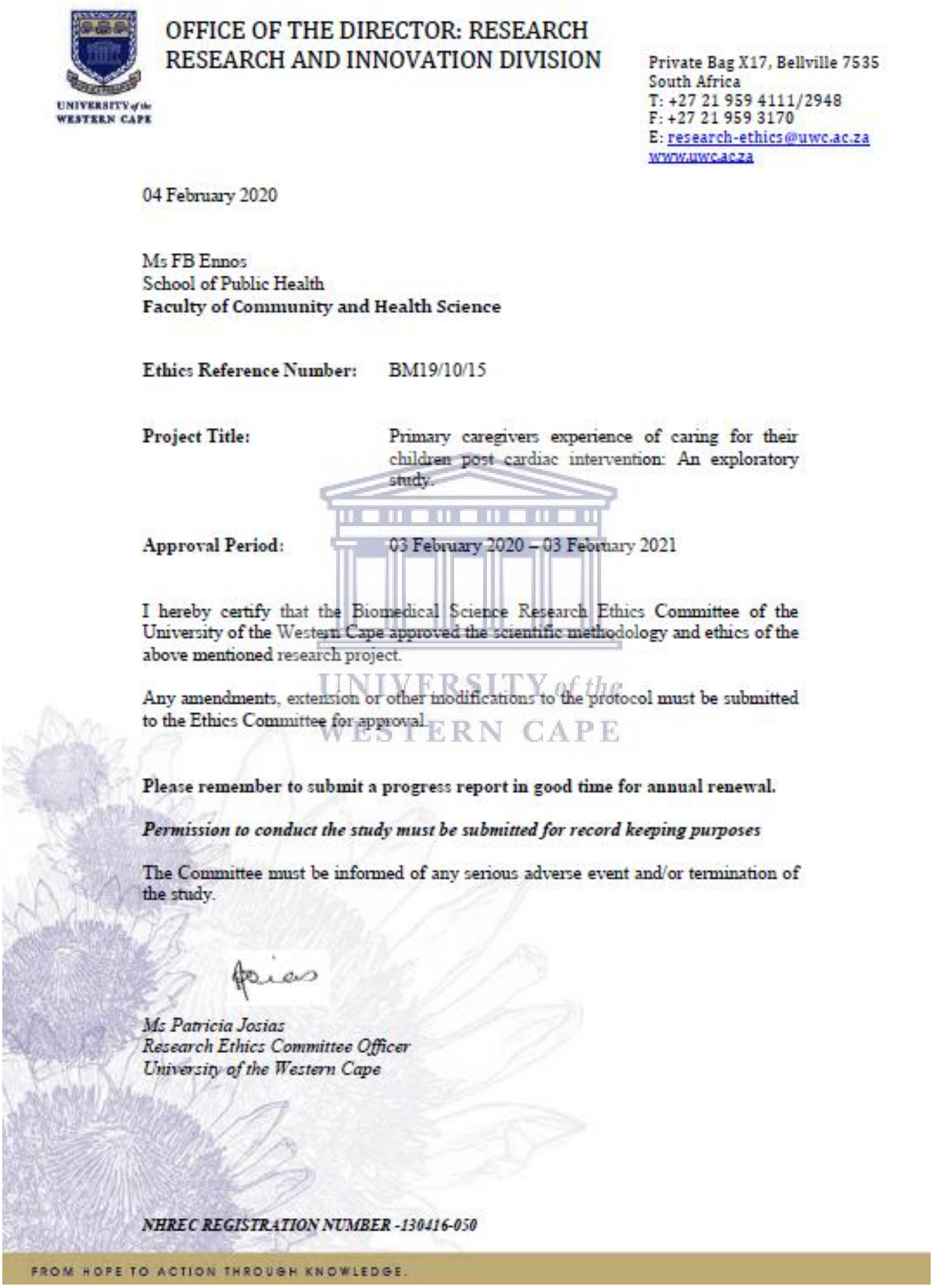
Yours faithfully

……………………………

Dr L ~~P Mtshali~~ Dr N. Tathiah
Medical Manager (Acting)

Fighting Disease, Fighting Poverty, Giving Hope

APPENDIX 12: Permission letter to conduct study (UWC)



UNIVERSITY of the WESTERN CAPE

OFFICE OF THE DIRECTOR: RESEARCH
RESEARCH AND INNOVATION DIVISION

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E: research-ethics@uwc.ac.za
www.uwc.ac.za

04 February 2020

Ms FB Ennos
School of Public Health
Faculty of Community and Health Science

Ethics Reference Number:	BM19/10/15
Project Title:	Primary caregivers experience of caring for their children post cardiac intervention: An exploratory study.
Approval Period:	03 February 2020 – 03 February 2021

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report in good time for annual renewal.

Permission to conduct the study must be submitted for record keeping purposes

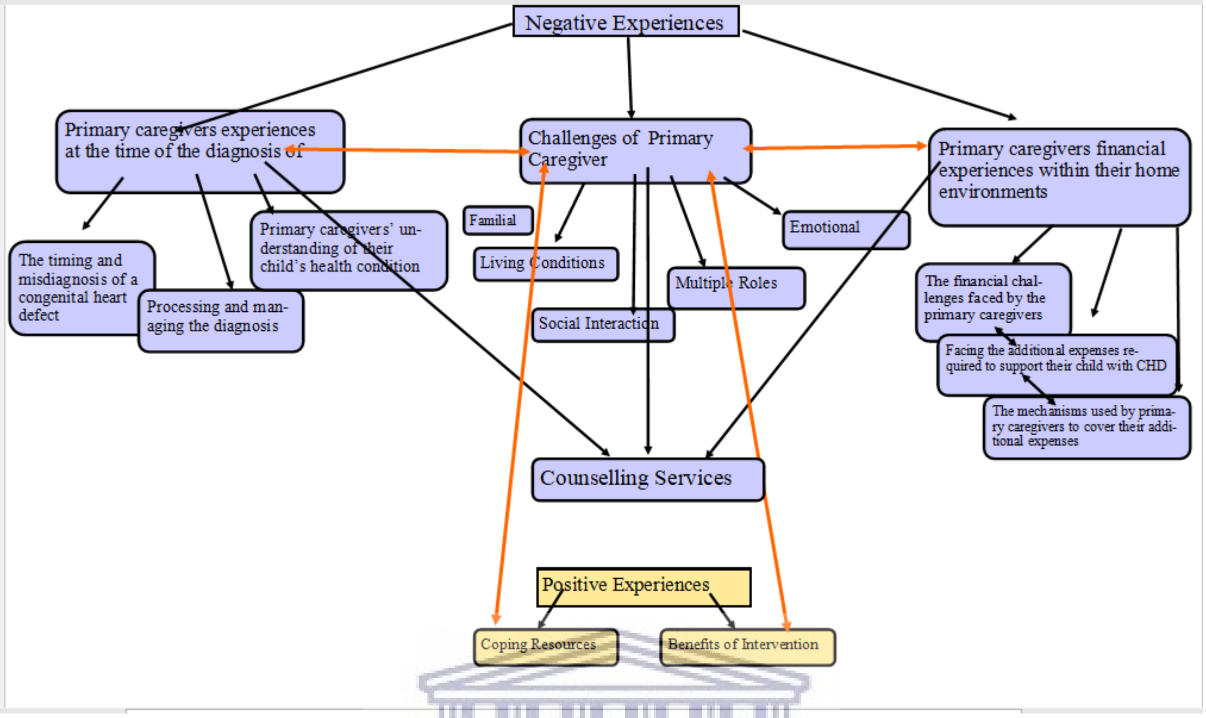
The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

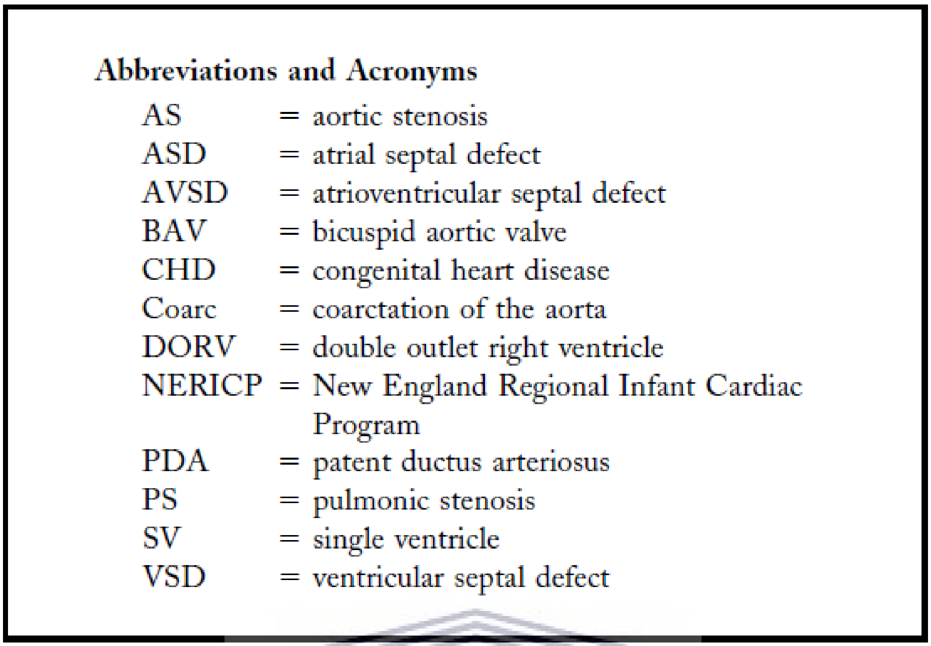
NHREC REGISTRATION NUMBER -130416-050

FROM HOPE TO ACTION THROUGH KNOWLEDGE.

APPENDIX 13: Concept Map



APPENDIX 14: CHD Classifications



Abbreviations and Acronyms

AS = aortic stenosis
ASD = atrial septal defect
AVSD = atrioventricular septal defect
BAV = bicuspid aortic valve
CHD = congenital heart disease
Coarc = coarctation of the aorta
DORV = double outlet right ventricle
NERICP = New England Regional Infant Cardiac Program
PDA = patent ductus arteriosus
PS = pulmonic stenosis
SV = single ventricle
VSD = ventricular septal defect

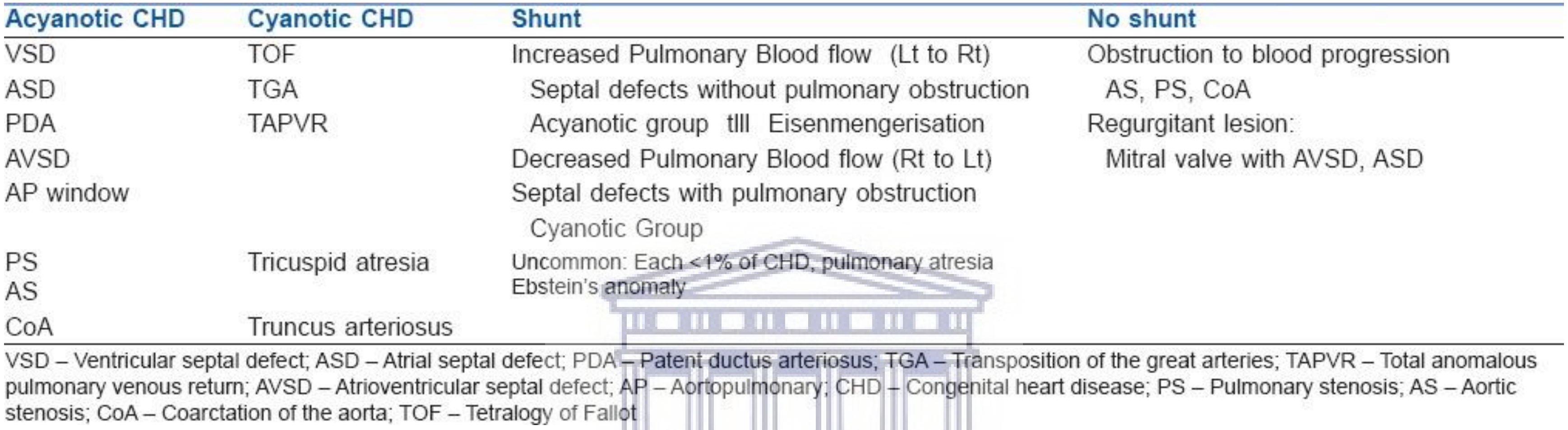
Adapted from Hoffman & Kaplan, 2002

Classification of CHD by Severity and Cyanotic versus Acyanotic Defects

	Cyanotic	Acyanotic
	All those with cyanotic heart disease	*All those with acyanotic lesions*
Severe	1. d-transposition of the great arteries	1. AVSD
This category includes the majority of the patients who present as severely ill in the newborn period or early infancy	2. Tetralogy of Fallot, including pulmonary atresia and absent pulmonary valve	2. Large VSD
	3. Hypoplastic right heart a. Tricuspid atresia b. Pulmonary atresia with an intact ventricular septum c. Ebstein anomaly	3. Large PDA
	4. Hypoplastic left heart a. Aortic atresia b. Mitral atresia	4. Critical or severe AS
	5. SV	5. Severe PS
	6. DORV	6. Critical Coarctation
	7. Truncus arteriosus	
	8. Total anomalous pulmonary venous connection	
	9. Critical PS	
	10. Miscellaneous uncommon lesions like double out-	
Moderate CHD *These require expert care, but less intensive than those listed above.*	A. Mild or moderate AS or aortic incompetence	D. Large ASD
	B. Moderate PS or incompetence	E. Complex forms of VSD
	C. Noncritical Coarc	
Mild CHD *This is the most numerous group.*		A. Small VSD B. Small PDA C. Mild PS D. BAV without AS or aortic incompetence; these may move to moderate or severe categories if they deteriorate with age E. Small or spontaneously closed ASD

Adapted from Hoffman & Kaplan, 2002

Classification of CHD including Shunt and No Shunt variations



Acyanotic CHD	Cyanotic CHD	Shunt	No shunt
VSD	TOF	Increased Pulmonary Blood flow (Lt to Rt)	Obstruction to blood progression
ASD	TGA	Septal defects without pulmonary obstruction	AS, PS, CoA
PDA	TAPVR	Acyanotic group tlll Eisenmengerisation	Regurgitant lesion:
AVSD		Decreased Pulmonary Blood flow (Rt to Lt)	Mitral valve with AVSD, ASD
AP window		Septal defects with pulmonary obstruction	
		Cyanotic Group	
PS AS	Tricuspid atresia	Uncommon: Each <1% of CHD, pulmonary atresia Ebstein's anomaly	
CoA	Truncus arteriosus		

VSD – Ventricular septal defect; ASD – Atrial septal defect; PDA – Patent ductus arteriosus; TGA – Transposition of the great arteries; TAPVR – Total anomalous pulmonary venous return; AVSD – Atrioventricular septal defect; AP – Aortopulmonary; CHD – Congenital heart disease; PS – Pulmonary stenosis; AS – Aortic stenosis; CoA – Coarctation of the aorta; TOF – Tetralogy of Fallot

Adapted from Junghare & Desurkar, 2017