

**EXPERIENCES OF CAREGIVERS AND CARE NEEDS OF CHILDREN
WITH CONGENITAL HEART DISEASE AT KENYATTA NATIONAL
HOSPITAL**

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H58/38041/2020
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**RESEARCH DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT FOR THE
AWARD OF THE DEGREE OF MASTERS OF MEDICINE IN PAEDIATRICS AND CHILD
HEALTH, FACULTY OF HEALTH SCIENCES, UNIVERSITY OF NAIROBI.**

2023

DECLARATION

I declare that this dissertation is my work and has not been published or presented for a degree in any other institution

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ABBREVIATIONS AND ACRONYMS

ACEIs	Angiotensin Converting Enzyme Inhibitors
AV	Atrioventricular
CHD	Congenital heart disease
CHF	Congestive Heart Failure
ICD	Implantable Cardioverter Defibrillator
KNH	Kenyatta National Hospital
PDA	Patent Ductus Arteriosus
SPSS	Statistical Package for Social Sciences
UON	University of Nairobi
VSD	Ventricular Septal Defects
WHO	World Health Organization

DEFINITION OF TERMS

Etiology: The cause, origin or manner of causation of a condition or disease. In this study expected causes of heart failure include, infections, rheumatic heart disease, cardiomyopathies and nutritional deficiencies among others.

Congenital heart disease: are ranges of birth defects that affect the normal way the heart works

Congestive heart failure: A medical condition in which the heart is progressively unable to pump blood at a rate commensurate with the body metabolic needs.

Coping: Any strategies that effectively manage emotional, physical or psychological burdens, and was considered sufficient and appropriate to cover the breadth of literature exploring parental coping

Cardiomyopathies: Diseases of the heart muscle affecting the heart's structure, shape, and size.

Experiences: An event or occurrence which leaves an impression on someone

ABSTRACT

Background: Congenital heart disease (CHD) is one of the common diagnosed congenital disorders affecting approximately 0.8% to 1.2% live births globally. This disorder has been significantly associated with increased burden of care among caregivers. Thus, understanding the experiences and care needs of these children would be fundamental in defining improved focus on their wellbeing. However, in local context, these components have not been fully investigated.

Purpose of the study: To assess the experiences of caregivers and the needs of children with congenital heart disease at Kenyatta National Hospital.

Methods: The study adopted a cross sectional method utilizing both qualitative and quantitative approaches. The quantitative arm was conducted before the qualitative arm. The quantitative data was collected consecutively among caregivers of children attending clinic and those admitted in pediatric wards. Descriptive analysis was done to describe study population where frequencies and percentages were used for categorical data while Mean and standard deviation was used for continuous data. Logistic regression was used to investigate factors associated with caregiver mental wellbeing. Thematic analysis was done to develop themes from qualitative data.

Results: the findings showed that 79.3% of caregivers were female, 40.7% had secondary level education, and 64% were unemployed. The mode of delivery was also assessed where 78% of the mothers had vaginal deliveries. Common types of CHD identified included atrioventricular septal defect (AVSD) (32.7%), patent ductus arteriosus (PDA) 28.2% and atrial septal defect (ASD) (10.5%). The results also showed that 40.7% had medical insurance, 22.7% received some form of financial support from the government, and 39.3% were able to perform some physical activities. Mental wellbeing of the caregiver's assessment revealed that 68% had depression and 73% had mild/moderate burnout. Four main themes and seven sub-themes were identified. The themes identified include shock and denial, psycho-social wellbeing, uncertainty about future and coping strategies.

Conclusion and recommendation: The findings have showed that the level of depression and burnout among caregivers of CHD patients is high which provide the need to ensure that the needs of these children are addressed. Creation of strong support groups should be integral in championing the needs of children with CHD.

CHAPTER ONE: INTRODUCTION

1.1. Background

Congenital heart defects are structural or functional heart problems caused by a defect or abnormality that exist at birth, affects approximately 8 to 12 of every 1,000 live births accounting for two-thirds of all major birth defects (1). Globally, the reported prevalence of CHD births has increased over time, going from 0.6 per 1,000 live births in the 1930s to 9.1 per 1,000 live births(2).

Development of safe diagnostic imaging and especially non-ionizing technics like the 3D echocardiography and implementation of nationwide programs of prenatal neonatal screening are some of the plausible reasons for the apparent increase in the prevalence of CHD. For instance in the United States, one of the most technologically advanced nation, CHD is the commonest type of birth defect (3). Due to a lack of screening and diagnosing the existence of problems rather than the absence of defects, the prevalence of CHD in many other parts of the world remains unknown. According to the Kenya Ministry of Health, approximately 200,000 children under the age of 18 have heart disease, and over 10,000 babies are born with CHD each year.

Advances in the implementation of high impact child survival strategies, that include childhood immunization, breastfeeding and care of the critically ill child is driving an epidemiologic transition from infectious diseases as leading cause of morbidity and mortality and emergence of non-communicable diseases, and CHD is one of them (4). The changes in medical and surgical techniques have led to CHD being considered as a major paediatric illness. Case fatality associated with this condition is approximately 3-7 percent in developed settings while in developing countries the rate is significantly at around 20 percent (5). The

common symptom among children with congenital heart disease include developmental delay which is present in around 87 percent of these children (6).

Caring for a child with chronic illness has many challenges that affect the well-being of the carer. Parents of children with CHD are faced with the uncertainty of their children living past their adulthood including different challenges such as regular medical appointments to review the wellbeing of their children (7). Providing medical and emotional care for their new-born child is typically a difficult challenge for the family unit. Furthermore, these parents face increased financial insecurity as a result of unemployment, sick leave, and medical costs associated with caring for their children - all of which contribute to a lower standard of living (8).

The Government of Kenya has put in place strategic social protection measures that have focused on improving the needs and wellbeing of all children's including those with chronic disease such as CHD. In order to be effective, the services need to be responsive to the actual needs. There is limited information on the caregiver experiences when taking care of the wellbeing of children with CHD and the attendant social and health needs (7). KNH provides for the only dedicated paediatric cardiology service in the public sector. The patients who utilize these services are from all over Kenya. Understanding the needs of families of children with chronic illness and especially a condition like CHD that requires timely intervention to avert severe morbidity, would enable the health services to offer appropriate multidisciplinary services. From past literature, it has been identified that parents/caregivers of children with congenital heart disease have had stressful experiences, hopeful, hopeless and uncertainty with regards to future (4,5). In the local context, the needs and wellbeing of caregivers of children with congenital heart diseases have not been explored despite. This study seeks to describe the experiences of caregivers and the needs of children with congenital heart disease at Kenyatta National Hospital.

CHAPTER TWO: LITERATURE REVIEW

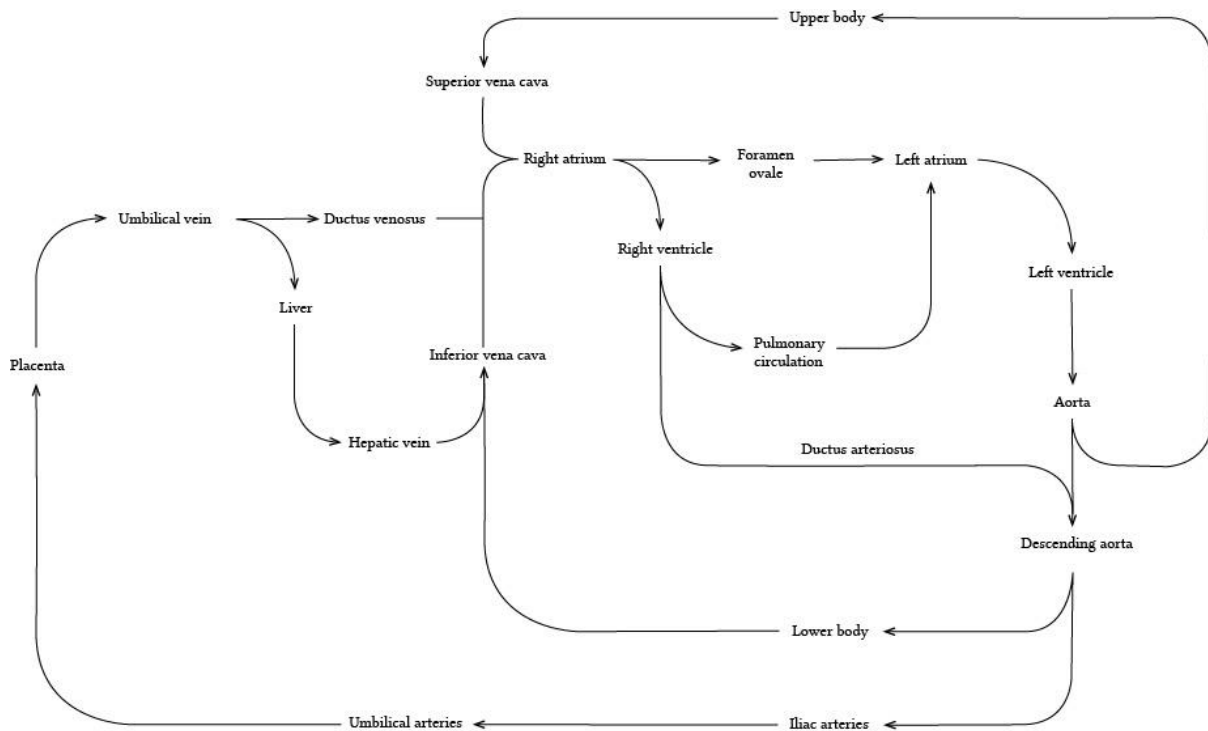
2.1. Introduction

This section provides an understanding on the experiences of caregivers and the needs of children with congenital heart disease. The key sections will focus on the development of congenital disease, existing burden experiences and care needs. Peer reviewed journals such as PubMed, Cochrane Library and Hinari will be used in searching for relevant literature. Mendeley Desktop will be used in organizing and referencing of information.

2.2. Anatomy of the heart and flow of blood

Understanding the flow of blood before and after birth is instrumental in understanding the development of this condition. Blood circulation through the heart is vital. Oxygenated blood from the placenta returns through the umbilical vein. The umbilical vein is responsible for distributing approximately 40 percent of blood to the liver and 60 percent flows to the inferior vena cava through the ductus venosus (9). The right atrium receives the inferior vena cava's drainage. The flow separates into parallel circuits from the right atrium: Through the ductus arteriosus, which connects the pulmonary trunk to the proximal descending aorta, into the right ventricle, then into pulmonary circulation, back to the left atrium and left ventricle, and finally into the systemic circulation. Through the foramen ovale, into the left atrium, and ultimately to the left ventricle (10).

Upper body blood flow is entirely from the left ventricle, into the aorta, and then out of the aorta, whereas lower body blood flow is the combined output of the LV and RV. Venous blood returns from three important bodily parts, including the common iliac arteries through the umbilical arteries, to the placenta, from the upper body to the right atrium, and from the lower body to the right atrium, via the systemic circulation (11).



Source: Marty et al., 2021) (11)

The transformation from a foetus to a baby is the most difficult adaptation a person can go through. The elimination of embryonic lung fluid, surfactant secretion and the commencement of continuous breathing are all required for lung adaption. The cardiovascular response to the removal of the low-pressure placenta necessitates dramatic changes in blood flow, pressures, and pulmonary vasodilation. In addition, the baby must swiftly regulate its energy metabolism and temperature (12).

The flow of blood through the uterus is not self-regulating. It is inversely related to uterine vascular resistance and fluctuates directly with systemic maternal blood pressure. Uterine hypoperfusion and fetal bradycardia can occur if the maternal systolic blood pressure is less than 100 mm Hg. Hypotension can occur during aneurysm clipping because to hypovolemia, aesthetic drugs, excessive positive-pressure breathing, bleeding, or the use of nimodipine. Maternal hypotension, whatever the aetiology, must be treated aggressively. Although

induced hypotension has the potential to harm the fetus, it has been effectively utilized to aid in aneurysm clipping (13).

2.3. Classification of CHD

CHD in severe cases is normally noticed immediately after birth or the first few months of life while less severe cases might be diagnosed late in child development. Congenital heart diseases are broadly classified into two major categories which include cyanotic heart disease and a cyanotic heart disease (14).

Classification of CHD	
Cyanotic Heart Disease	Acyanotic Heart Disease
<ul style="list-style-type: none">• <u>Decreased pulmonary flow:</u><ul style="list-style-type: none">– Tetralogy of Fallot– Tricuspid atresia– Other univentricular heart with pulmonary stenosis.• <u>Increased pulmonary flow:</u><ul style="list-style-type: none">– Transposition of great arteries– Total anomalous pulmonary venous return.	<ul style="list-style-type: none">• <u>Left – Right shunt lesions:</u><ul style="list-style-type: none">– Ventricular septal defect– Atrial Septal Defect– Atrio-ventricular Septal Defect– Patent Ductus Arteriosus• <u>Obstructive lesions:</u><ul style="list-style-type: none">– Aortic stenosis– Pulmonary valve stenosis– Coarctation of Aorta

Source: Bredy et al., 2018) (14)

2.4. Impact of Congenital heart disease

A congenital heart defect (CHD) is a cardiac structural abnormality that occurs before birth. When a catastrophe occurs during heart development shortly after conception – frequently before the woman is aware that she is pregnant – such abnormalities emerge. Such issues may or may not cause problems with a person's circulatory system. However, having a congenital heart abnormality raises your chances of getting certain medical problems. Simple difficulties, such as "holes" between chambers of the heart, to severe anomalies, such as the

complete lack of one or more chambers or valves, are all examples of congenital heart defects (10).

Congenital heart disease, congestive heart failure, and cyanosis, a condition in which blood pumped to the body contains less oxygen than normal, cause infants and children to gain weight more slowly. For a new-born with a heart abnormality, an eight-ounce to one-pound increase in a month may be sufficient. Some of key factors that are related to congenital heart defects that have detrimental influence on child growth include rapid heart rate, increased respiratory rate, poor appetite, higher caloric needs, high frequency of respiratory infections, poor absorption of nutrition and decreased oxygen supply in the body (15). Developmental delay restricts key developmental processes such as participating in physical activities, learning and interacting with others fully. This warrants integration of better strategies such as special education. In addition, most families in developing countries do not have health insurance covers hence lead to increased financial burden on caregivers (16).

2.5. Empirical Literature

Caregivers of children with congenital heart disease experience diverse challenges in taking care of the needs of these children. Therefore, this review seeks to investigate these children's characteristics, experiences, and care needs.

2.5.1. Characteristics of children with congenital heart disease

There is a mixture of cross-sectional studies and prospective of children with CHD. The studies in developing nations report on children followed up in paediatric clinics or referred from other facilities (17)(18)(Animasahun 2018, Xiang et al 2019, Thomford et al 2020, Al-Fahham and Ali) while some of the studies in developed nations are based on routine newborn screening (Shima et. al. 20021). The majority of patients are aged between one and five years of age. In the Nigerian study 70% of the children were > 1 year of age, (17), while the Chinese children had a median age was 4.2 years (range of 2 to 12 years) (Xiang et al).

There is a slight preponderance of females with a reported male to female ratio of 1: 1.1-1.2. (17), Al-Fahham and Ali). In countries with active new-born screening, the majority of babies are identified before the age of one year (Shirma et al., Al-Fahham and Ali) for example in the Egyptian study, 86.7% were diagnosed within the first year of life and were born to young mothers (91.3%).

The children have symptoms for a long period of time before diagnosis. For instance, 70 percent of the Nigerian children were symptomatic for more than a year before diagnosis (17) and the presenting symptoms included fast breathing and cough while bronchopneumonia, upper respiratory infections, and pneumonia were the most commonly diagnosed comorbidities accounting for over 35% of non-cardiac sequelae (19). A three-year retrospective study conducted in Egypt by Al-Fahham and Ali (20) in 2021 investigated the pattern of congenital heart disease among Egyptian children. The accidental discovery of a murmur was the most frequent presentation (35%). Heart failure was detected in 44%, audible murmurs in 74.4%, and extracardiac anomalies in 3.6% of the studied population.

This experience is very different for children who had access to prenatal and early neonatal diagnosis. In the study by Shima et al. in of 43 Japanese neonates with CHD 34% had low birth weight (<2,500g) and 26% were premature (<37 weeks of gestation) (21). The prevalence of prematurity was 19.3% in the Egyptian study (20).

The pattern of CHD is similar across different populations. The commonest congenital heart lesions were acyanotic CHD found in 72%-76.3% Nigerian, Ghanaian, and Japanese children (17), (20), (21),(19). Echocardiography was the most common method of diagnosis. The three commonest congenital heart disease types were ventricular septal defect (32.7%), atrial septal defect (21.8%), and patent ductus arteriosus (17%).The prevalence of cyanotic heart disease was 23.7% to 28% among the Nigerian and Japanese children respectively (17), (20),

(21),(19). The commonest cyanotic CHD were tetralogy of Fallot (63.4%) and double outlet right ventricle (18.3%) (17). One study collected data on potential risk factors and found 54% had a history of maternal illnesses, consanguinity in 44.6%, assisted reproduction in 11.7%, family history of CHD in 9.2%, abortions in 7.1%, (19).

The cohort studies provide additional information on the outcome of the CHD. In the Japanese 4 of the 43 children died all neonatal deaths and suffering from a cyanotic heart disease. Twelve babies (27.9%) underwent surgery during the study period, and 7 (16.2%) reached final anatomical correction (21).The Chinese study reports on the post-surgery follow up of children with CHD in their cohort. Sixty-four percent of the survivors were boys, 58 percent came from rural areas, and 14.6 percent came from low-income counties (18).

2.5.2. Care needs of children with congenital heart disease

Studies have effectively investigated underlying health needs of children with congenital heart disease especially considering the underlying burden associated with the disease. Children with congenital heart disease are vulnerable and highly dependent on their caregivers, which presents the need to understand the underlying healthcare needs. Brady et al. (22), in a study investigating physical needs of children with congenital heart disease, the findings revealed that 75.9% of the patients attained 60 minutes of physical activity on a weekly average according to the World Health Organization criteria as 81 (84.3%) of the healthy peers did.

Survey studies have also been conducted which have effectively outlined a strong basis for understanding the healthcare needs of children with CHD. A national survey conducted in Germany found that children with CHD are faced with difficulties especially in physical activity. Peterson et al. (23) using 2007 to 2018 National Health Interview Survey data. The researchers discovered that 10% of the 233 children with CHD in the study had fair or poor

health, 38% had any health-related limitations on their typical activities, 11% required special equipment, and 27% received special education services.

Educational attainment has also been a major challenge among CHD patients. According to Girouard and Kovacs (24), children with CHD were more likely to have neurodevelopmental deficits which limited them to pursue usual education system but undertake special education. Marino et al. (25) further state that neurodevelopmental impairments and abnormalities are more common in children with CHD, especially those with more complex types. Deficits in domains relevant to academic attainment, such as language and speech, attention, and executive processes, are frequently found. CHD patients are also more likely to develop autistic spectrum disorder. A systematic review and meta-analysis conducted by Huisenga et al.(26), including 182 peer-reviewed papers, found that children with complex subtypes of CHD, such as single ventricle CHD, have the worst neurodevelopmental outcomes. Special education and/or remedial academic services are consequently more common among children with complex forms than among their healthy counterparts, with rates ranging from 15% to as high as 49%.

A population-based cohort study conducted in the United States by Oster et al. (27) in 2017 revealed that children with CHD had 1.24 times the chance of failing to reach reading or math standards, with 44.6 percent of children with CHD failing in at least one of these areas, compared to 37.5 percent of children without CHD. Furthermore, while both children with critical and non-critical CHD had lower outcomes, those with critical CHD were 1.46 times more likely than the non-critical group to receive excellent treatment. As a result of these findings, children with all forms of CHD do worse in school than their counterparts. As a result, children with any type of CHD should be evaluated for extraordinary assistance.

Patients with CHD require a high level of care hence presenting a broader need to develop a more appropriate understanding of the existing status quo. A cross-sectional study conducted in Nigeria by Duru et al. (28) investigated caring for children with congenital heart diseases, emphasizing the economic burden. The findings showed that of the 108 parents interviewed, 81.0% paid for healthcare using an out-of-pocket payment mechanism. The median direct monthly medical costs were \$10.07 ranging between \$0.56 and \$164.8. Non-medical costs were \$1.17 ranging between \$0.42 and \$30.56. The majority of direct medical and non-medical costs were accounted for by hospitalization and transportation, respectively. A financial disaster afflicted 36.1 percent of families. Above the 10% income barrier, catastrophic overshoot was 5.6 percent and mean positive overshoot was 30.8 percent. Families with children who had CHD complicated by heart failure and pulmonary hypertension, as well as those who had experienced financial hardship, spent much more on healthcare. Health insurance did not result in a significant reduction in healthcare spending among those who were covered. The findings revealed that the cost of pre-surgical treatment of children with CHD in Nigeria is considerable. This necessitated proper government and non-government actions to ease the financial burden of healthcare bills on impacted households.

According to a study conducted in Ethiopia by Choi et al. (29) , it was found that, most of the children diagnosed with CHD at birth were born at a healthcare facility where symptoms were noted and investigations done. However, there was longer waiting line for surgery with some patients waiting for more than one year.

2.5.3. Experiences of caregivers

Experiences include individual perceptions of a given issue under consideration, clearly emphasizing its influence. Caregivers of children with congenital heart disease have diverse experiences that define their well-being and child development. Learning of child condition

was done differently. In most cases, caregivers did not understand the condition until they received an expert opinion. According to a qualitative study conducted in Ethiopia by Choi, it was identified that identification of candidacy, navigation experiences, the permeability of services, appearances at health services, and lack of clear guidelines were the main themes (29). Many of the caregivers had navigated the difficult referral system to the teaching hospital, according to the study's findings. Caregivers said that once a CHD diagnosis had been given, health centers and hospitals were relatively open to follow-up appointments. Surgical care, on the other hand, was difficult to come by. Some caregivers have been on the waiting list for over three years. After two to three visits, caretakers were told that the surgery would have to be postponed indefinitely. Diagnoses, treatments, follow-up visits, and emergency care are all available to caregivers for their children. Unfortunately, children who were born at home were more likely to have a diagnostic delay(29).

In a qualitative study conducted in Iran by Nayeri et al. (30), it was found that some parents avoid communicating with others and isolate themselves from the community after being informed of a child's CHD. As a result, some of the parents received the news of their child's condition with sadness. Further, diagnosing a child with illness by others based on their appearance is a discomfort to the parent, as people look for the cause as soon as they notice it. In another qualitative study conducted by Simeone et al. (31) in Italian hospitals among parents whose children were discharged to home after cardiac surgery for CHD, the common theme identified was the feeling of chronic psychophysical fatigue. Among all parents, the return home increased their workload led to chronic tiredness. Participants described this tiredness as both physical and mental. Participants said they felt trapped in a vicious circle generated by an overload of work.

Another meta-analysis review conducted by Dellafiore (32) including six major articles, four main themes were identified, they include also exploring four main contradictions that

characterize the life experiences of CHD adolescents' parents: "fear and uncertainty of the future versus positive coping strategies"; "parents hyper-responsibility and overprotection versus adolescents' independence desire"; "desire to give support, but not to be supported"; "normality desire versus awareness to live with particular conditions ."These findings have shown that the role of the CHD adolescents' parents is difficult, and they experience some contradictions.

Another study conducted by Ahmadi et al investigating burnout among caregivers of children with congenital heart disease, it was identified that using the Maslach burnout inventory scale, 62.3% of the caregivers experienced high emotional exhaustion and 47.9% experienced moderate level depersonalization. Almost all of the caregivers experienced reduced personal accomplishment (33). The high level of burnout as observed in the study revealed that, age of the child, type of chronic condition as well as the frequency of medical visits, caregiver's job, income and family size were significantly associated with high level burnout.

Caregivers of children with chronic illness have also been associated with increased prevalence of depression. A descriptive cross-sectional study conducted by Kihiu et al in 2020 among children with HIV/AIDS aged 10 years and below, the results revealed that 54 percent were depressed of whom 62 percent had mild depression while 35% had moderate depression. The findings from the study further found that PHQ-9 scores of greater or equal to 10 were significantly associated with 31 times increased chance of having children who is not virally suppressed and was associated with lower likelihood of achieving better ART adherence among children (34).

2.5.4. Challenges faced by caregivers

Heart diseases require advanced diagnostic skills and delicate surgical procedures, which require a well-organized health system. The key challenges faced by caregivers include an inefficient healthcare system, financial challenges, a high burden of care, and ensuring that

these children lead almost a normal life. Prior research shows that most health care systems in developing countries do not have enough medical personnel to diagnose CHD, making it difficult for caregivers to ensure that caregivers provide appropriate care needed to improve their condition (35). In addition to an inefficient healthcare stem, the cost of preventing and treating heart diseases poses a great burden on households. As a result, most caregivers are unable to fully provide care and the needs of CHD patients due to the high cost of care and regular medication needed (36).

It has also been found that CHD has detrimental influence on the financial situation of parents or caregivers of children with this condition as well as having a detrimental influence on the quality of life (37). The emotional distress that is associated with treatment seeking has been identified as a major challenge for both the child and their caregiver (38).

Developing countries have been having challenges such as late diagnosis due to limited resources (39).

CHD is not a disease that can be surgically treated at any point in time. If the diagnosis and operation are missed or delayed, many CHD patients will die. Hypoplastic left heart syndrome or transposition of the great arteries may necessitate surgery within one month of birth in some situations. In the case of CHD, delaying surgery increases the risk of bleeding during the procedure and necessitates more stringent post-operative infection prevention measures. Complications such as endocarditis and cardiac failure are also more common (40).

2.5.5. Coping strategies

Coping with the care needs of CHD patients is difficult. However, parents and caregivers are expected to integrate proper approaches to improve their well-being and the needs of children. According to a systematic review and meta-analysis conducted by Lumsden et al. (41), 22 studies revealed that common themes were evident. Individuals used their approaches and strategies depending on their previous experiences, social support, personal

attributes, and beliefs. Parents attempted to retain a sense of normalcy by integrating CHD into their lives without it having a significant influence, except during transitions and hospitalizations, when they needed to rely on additional measures or help to cope with the stress (42).

Many of the parents coped with the situation through positive thinking. This concept explored how parents coped with their child's condition's often honest or blunt prognosis. Healthcare providers, however, have been instrumental in ensuring that care providers provide quality care. Parents and caregivers coped with these dilemmas by believing their child was on the other side of the odds, hoping that they were not part of the risk statistic and doctors were wrong with their prognosis (43).

Various people were mentioned by parents as people they sought help from at various points of their journey, whether emotional, practical, reassuring, or offering information. While the majority of parents sought help, they admitted that others could not completely comprehend what they were going through unless they had gone through something similar. Parents also stated that they sought emotional and practical support from someone close to them. Because the majority of the participants were married or cohabiting, they frequently communicated their experiences with their partners, who could empathize with their anguish and offer assistance first-hand (44).

Author, study title, year, setting	Research design	Sample size	Findings
Choi et al. (2021). How do caregivers of children with congenital heart diseases access and navigate the healthcare system in Ethiopia? Ethiopia	A qualitative study	Semi-structured interviews with 13 caregivers	<p>Delayed access to care was largely due to the lack of early CHD recognition and financial hardships, related to the inefficient and disorganized health care system.</p> <p>Fee waivers were available to assist low-income children in gaining access to health services or medications, but application information was not readily available. Indirect costs like long-distance travel contributed to this challenge.</p>
Sharma & Mishra (2020). Burden of Care Among Mothers Having Children with Congenital Heart Diseases. Nepal	Cross sectional study	95 mothers having children with CHD attending outpatient department	<p>77.9% of the mothers were regularly strained to find that their children's health condition was deteriorating due to CHD. 44.2% had financial strain while giving care.</p> <p>40% of the mothers had done emotional adjustments to take care of their children with CHD. 28.4% had disturbed sleep 50.5% of the mothers had high level of burden of care.</p> <p>Age of the mother, type of family, age of child, type of CHD were significantly associated with burden of care</p>
Wei (2015). The Experiences and Care Needs of Parents Whose Children are Born with Congenital Heart Disease. North Carolina	A qualitative study - Phenomenological study	Semi-structured interviews with 13 caregivers	<p>Parents experienced a "rollercoaster" of emotions as their child underwent surgery. Critical times were when parents received their child's diagnosis, were informed that their child required heart surgery, handed their child over to the surgical team, and visited their child for the first time after surgery.</p> <p>Related stressors were the uncertainty of outcomes after surgery, the loss of parental control, the physical appearance of their child after surgery, and the fear of the technological atmosphere in the intensive care unit.</p>

			Parents' experiences moved from shocking to blessing.
Dalir et al. (2021). Caregiving strategies in families of children with congenital heart disease: A qualitative study. Iran	Qualitative study	40 caregivers of children with CHD	<p>The main themes identified were:</p> <p>Monitoring the child's health conditions such as paying attention to the child's physical needs.</p> <p>Organizing family life such as meeting one's own needs</p> <p>Optimizing family life such as Modifying living conditions.</p> <p>Establishing interaction such as Communication with peers and interaction with healthcare professionals.</p>

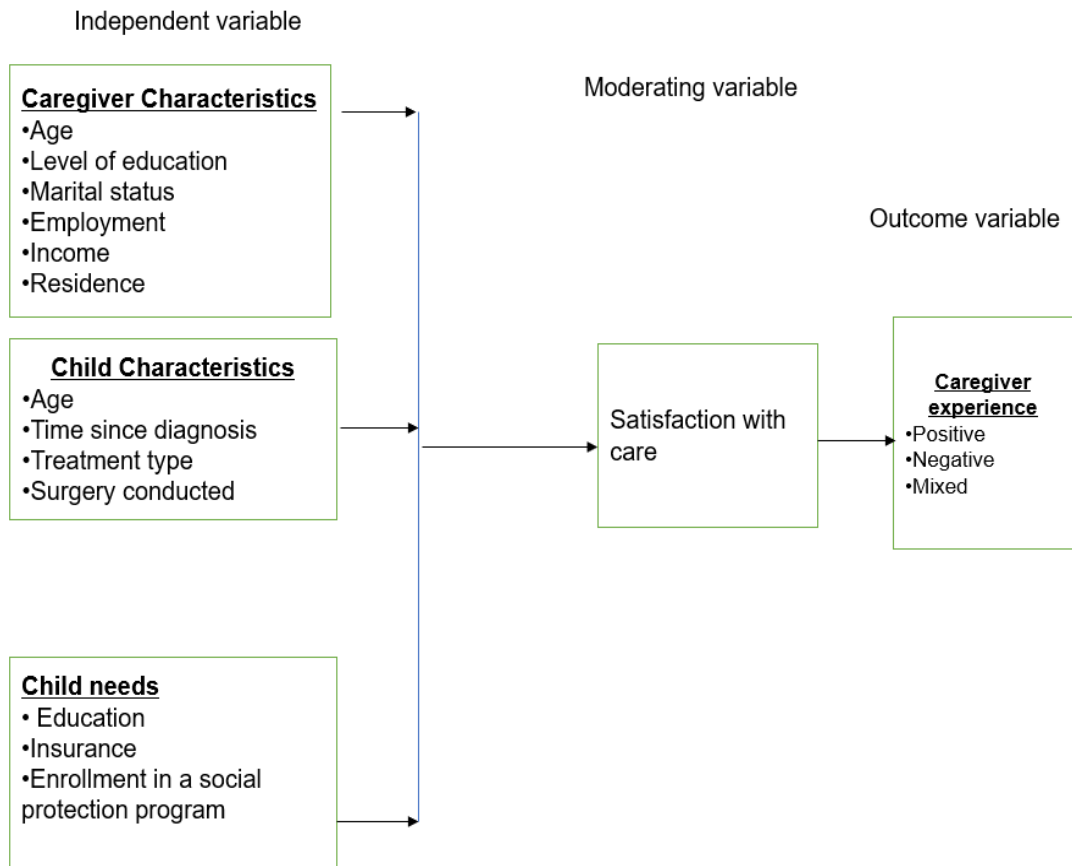
2.6. Summary of Literature

2.7. Conceptual Framework

2.7.1. Conceptual framework narrative

The basis of this study is to determine the experiences of caregivers of children with congenital heart disease and healthcare needs, challenges, and mitigating strategies that can be adopted to improve caregivers' experiences in the management of children with CHD. The care needs investigated in this case include health-related such as clinic attendance, medication adherence, and socio-economic needs. Social needs include education attendance enrolment in social protection. This study thus seeks to investigate the influence of these factors on caregiver experiences.

2.7.2. Conceptual Framework figure



2.8. Justification

Parents of children with CHD have to combat difficulties on two main fronts; dealing with their children's disease and the process of treatment while simultaneously navigating through the medical system. Children with CHD are highly dependent and thus present a major burden to their parents or caregivers. Regular clinic visits and the inability to lead a normal life compared to other children are key issues that have increased caregivers' burden. However, in the local context, the healthcare needs of these children, experiences of caregivers, and challenges they face have not been exhaustively investigated, which form the basis of this study. Caring for patients with CHD can be complex and may require continuity of care, such as regular outpatient visits and drugs. The social well-being of these patients has also become a major issue. However, the efficacy of these processes can be effectively assessed with a specific emphasis on experiences and existing needs among these children.

2.9. Research question

What are the experiences of caregivers and the needs of children with congenital heart disease at Kenyatta National Hospital?

2.10. Objectives

2.10.1. Broad objective

To explore the experiences of caregivers and the needs of children with congenital heart disease at Kenyatta National Hospital

2.10.2. Specific objectives

- 1) To establish demographic and clinical characteristics of children with congenital heart disease at Kenyatta National Hospital in 2022.
- 2) To establish the care needs of children with congenital heart disease at Kenyatta National Hospital in 2022.

- 3) To assess the experiences and care needs of caregivers of children with congenital heart disease at Kenyatta National Hospital in 2022.

CHAPTER THREE: METHODOLOGY

3.1. Study design

This study utilized a cross sectional study design utilizing quantitative and quantitative techniques.

3.2. Study setting

The study was conducted at Kenyatta National Hospital Pediatric unit, both outpatient and inpatient. Kenyatta National Hospital is the largest referral hospital in East and Central Africa, with a bed capacity of approximately 2,000. The hospital is located 5 km from Nairobi Central Business Unit. The hospital complex houses Kenya Medical training college and the University Of Nairobi College Of Health Sciences. The hospital caters to about 30,000 pediatric in-patients each year. Pediatric patients with congestive heart failure are managed at the pediatric wards. The children are usually admitted together with their parents or guardians. They are then discharged through the pediatric outpatient cardiology clinic.

3.3. Study population

Caregivers of children aged 12 years and below and diagnosed with congenital heart disease at Kenyatta National Hospital.

3.3.1. Inclusion criteria

- Caregivers/parents of children aged 12 years and below.
- Caregivers/parents of children aged 12 years and below diagnosed with congenital heart disease ≥ 1 year ago.
- Caregivers/parents who consent.

3.3.2. Exclusion criteria

- Caregivers/ parents of children aged less or equal to 12 years diagnosed with congenital heart disease who decline to consent to the study.

3.2. Sampling technique

3.2.1. Sampling for quantitative data

A consecutive sampling technique was conducted. The caregivers of children with CHD were sampled consecutively until the sample size is attained.

3.2.2. Sampling for qualitative data

A purposive sampling method was used to identify the study. Eligible participants were invited to take part in the study. Purposive sampling is a non-probability sampling method in which subjects are chosen depending on population characteristics and the aims of the study.

3.3. Sample size determination

3.3.1. The sample size calculation for quantitative data

The sample size was calculated using Fischer's formulae (45).

$$n = \frac{z^2 p(1-p)}{e^2}$$

was used to determine the number of children to include in this study.

where

n is the minimum samples size,

p is the estimated proportion of children with CHD (9.75%)(46)

e is the level of precision (10%)

z is the normal deviate at the alpha of 5% and 95% confidence level (Z=1.96). Hence;

$$n = \frac{1.96^2 * 0.0975 * (1 - 0.0975)}{0.05^2} = 136$$

Considering attrition of 10%, the sample size was 150

The sample size included 150 caregivers.

3.3.2. The sample size for qualitative data

The study included two focus group discussions (FGD). The Outpatient focus group discussion (FGD1) included seven participants while Inpatient focus group discussion (FGD2) included six participants. A focus group including 6-8 participants is appropriate considering that it is easy to manage and participants can interact freely to provide honest responses. This was essential in identifying challenges and coping strategies that they have put in place to help improve the wellbeing of their children. Focus group discussion is appropriate in this case considering that the population includes caregivers with the same characteristics; hence they are more likely to open up and provide honest and accurate responses since they are able to relate with their respective settings. The focus on inpatient and outpatient is mainly associated with the likelihood of varied healthcare needs of children who are admitted and outpatient. This would automatically have an influence on the experiences of caregivers in these two contexts.

3.4. Recruitment of research assistants

The researcher recruited two research assistants. The research assistants were trained nurses with diploma level qualification as the minimum academic qualification. The research assistants were trained on the data collection approach and how to approach and interact with patients. The training was a two-day session. The first day involved familiarization with the data collection tool and the second day involved visiting data collecting setting to understand any possible gaps in the outlined data collection method.

3.5. Data Collection procedure

3.5.1. Quantitative data collection

The data collection process began after approval from KNH-UoN ERC and Kenyatta National Hospital administration. The researcher, with the help of research assistants, the principal investigator approached mothers with children diagnosed with congenital heart disease attending care as well as those admitted in pediatric wards. At the outpatient clinic, the principal was recruited the first caregiver who meets the inclusion criteria and consents as the starting point. Other respondents were selected each clinic day consecutively until the sample size is attained. In the pediatric wards, the principal investigator was recruited caregivers who meet the inclusion criteria consecutively.

For quantitative data, a standard questionnaire was used to obtain relevant information, including the age of the child, duration of illness, the number of hospital admissions, length of most recent admission, diagnosis, stage of follow-up, and investigations done. Socio-economic information from the caregiver will also be sought, which included NHIF /fully paid employment, SES-use, demographic health survey variables, and family structure.

3.5.2. Qualitative data collection

The participants were assessed to ensure that they did not participate in the quantitative data collection process. The researcher recruited focus group participants from the population that did not participate in answering the questionnaire. The participants provided their contacts to the researcher, having agreed to participate in the Focus group discussions at a later date to be communicated. The FGD were moderated by the researcher, and a note-taker was used to document the proceedings of the session. The session was audiotaped and transcribed verbatim to derive meaning. A Focus group discussion guide was used to assess challenges and mitigation strategies that caregivers are putting in place to improve their wellbeing and reduce the burden.

3.6. Data collection tools

3.6.1. Maslach Burnout Inventory (MBI) tool

The MBI has been recently revised in 2018 and includes 22 items. The MBI which forms the multidimensional theory identifies burnout as a psychological state exhibited by three (3) components namely, emotional exhaustion, depersonalization, and reduced personal accomplishment due to chronic work-related stress (47,48).

Emotional exhaustion, a component of burnout is described as physical lethargy, emotional, and cognitive fatigue. The individual loses energy as a result of overexertion at work and unrealistic obligations and is therefore chronically drained. The effect of emotional exhaustion is depersonalization typically characterized by disengagement and cynicism where the individual exhibits negative attitude and disinterest towards work, and becomes impersonal towards colleagues and clients (49).

The final stage of burnout is lack of personal accomplishment at work. This is evidenced by individual's lack of professional developments, worthiness, or productiveness at work. (48,50).

3.6.2. PHQ-9 tool

The PHQ-9 was used to screen for depression. It is a self-administered questionnaire consisting of 9 items graded on a four-point Likert scale (0–3). Using this tool, a total score of five (5) or above indicated presence of depression. The PHQ-9 was found to have high validity and reliability among people living with HIV in a study conducted in Western Kenya (51).

3.7. Study variables

Independent variables: Caregiver characteristics (age, marital status, level of education, employment status, monthly average income, residence), child characteristics (age, time since diagnosis, treatment, surgery conducted, education, insurance, enrollment in social protection program).

Dependent variable: Experiences of caregivers (Positive, negative, mixed)

3.8. Data quality control

The data collection tool was filled by a trained research assistant under the guidance and supervision of the principle investigator to obtain the demographic and clinical data. The research assistant recruited had a minimum of diploma in nursing qualification, therefore knowledgeable. Additionally, the research assistants were trained for two days to ensure that they are well conversant with the research tool and ethical research practices. The researcher led the data collection procedure and continuously monitors research assistants in ensuring that they collect quality data. To avoid duplicate findings, the questionnaires were assigned serial numbers. Following collection, the data was reviewed on a weekly basis to ensure completeness. Continuous data entry was made into a password-protected Epi data database. The Principal Investigator recruited a qualified statistician who assess, clean and analyze the data to achieve the intended goals.

3.9. Data analysis

Quantitative data analysis

The data cleaning and analysis was done using Stata version 17. Descriptive statistics was used to analyse the sociodemographic and clinical characteristics of the patients and presented as frequencies and percentages for categorical data and as means with standard deviations for continuous data. Binary logistic regression was used to investigate the association between caregiver, child characteristics and depression. The level of significance was assessed at $p < 0.05$.

Qualitative data analysis

The researcher familiarized himself with data through review of the transcripts and the notes written during data collection. Transcription of the original recordings was done verbatim by

a trained and qualified transcriber together with the researcher. An independent transcription was done by the researcher to verify consistency of data in the transcripts as one of the verification processes to enhance trustworthiness. Different categories were identified and assigned codes so as to describe the content. As an analytic strategy content analysis of data was done inductively through line by line manual coding process. This was done to identify themes based on the underlying study objectives. Nvivo 11 software was used for data analysis.

3.10. Ethical consideration

The study sought the approval from the KNH-UoN Ethics committee which reviewed the ethical aspects of the study. Permission was sought from the KNH administration to access patient health information in the files. In addition, only those who agreed to consent to the study were recruited. Thus, only health information of those who agree to consent was accessed. Confidentiality, anonymity, and privacy were fully guaranteed throughout the study. The data obtained was used for the purpose of this research only and were not being shared with any platform. All the Covid-19 prevention guidelines were observed. Strict confidentiality and anonymity were observed when collecting, storing, processing data, and handling the results. Summary of study findings shall be presented to KHN administration. As for the potential risks of the study; there will be no harmful physical effects on the participants because the study is non-invasive. However, in the event a participant gets distressed, the researcher is a trainee psychiatrist and can manage or refer appropriately to the Mental Health Department at the Kenyatta National Hospital.

3.11. Dissemination of results

The findings from the study will be presented to the University of Nairobi Paediatric and Child health department as well as Kenyatta National Hospital. The results will also be

published in a known peer-reviewed paediatric journal to enhance information sharing on the burden of congenital heart diseases among children and shared in conferences.

CHAPTER FOUR: RESULTS

The study sought to explore the experiences of caregivers and the needs of children with congenital heart disease at Kenyatta National Hospital. A total of 150 caregivers were recruited to participate in the study. All of the questionnaires were returned for analysis representing a 100% response rate.

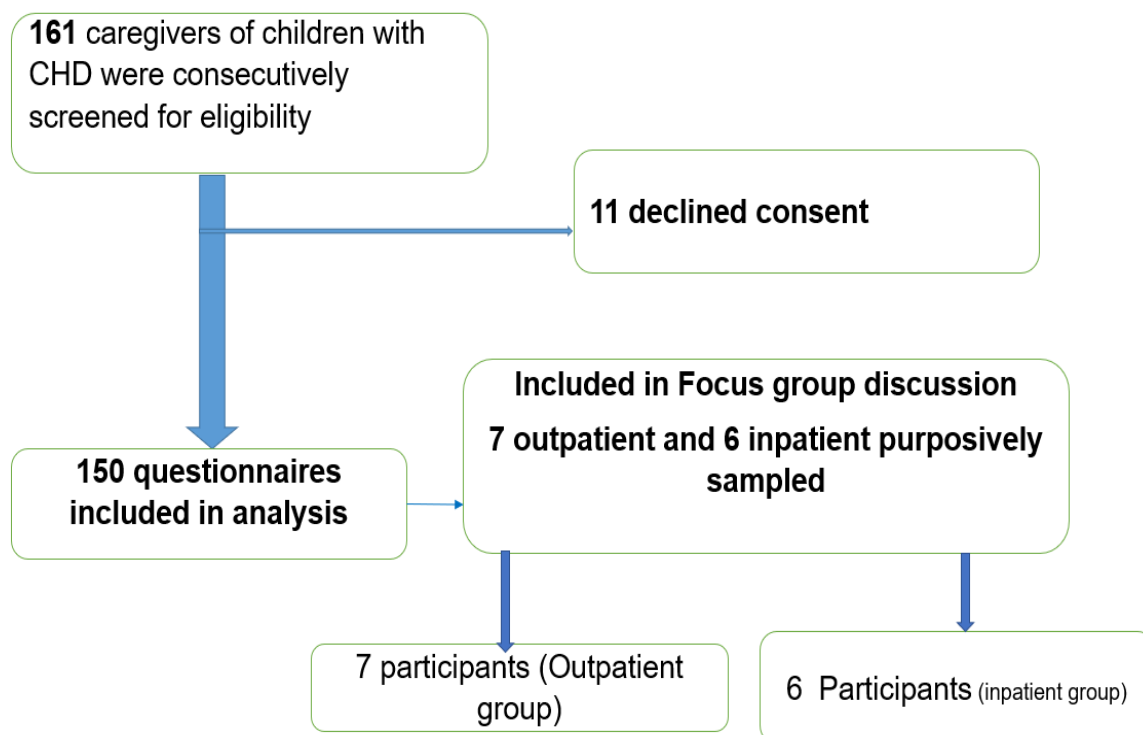


Figure 1: Study flowchart

4.1. Characteristics of caregiver of children with congenital heart disease at Kenyatta National Hospital

Results showed that 79.3% (119) of the participants were female, 61.3% (92) were aged 30 years and above. In investigating residence, 56.7% (85) were residing in rural setting. Further, 40.7% (61) had secondary level of education, 64% (96) were unemployed, and 36% (54) had an average monthly income of less than Ksh.10, 000. In addition, 53.3% (80) of the respondents had three or more children. Presence of underlying conditions revealed that 10.7% (16) had underlying condition which include hypertension and diabetes mellitus. The findings also revealed that 78% (n =117) had vaginal delivery as shown in Table 1.

Table 1: Characteristics of caregiver of children with congenital heart disease at Kenyatta National Hospital

Caregiver characteristics	Frequency	Percent
Gender		
Male	31	20.7
Female	119	79.3
Marital status		
Single	63	42.0
Married	87	58.0
Age		
<30 years	58	38.7
30 years and above	92	61.3
Residence		
Urban	65	43.3
Rural	85	56.7
Education level		
No formal education	4	2.7
Primary level	46	30.7
Secondary level	61	40.7
Tertiary level	39	26.0
Employment status		
Employed	54	36.0
Unemployed	96	64.0
Average monthly income		
Less than Ksh,10,000	93	62.0
Ksh.10,000 - 20,000	33	22.0
>20,000	24	16.0
Number of children		
<3	70	46.7
3 and above	80	53.3
Presence of underlying conditions		
Yes	16	10.7
No	134	89.3
Comorbidities (n =16)		
Hypertension	6	37.5
Diabetes mellitus	4	25
Both hypertension and Diabetes	5	31.3
Place of delivery		
KNH	16	10.7
Home	7	4.7
Other health facility	127	84.7
Mode of delivery		
Vaginal delivery	117	78.0
Caesarean section	33	22.0

4.2. Characteristics of children diagnosed with congenital heart disease at Kenyatta National Hospital

The findings showed that 53.3 %(80) of the patients were female. In investigating birth order, 34 %(51) were second born children. Age at diagnosis analysis revealed that 84.7 %(127) were diagnosed with CHD when they were less than six months of life. Common presenting symptoms identified included fast breathing 53.3 %(80), rapid heartbeat 36.7 %(55), coughing 36 %(54) and bluish colour 33.3 %(50). Majority of the patients, 86 %(129) were referred to KNH. In investigating treatment modality, 74.7 %(112) were on medication while 34 %(51) had surgery as shown in Table 2.

Table 2: Characteristics of children diagnosed with congenital heart disease at Kenyatta National Hospital

Child characteristics	Frequency	Percentage
Gender		
Male	70	46.7
Female	80	53.3
Birth order		
1	34	22.7
2	51	34
3	32	21.3
4	33	22
Age at diagnosis		
<6 months	85	56.7
6 - 12 months	4	2.7
13 - 36 months	9	6.0
37 - 60 months	28	18.7
>60 months	24	16.0
Presenting complaints		
Fast breathing	80	53.3
Cough	54	36
Fever	23	15.3
Fatigue	44	29.3
Rapid heartbeat	55	36.7
Fainting	5	3.3
Bluish colour	50	33.3
Referred to KNH		
Yes	129	86
No	21	14
Treatment modality		
Medication (n =150)	112	74.7
Catheter procedures (n =150)	11	7.3

4.3. Types of congenital heart diseases among patients at Kenyatta National Hospital

The findings established that 32.7 % (49) had Atrioventricular septal defect (AVSD), 28.2 % (44) had patent ductus arteriosus (PDA) and 10.5 % (16) had atrial septal defect (ASD) as shown in Figure 2.

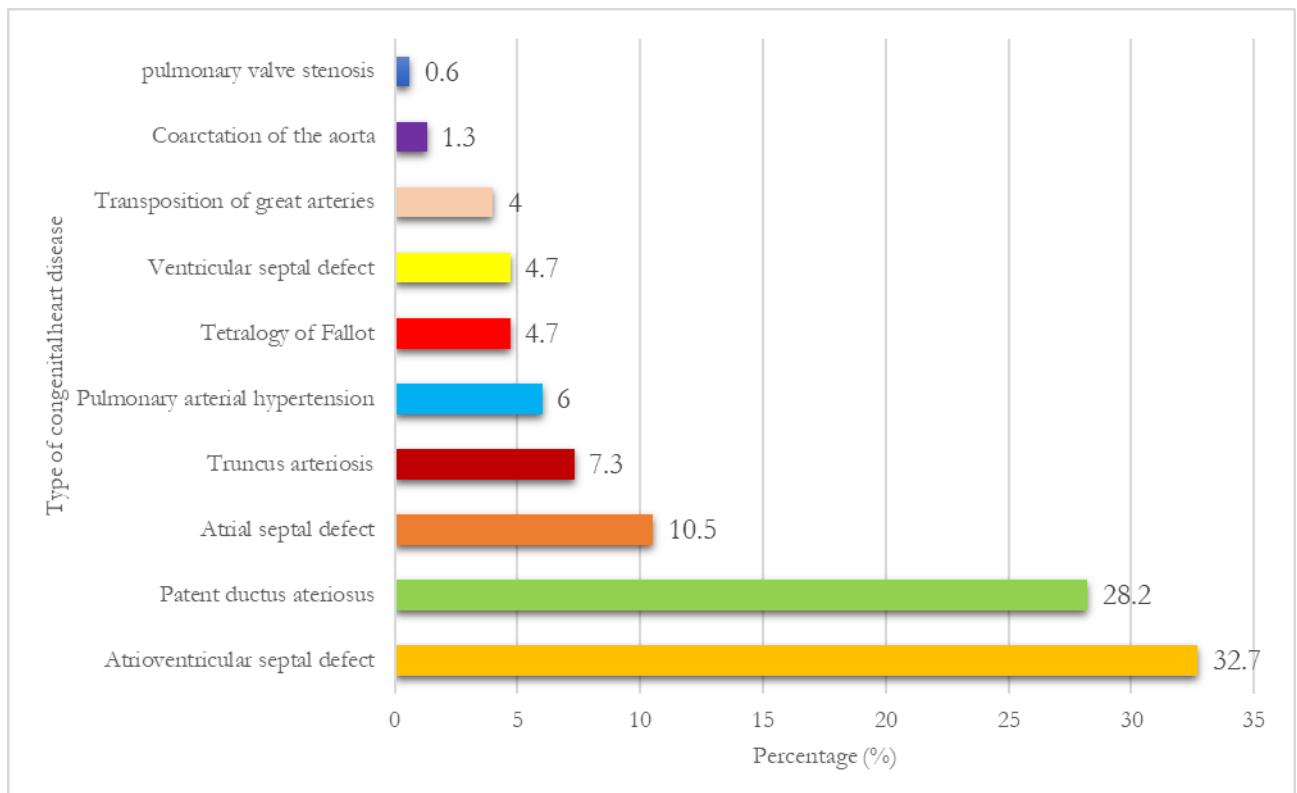


Figure 2: Types of congenital heart diseases among patients at Kenyatta National Hospital

4.4. Healthcare needs of children with congenital heart disease at Kenyatta National Hospital

The results revealed that 40.7 % (61) of children with CHD had a medical insurance, 22.7 % (34) receive support from the government. Further, 39.3 % (59) of children are able to perform physical activities. The findings also showed that 67.3 % (101) of children had been admitted in the first year of life as shown in Figure 3.

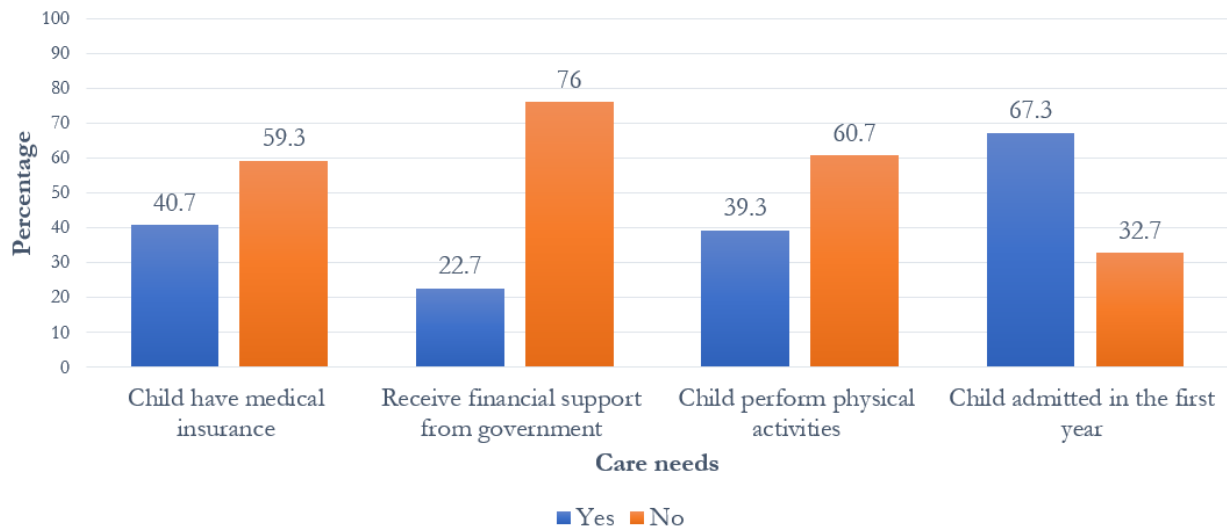


Figure 3: Healthcare needs of children with congenital heart disease at Kenyatta National Hospital

4.5. Level of depression among caregivers of children with congenital heart disease at Kenyatta National Hospital

The PHQ-9 was used to screen for depression. It is a self-administered questionnaire consisting of 9 items graded on a four-point Likert scale (0–3). The scores for each item are then added up to give a total score ranging from 0 to 27. The interpretation of the total score include 0-4: Minimal or no depression (0 – 4), mild depression (5 – 9), moderate depression (10 – 14), moderately severe depression (15 – 19), severe depression (20 – 27). The findings revealed that 40 %(60) of caregivers had severe depression, 17.3 %(26) had moderate depression while 10.7 %(16) had mild depression as shown in Figure 4.

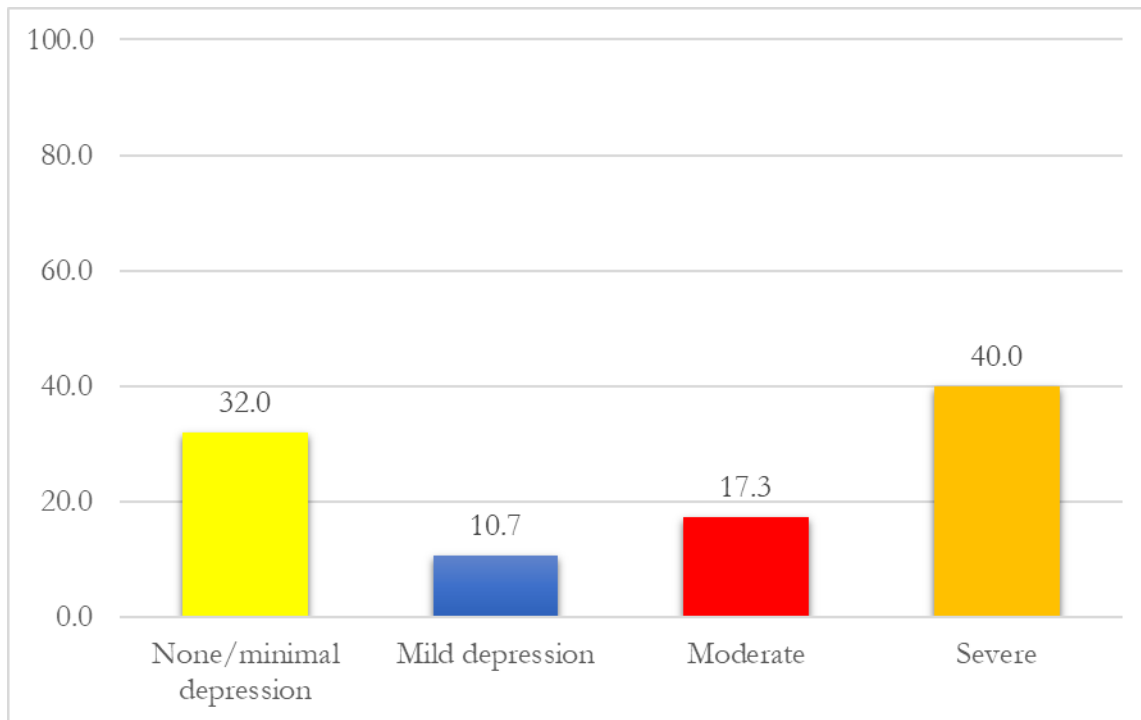


Figure 4: Level of depression among caregivers of children with congenital heart disease at Kenyatta National Hospital

4.6. Burnout among caregivers of children with congenital heart disease at Kenyatta National Hospital

Maslach burnout inventory (MBI) was utilized to investigate burnout among caregivers of children with CHD. The MBI consists of three subscales, each with its own set of items, and each item is scored on a seven-point Likert scale ranging from 0 (never) to 6 (every day). The results showed that 29.3 % (22) of the respondents had high level burnout, 43.3 % (65) had moderate level burnout while 27.3 % (41) had low/no burnout as shown in Figure 5.

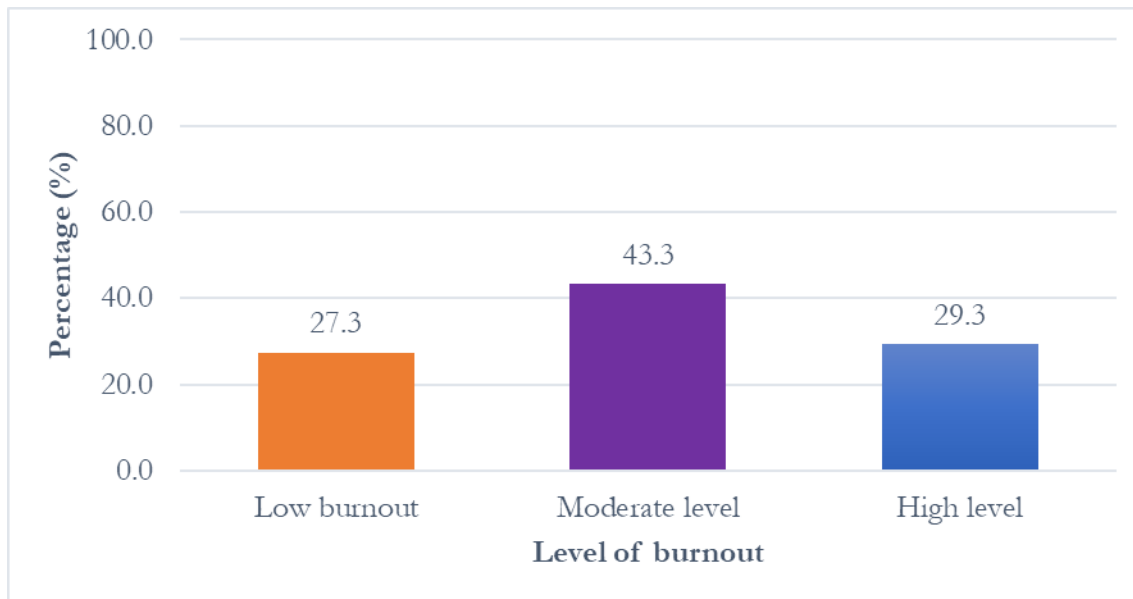


Figure 5: Level of Burnout among caregivers of children with congenital heart disease

4.7. The experiences and care need of caregivers of children with congenital heart disease at Kenyatta National Hospital

Experiences the study also sought to investigate the experiences of caregivers and the care needs of children with congenital heart disease. Qualitative analysis was done using thematic analysis where four main themes and seven sub-themes were identified. The themes identified include shock and denial, psycho-social wellbeing, uncertainty about future and coping strategies.

Table 6: Themes and sub-themes

Themes	Sub-themes
Theme 1: Shock and denial	Mixed reaction
Theme 2: Psycho-social wellbeing	Family support
	Social and healthcare provider support
Theme 3: Uncertainty about future	Never be the same
	Feeling of hope and belief
Theme 4: Coping strategies	Encourage family and social support
	Stakeholder support (Government, healthcare providers, NGOs)

Theme 1: Shock and denial

The participants were asked whether they knew about the condition of their child and their reaction. Participants had mixed reaction to the news about their child.

Sub-theme 1: Mixed reaction

Majority of the participants showed mixed reactions regarding the condition of their children. Some of the participants were shocked about the news of their child having a congenital heart disease. One of the participants asserted that, *“When I was told about the condition my daughter was having, I was shocked and did not know what to do, and everything seemed standstill”* (FGD1 Participant 1). Another participant stated that, *“I was shocked at first but I came to learn about the condition of my son as time progressed and I realized that I am not the only one”* (FGD 1 Participant 3). Further, another participant affirmed that, *“It was very difficult for me considering that I come from poor background, I didn’t know what I will do with my Kid. I thought it was a punishment from God because from our home, there is no one with this condition.”* (FGD2 Participant 2).

Some of the participants showed resilience and the will to fight on after receiving the news about their children. One of them stated that, *“I was surprised because even though my kid has been unwell since birth, I believe that this is just a temptation from God and I will overcome”* (OP4). Another one affirmed that, *“The news left me shocked for a moment but I know that having a heart condition is not a death sentence and my child will survive and raise her own children”* (IP5). Another one maintained that, *“aah... medical conditions are difficult to deal with especially chronic condition and diagnosis of my child with heart disease is difficult but maybe it could have been worse so I think it is a journey that I will have to brave for to ensure that my child has everything”* (FGD1 Participant 6).

Theme 2: Psycho-social wellbeing

The participants were asked about whether they received counselling from hospital professional after receiving the news about their child as well as whether they have received

support from spouse, family, friends and government. Two sub-themes were identified which include family support and social and healthcare provider support.

Sub-theme 1: Family support

The findings revealed varied level of family support and involvement in the needs and wellbeing of the child. Some of the participants stated that their families including spouse and siblings have been very helpful and have played a major role in their progress. They stated that, *“My husband has been very supportive throughout and this has been very encouraging to all of us as family”* (FGD1 Participant 3). Another one added that, *“my family has been a key pillar in prayers, financial and emotional help. My child has been having successful progress which is down to the support I get from my family”* (FGD2 Participant 6).

Few of the participants however asserted that they have been neglected by family members and have not received any family support towards the wellbeing of their children. One of them affirmed that, *“Right now my child is five years old but I have never seen his father since we knew that he had a chronic condition, he just disappeared so am all alone with no one to support me”* (FGD1 Participant 5). Another one added that, *“My family has shunned me ever since my kid became sickly; they believe that my kid has very weak genes and should not interact with their children because they fear something bad might happen”* (FGD2 Participant 3). Additionally, *“When I look at my journey, I just thank God, because it has been difficult for me. I am all alone with no one to really help me or offer a helping hand apart from my doctors”* (FGD2 Participant 4).

Sub-theme 2: Social and health provider support

Majority of the participants stated that healthcare providers have been supportive in taking care of their children throughout their journey. One of the participants stated that, *“Healthcare providers in this hospital (KNH) have been really helpful; I even have contact of*

one of my doctors who I talk to every time I have an issue. This has been really encouraging” (IP1). Another one stressed that, *“I think that without the support of healthcare providers, I would be really depressed and exhausted. They are always willing to listen to me and my problems”* (FGD1 Participant 2).

However, few of the participants also stated that some of the healthcare providers have not been very helpful. One of them stated that, *“I know majority are always good when I talk to them but some of you have a very bad attitude even someone talking to you is difficult because they never show interest at all.* (IP3). Another one itemised that, *“Some of healthcare providers have negative attitude, they do not even care that we already have a lot on our minds because taking care of a child with heart disease is not easy”* (FGD1 Participant 7).

Most of the participants asserted that the government has not been helpful enough in helping care for the needs of their children as they would have wished. They understood that their children are vulnerable and require protection from the government especially in policy formulation and provision of financial support in care. The participants stated that, *“I have never known that I need government support or whether there are any organizations that help patients with this condition”*(FGD1 Participant 2). Another one affirmed that, *“I tried following up with the government to help me considering that I am unable to fully take care of my child, I have never received any feedback from them. I am left on my own but I will try my best to take care of my baby even without their support”* (FGD2 Participant 5).

Theme 3: Uncertainty about the future

The participants were also asked about their thoughts about their child and whether they think their children will lead normal lives. Almost all of the participants were unsure about the future of their children since they thought that life will never be the same and some were

feeling hope and had strong belief about the wellbeing of their children despite their condition.

Sub-theme 1: Never be the same

Some of the participants stressed that their children will never recover and lead normal life. They thought their children will always be depended which limit their ability to achieve anything tangible in life. One of them stated that, *“My child is dependent and weak, I am not sure she can have a normal life like the rest. Also, I don’t have money for a heart transplant which might improve her condition”* (FGD2 Participant 3). Another one stated that, *“I am being honest with myself by not expecting too much from my child. The fact that she is here with me today is a gift from God”* (FGD1 Participant 7).

Sub-theme 2: Feeling hope and belief

Some of the participants maintained strong feeling of hope and belief that their children will lead a normal life considering the management approaches put in place. One of the participants stated that, *“I believe my child will lead a normal life, since he started medication, he has been improving and is currently enrolled in school which is a huge step”* (FGD1 Participant 6). Another one stressed that, *“Yeah, indeed, I believe that my child will lead a normal life, my child needs a heart transplant to fully recover but I know by the grace of God, everything will be fine”* (FGD1 Participant 2).

Theme 4: Coping strategies

The participants were also asked on what can be done to help improve their wellbeing as they continue to provide care for the children with CHD. Family support and stakeholder involvement were identified as key opportunities that can be exploited to achieve improved experiences.

Sub-theme 1: Family and social support

Majority of the participants credited their wellbeing to family as being integral in their resilient attitude and ability to provide continuous care to their children. They also asserted that continued family support would be crucial. One of them stated that, *“I think that continuous family support would be vital in helping navigate through major challenges that are associated in providing care to CHD child”* (FGD1 Participant 1). Another one stressed that, *“Family is a key pillar in provision of physical, psychological and emotional support. Their effortless nature in helping those having challenges should be encouraged to ensure that caregivers remain steadfast and focused with little or no depression and exhaustion,* (FGD2 Participant 6).

Sub-theme 2: Stakeholder involvement

The findings also established that stakeholder involvement in care needs of CHD patients would be integral in improving caregiver wellbeing. One of the participants asserted that, *“I think it would be very helpful if the government provide medical subsidy to us because the cost of care is very expensive and regular hospital visits mean that I need to look for money as well as take my child to hospital which is tedious and tiresome,* (FGD2 Participant 4). Additional, *“KNH is a major referral hospital, if they can liase with non-governmental agencies that focus on the needs and wellbeing of children with condition such as this to help us overcome stress and stigma through provision of psychological and financial support”* (FGD1 Participant 5).

4.8. Sub group analysis

4.8.1. Factors associated with depression among caregivers of children with congenital heart disease at Kenyatta National Hospital

The findings revealed that those who were aged less than 30 years were 8.7 times likely to have depression as compared to those aged 30 years and above, OR =8.74, 95%CI:3.59 – 21.27, p<0.001. Caregivers who were residing in rural area were 2.2 times likely to have depression compared to those in urban setting, OR =2.17, 95%CI: 1.08 – 4.35, p =0.030. The findings also revealed that those who have less than three children were 2.3 times more likely to have depression compared to those with three or more children, OR =2.25, 95%CI:1.10 - 4.60, p =0.035 as shown in Table 4.

Table 3: Factors associated with depression among caregivers of children with congenital heart disease at Kenyatta National Hospital

Factors	Depression		OR(95%CI)	P-value
	Yes n(%)	No n (%)		
Gender				
Male	9(8.8)	22(45.8)	Ref	
Female	93(91.2)	26(54.2)	8.74(3.59 - 21.27)	<0.001
Age of caregiver				
<30 years	41(40.2)	17(35.4)	1.23(0.60 - 2.50)	0.593
30 years and above	61(59.8)	31(64.6)	Ref	
Residence				
Urban	38(37.3)	27(56.3)	Ref	
Rural	64(62.7)	21(43.8)	2.17(1.08 - 4.35)	0.030
Education level				
Primary level	31(30.4)	19(39.6)	1.56(0.63 - 3.84)	0.334
Secondary level	43(42.2)	18(37.5)	1.07(0.44 - 2.59)	0.889
Tertiary level	28(27.5)	11(22.9)	Ref	
Employment status				
Employed	34(33.3)	20(41.7)	0.70(0.35 - 1.42)	0.364
Unemployed	68(66.7)	28(58.3)	Ref	
Average monthly income				
Less than Ksh,10,000	69(67.6)	24(50.0)	0.49(0.19 - 1.24)	0.131
Ksh.10,000 - 20,000	19(18.6)	14(29.2)	1.03(0.36 - 2.99)	0.954
>20,000	14(13.7)	10(20.8)	Ref	
Number of children				
<3	54(52.9)	16(33.3)	2.25(1.10 - 4.60)	0.035
3 and above	48(47.1)	32(66.7)	Ref	
Underlying comorbidities				
Yes	13(12.7)	3(6.3)	2.19(0.59 - 8.08)	0.272

No	89(87.3)	45(93.8)	Ref	
Place of delivery				
KNH	14(13.7)	2(4.2)	13.05(1.52 - 112.01)	0.341
Home	1(1.0)	6(12.5)	0.31(0.07 - 1.43)	0.134
Other health facility	87(85.3)	40(83.3)	Ref	
Mode of delivery				
Vaginal delivery	80(78.4)	37(77.1)	1.08(0.48 - 2.46)	0.836
Caesarean section	22(21.6)	11(22.9)	Ref	
Burnout				
High	86(84.3)	23(47.9)	5.84(2.68 - 12.72)	<0.001
Low	16(15.7)	25(52.1)	Ref	

4.8.2. Child characteristics and care needs associated with depression among caregivers of children with congenital heart disease at Kenyatta National Hospital

The findings established that caregivers who had male children with CHD were two times more likely to have depression compared to those who had female children with CHD, OR =1.97, 95%CI:1.13 – 4.0, p =0.048. The findings showed that those who had treatment modality as catheter procedures, OR =95%CI: 1.35 – 1.72, p =0.035 and those who had surgery OR =3.03, 95%CI: 1.33 – 6.92, p =0.009 were more likely to have depression compared to those who were on medication. Those who lacked medical insurance were 4.3 times likely to have depression compared to those with medical insurance, OR =4.38, 95%CI: 2.11 – 9.07, p<0.001. Caregivers of children who were admitted in first year of life were 7.3 times more likely to have depression compared to those whose children were not admitted in first year of life, OR =7.28, 95%CI:3.38 – 15.69, p<0.001. caregivers who had high level burnout were 5.8 times more likely to be depressed compared to those with low burnout level, OR =5.84, 95%CI:2.68 – 12.72, p<0.001 as shown in Table 5.

Table 4: Child characteristics associated with depression among caregivers of children with congenital heart disease at Kenyatta National Hospital

Factors	Depression		OR(95%CI)	P-value
	Yes n(%)	No n(%)		
Gender of child				
Male	53(52.0)	17(35.4)	1.97(1.13 - 4.0)	0.048
Female	49(48.0)	31(64.6)	Ref	
Birth order				
1	25(24.5)	9(18.8)	0.72(0.25 - 2.06)	0.54
2	35(34.3)	16(33.3)	0.91(0.36 - 2.33)	0.851
3	20(19.6)	12(25.0)	1.20(0.43 - 3.32)	0.726
4	22(21.6)	11(22.9)	Ref	
Referred to KNH				
Yes	86(84.3)	43(89.6)	0.63(0.22 - 1.82)	0.458
No	16(15.7)	5(10.4)	Ref	
Treatment modality				
Medication	77(75.5)	35(72.9)	Ref	
Catheter procedures	10(9.8)	1(2.1)	1.52(1.35 - 1.72)	0.035
Surgery	42(41.2)	9(18.8)	3.03(1.33 - 6.92)	0.009
Presence of medical insurance				
Yes	30(29.4)	31(64.6)	Ref	
No	72(70.6)	17(35.4)	4.38(2.11 - 9.07)	<0.001
Child perform physical activities				
Yes	36(35.3)	23(47.9)	0.59(0.30 - 1.19)	0.155
No	66(64.7)	25(52.1)	Ref	
Admission in first year of life				
Yes	83(81.4)	18(37.5)	7.28(3.38 - 15.69)	<0.001
No	19(18.6)	30(62.5)	Ref	

4.8.3. Caregiver characteristics associated with burnout among caregivers of children with CHD

The findings revealed that those who were residing in rural areas were 0.43 times less likely to have high burnout compared to those residing in rural areas, (OR =0.43, 95%CI:0.21 – 0.89, p =0.027) as shown in Table 6.

Figure 6: Caregiver characteristics associated with burnout among caregivers of children with CHD

Factors	Burnout		OR(95%CI)	P-value
	High	Low		
Gender				
Male	19(17.4)	12(29.3)	0.51(0.22 - 1.18)	0.119
Female	90(82.6)	29(70.7)	Ref	
Age of caregiver				
<30 years	41(37.6)	17(41.5)	0.85(0.41 - 1.77)	0.709
30 years and above	68(62.4)	24(58.5)	Ref	
Residence				
Urban	41(37.6)	24(58.5)	0.43(0.21 - 0.89)	0.027
Rural	68(62.4)	17(41.5)	Ref	
Education level				
Primary level	38(34.9)	12(9.3)	1.05(0.39 - 2.83)	0.919
Secondary level	41(37.6)	20(48.8)	1.63(0.65 - 4.07)	0.299
Tertiary level	30(27.5)	9(22.0)	Ref	
Employment statu				
Employed	38(34.9)	16(39.0)	0.84(0.40 - 1.75)	0.704
Unemployed	71(65.1)	25(61.0)	Ref	
Marital status				
Single	45(41.3)	18(43.9)	0.90(0.44 - 1.86)	0.853
Married	64(58.7)	23(56.1)	Ref	
Average Monthly Income				
Less than Ksh,10,000	68(62.4)	25(61.0)	0.74(0.28 - 1.93)	0.532
Ksh.10,000 - 20,000	25(22.9)	8(19.5)	0.64(0.20 - 2.05)	0.452
>20,000	16(14.7)	8(19.5)	Ref	
Number of children				
<3	50(45.9)	20(48.8)	0.89(0.43 - 1.83)	0.855
3 and above	59(54.1)	21(51.2)	Ref	
Presence of underlying conditions				
Yes	14(12.8)	2(4.9)	2.87(0.62 - 13.24)	0.237
No	95(87.2)	39(95.1)	Ref	
Mode of delivery				
Vaginal delivery	84(77.1)	33(80.5)	0.82(0.33 - 1.99)	0.825
Caesarean section	25(22.9)	8(19.5)	Ref	

4.8.4. Child characteristics associated with burnout among caregivers of children with CHD

The findings established that those who were using medication only were 76% less likely to have high burnout (OR = 0.24, 95%CI: 0.08 – 0.72, p =0.009). Those whose children had

undergone surgical procedure were 2.3 times more likely to have high burnout (OR =3.29, 95%CI: 1.34 – 8.08, p =0.007). Those who received some form of financial support from the government were 17 times more likely to have high burnout (OR =17.16, 95%CI: 2.26 – 130.23, p<0.001). Those whose children were admitted in the first month of birth were three times more likely to have high burnout (OR =3.04, 95%CI: 1.44 – 6.42, p=0.006) as shown in Figure 7.

Figure 7: Child characteristics associated with burnout among caregivers of children with CHD

Factors	Burnout		OR(95%CI)	P-value
	High	Low		
Gender of child				
Male	50(45.9)	20(48.8)	0.89(0.43 - 1.83)	0.855
Female	59(54.1)	21(51.2)	Ref	
Birth order				
1	25(22.9)	9(22.0)	0.96(0.33 - 2.83)	0.941
2	37(33.9)	14(34.1)	1.01(0.38 - 2.70)	0.941
3	23(21.1)	9(22.0)	1.04(0.35 - 3.09)	0.939
4	24(22.0)	9(22.0)	Ref	
Age at diagnosis				
<6 months	62(56.9)	23(56.1)	0.66(0.26 - 1.69)	0.386
More than 6 months	47(43.1)	18(43.9)	Ref	
Medication only				
Yes	75(68.8)	37(90.2)	0.24(0.08 - 0.72)	0.009
No	34(31.2)	4(9.8)	Ref	
Surgery				
Yes	44(40.4)	7(17.1)	3.29(1.34 - 8.08)	0.007
No	65(59.6)	34(82.9)	Ref	
Does the child have insurance				
Yes	30(27.5)	31(75.6)	0.12(0.05 - 0.28)	<0.001
No	79(72.5)	10(24.4)	Ref	
Receive financial support from the government				
Yes	33(30.6)	1(2.5)	17.16(2.26 - 130.23)	<0.001
No	75(69.5)	39(97.5)	Ref	
Child admitted in first month of birth				
Yes	81(74.3)	20(48.8)	3.04(1.44 - 6.42)	0.006
No	28(25.7)	21(51.2)	Ref	

CHAPTER FIVE: DISCUSSION

The focus on both quantitative and qualitative approaches is to identify specific issues and elaborate them in depth which helped effectively understand the underlying challenges within the local context. The demographic and needs of children with congenital heart diseases were investigated quantitatively with key need to identify key need to understand the existing association between demographics and the needs. The study also aimed at assessing the experiences of caregivers/parents of children with congenital heart diseases which appropriately explored using qualitative approaches to understand in depth the wellbeing of study participants while also emphasizing on stressors and coping approaches as well as the existing gaps in care.

5.1. Demographic and clinical characteristics of children with congenital heart disease

The findings showed that more than half of patients with congenital heart disease were female, 53%. These findings are comparable to a meta-analysis review by Diogenes et al. (2017) which revealed that patients with CHD were 1.5 times more likely to be female (52). Similarly, a study conducted in Brazil revealed that 51.6% of children with CHD were female (6). However, these findings contrast those from a study conducted in Turkey which found that 43.8% of the children were female (53). The difference could be due to differences in children with CHD enrolled in the study. In the present study, most of the children were aged less than six months compared to their study, where the youngest child to be enrolled was six years. Another study in China by Zheng et al. (2021) found that 59.6% of the patients were male (54). This difference could be due to the study population. Their study investigated hospital CHD mortality between 2005 and 2017; males accounted for 59.6%.

The present study also revealed that 84.7% of the CHD patients were aged less than six months. These findings are comparable to a study in China which revealed that 70.8% of the children presenting with congenital heart disease were aged less than one year (54). Another

study in Nigeria revealed that 70% of the children were > 1 year of age (17). Most children presenting with congenital heart disease are less than one year old because many congenital heart defects are severe enough to cause symptoms or complications early in life. In some cases, these defects can even be life-threatening in infancy. Additionally, routine prenatal screening and fetal echocardiography have improved in recent years, allowing for earlier detection of congenital heart disease in utero. This means that some cases of congenital heart disease are diagnosed before the baby is even born, which can lead to earlier intervention and management.

This study also established that 53.3% of the children with congenital were presenting with fast breathing, 36% had a cough, 15.3% had a fever, 33.3% had bluish coloration, with 3.3% presented with fainting. These findings compare with those from a study conducted in Pakistan by Mohammad et al. (2014) which revealed that common clinical presentation in children with CHD included difficulty breathing (80%), cough (53%), fever (41%), and congestive cardiac failure (19.4%) (55).

In investigating types of congenital heart diseases, the common types presenting include atrioventricular septic defect (AVSD) (32.7%), patent ductus arteriosus (PDA) (28.2%), atrial septal defect (ASD) (10.5%) and truncus arteriosus (7.3%). Comparable findings were obtained by Mohammad et al. (2014), who found that the majority of CHD patients (74.6%) had cyanotic heart disease (55). Similarly, another study done in Ghana by Thomford et al. (2020) found that commonly presenting cyanotic lesion was atrioventricular septal defect (31.4%), followed by PDA(5.9%) and ASD (2.0%) (19). Another study in Egypt by Al-Fahham and Ali (2021) found comparable results that the three commonest congenital heart disease types were ventricular septal defect (32.7%), atrial septal defect (21.8%), and patent ductus arteriosus (17%) (20).

5.2. The care needs of children with congenital heart disease at Kenyatta National Hospital

The findings revealed that 40.7% of the children with CHD had medical insurance. Medical insurance is vital for children with chronic medical insurance to help ease the financial burden of frequent hospital visits or hospital admissions. These findings from the present study have shown that less than half have medical insurance, which points to a higher financial burden among caregivers. These findings are consistent with JIvanji et al. (2019) in East Africa, which found that most caregivers of children with congenital heart disease made out-of-pocket payments during hospital visits, increasing the financial burden (56). The findings also showed that 22.7% of the caregivers reported receiving government financial support. This was majorly related to NHIF, a national government initiative that helps fund the medical needs of children with CKD. The comparable findings were found in a study in the United States which found that the support from the government they received was financial subsidy towards the medical care of their children resulting in 89.1% of families with a CHD child experiencing at least one financial burden (57).

The present findings also revealed that 60.7% of the children could perform some form of physical activity. This could be since most of the study participants were less than six months and hence could do little or no physical activity. Comparable findings were found in a study conducted in Germany which found that among patients diagnosed with CHD, 8.8% reached the WHO-recommended 60 minutes of physical activity daily. However, in their study, the study population included children aged between 6 -17 years (58).

Most children in the study were admitted in their first birth year (67.3%). Most CHD diagnoses are made within the first three months after delivery which explains a higher number of admissions in the first year of birth. According to a study conducted in the United States, it was found that 34% of children were diagnosed during the prenatal period, which allows for better management (59).

5.3. The experiences and care needs of caregivers of children with congenital heart disease

The findings showed that most caregivers were in shock and denial after being diagnosed with their children having congenital heart disease. Comparable findings were obtained in a study conducted in Ethiopia by Choi et al. which found that most caregivers of children with CHD found it difficult to accept. Many of them highlighted that they waited for a long to have the diagnosis, which increased their level of anxiety (29). Similarly, another study in Iran found that most caregivers isolated themselves after knowing their children had been diagnosed with congenital heart disease. Some parents received the news of their child's condition with sadness (30).

The findings also showed that most of the caregivers highlighted that they received immense support from their family members and healthcare providers. Family and healthcare providers are majorly involved in caring for children with CHD. These findings were in line with those from a study done in Italy by Simeone et al. which revealed that family members were supportive after discharge especially considering that there was an increased workload and need to provide care to their needs (31). Further, a study in Iran also revealed that healthcare providers were crucial in offering psychological support, which was integral to the well-being of their children (30).

The findings also revealed that most caregivers were uncertain about their future and the well-being of their children. Consistent findings were obtained from a meta-analysis conducted by Dellafiore which revealed that fear and uncertainty of the future was a major challenge for the caregivers of children with CHD (32).

Present findings established that 68% of the patients had depression, with 40% reporting severe depression. These findings are consistent with a study done by Kihiu et al. (2020), which found that depression among caregivers of children with CHD is 54%. However, the

finding from the present study contrasts those from a study in the United States by Awaad and Darahim (2015), found that the prevalence of depression among caregivers of children with CHD was 32.2% (60). The difference could be attributed to the increased quality of care to patients with chronic illness in the United States, including financial support, which is a major challenge for the well-being of children with CHD.

The present findings also established that 72.7% of the caregivers had high to moderate burnout levels. Consistent findings were obtained by Ahmadi et al., who found that 62.3% of the caregivers had burnout, with 47.9% experiencing emotional exhaustion (33). Caregiving for a child with congenital heart disease can be emotionally and physically demanding, leading to high-stress levels and burnout among caregivers. Caregiving can be isolating, especially if the caregiver does not have a strong support network. This can lead to feelings of loneliness and frustration (61).

5.4. Strengths and limitations

5.4.1. Strengths

The study delves into under-researched area of caregiver burden and care needs of children with CHD.

5.4.2. Limitations

These are single center findings hence they may not be generalizable although the study was conducted at the biggest referral hospital in Kenya which offers services to majority of referred patients across the country.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1. Conclusion

Just over half of the patients with CHD were female, 84.7% aged less than six months and most commonly presented with fast breathing (53.3%), cough (36%) and fever (15.3%).

The CHD lesions were atrioventricular septic defect (AVSD) (32.7%), patent ductus arteriosus (PDA) (28.2%), atrial septal defect (ASD) (10.5%) and truncus arteriosus (7.3%).

Less than half, 40.7% had medical insurance, 22.7% received financial government support through NHIF.

Only 39.3% of the patients were able to perform some form of physical activities.

There was extremely high mental health morbidity among the care givers 68% had depression and 72.7% burnout.

The commonly identified experiences in care of CHD patients among caregivers included shock and denial, uncertainty and fear about the future.

6.2. Recommendations

To encourage early diagnosis of CHD especially during prenatal period to alleviate shock and denial among caregivers

Provide comprehensive mental health services to caregivers of children with CHD

The government should consider provision of financial leverage to help in care of children with special needs.

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APPENDICES

Appendix I: Consent form

The Study Title: **EXPERIENCES OF CAREGIVERS AND CARE NEEDS OF CHILDREN WITH CONGENITAL HEART DISEASE AT KENYATTA NATIONAL HOSPITAL**

Introduction

My name is Dr. Abdirahman, a student at University of Nairobi, Department of Paediatrics and Child Health. I am carrying out a study on **Experiences of Caregivers and Care Needs of Children with Congenital Heart Disease at Kenyatta National Hospital**

Participation in the study

Your participation in this study will be on a voluntary basis, and you may decide to withdraw from the study at any stage without any penalty. The study is purely descriptive, non-invasive, and will not attract any cost to your part.

Study Approval

This study is being conducted with the approval of the UoN Department of Paediatrics and Child Health and KNH-UoN Ethics and Review Committee. Approval No.....

Study Procedure

I, the principal investigator, together with my research assistants, will give you a full explanation of the procedure before you participate in this study. You will be required to answer the questions as asked in the questionnaire. The research assistants will help in making any clarifications regarding the questions. The completion of this questionnaire will take approximately 10 minutes of your time.

Confidentiality

Your identity will be protected with utmost confidentiality during the study. There are no identifiers that you will provide.

Risks and or discomforts

There are no major risks in the participation in the study. However, you may experience emotional distress because the questions asked are person relating to the health and wellbeing

of your child. You are encouraged to discuss any discomfort or distress with the research assistant openly.

Benefits during the study

There will be no monetary benefit to you for participating in the study but the results
However, the findings will help understand the care needs and experiences of caregivers of patients with congenital heart disease. If you develop any emotional distress and is recognized, we shall refer you to the appropriate KNH facility for support.

Harm during the study

The study is purely descriptive and will not cause any physical harm to you.

Communication

In case of any clarifications or queries during and after the study, you are free to contact me: Abdirahman Mohamed on my Phone at **0741-115-984** or my Supervisor: Prof. Nduati on: +254722235323 or email ruth.nduati2000@yahoo.com. You may also reach out my second supervisor: Dr. Osano at +254722646720 or email: bosano@uonbi.ac.ke.. You may also contact the Chair, KNH-UoN ERC email: uonknherc@uonbi.ac.ke or +254 721 257746, (020) 318262 Ext.28250.

Thank you

Signature

(Participant) Date.....

I confirm that I have clearly explained to the participant the nature of the study and the contents of this consent form in detail, and the participant has decided to participate voluntarily without any coercion or undue pressure.

Signature (Researcher).....Date.....

Kiambatisho II: Fomu ya Idhini

UZOEFU WA WALEZI NA MAHITAJI YA UTUNZAJI WA WATOTO WENYE UGONJWA WA MOYO WA CONGENITAL KATIKA HOSPITALI YA KITAIFA YA KENYATTA

Utangulizi

Jina langu ni Dr. Abdirahman, mwanafunzi katika Chuo Kikuu cha Nairobi, Idara ya Paediatrics na Afya ya Watoto. Ninafanya utafiti juu ya Uzoefu wa Watunzaji na Mahitaji ya Utunzaji wa Watoto wenye Magonjwa ya Moyo wa Congenital katika Hospitali ya Kitaifa ya Kenyatta

Kushiriki katika utafiti

Ushiriki wako katika utafiti huu utakuwa kwa hiari, na unaweza kuamua kujiondoa kutoka kwa utafiti katika hatua yoyote bila adhabu yoyote. Utafiti huo ni wa maelezo tu, usio wa uvamizi, na hautavutia gharama yoyote kwa sehemu yako.

Uidhinishaji wa Utafiti

Utafiti huu unafanywa kwa idhini ya Idara ya UoN ya Paediatrics na Afya ya Watoto na Kamati ya Maadili na Mapitio ya KNH-UoN. Imeidhinishwa Hapana.....

Utaratibu wa Kujifunza

Mimi, mchunguzi mkuu, pamoja na wasaidizi wangu wa utafiti, nitakupa maelezo kamili ya utaratibu kabla ya kushiriki katika utafiti huu. Utahitajika kujibu maswali kama ilivyoulizwa katika dodoso. Wasaidizi wa utafiti watasaidia katika kutoa ufafanuzi wowote kuhusu maswali. Kukamilika kwa dodoso hili itachukua takriban dakika 10 za wakati wako.

Usiri

Utambulisho wako utalindwa na usiri mkubwa wakati wa utafiti. Hakuna vitambulisho ambavyo utatoa. Hatari na au usumbufu Hakuna hatari kubwa katika ushiriki katika utafiti.

Hata hivyo, unaweza kupata shida ya kihisia kwa sababu maswali yaliyoulizwa ni mtu anayehusiana na afya na ustawi wa mtoto wako. Unahimizwa kujadili usumbufu wowote au shida na msaidizi wa utafiti wazi.

Faida wakati wa utafiti

Hakutakuwa na faida ya fedha kwako kwa kushiriki katika utafiti lakini matokeo Hata hivyo, matokeo yatasaidia kuelewa mahitaji ya utunzaji na uzoefu wa walezi wa wagonjwa wenye ugonjwa wa moyo wa congenital. Ikiwa unaendeleza shida yoyote ya kihisia na kutambuliwa, tutakuelekeza kwa kituo kinachofaa cha KNH kwa msaada.

Madhara wakati wa utafiti

Utafiti huo ni wa maelezo tu na hautasababisha madhara yoyote ya kimwili kwako.

Mawasiliano

Ikiwa kuna ufafanuzi wowote au maswali wakati na baada ya utafiti, uko huru kuwasiliana nami: Mahad Abdirahman kwenye Simu yangu kwa 0741-115-984 au Msimamizi wangu: Prof. Nduati kwenye: +254722235323 au barua pepe ruth_nduati2000@yahoo.com. Unaweza pia kufikia msimamizi wangu wa pili: Dr Osano kwa +254722646720 au barua pepe: bosano@uonbi.ac.ke. Unaweza pia kuwasiliana na Mwenyekiti, barua pepe ya KNH-UoN ERC: uonknherc@uonbi.ac.ke au +254 721 257746, (020) 318262 Ext.28250.

Asante

Saini (Mshiriki) Tarehe.....

Ninathibitisha kuwa nimemwelezea wazi mshiriki asili ya utafiti na yaliyomo kwenye fomu hii ya idhini kwa undani, na mshiriki ameamua kushiriki kwa hiari bila kulazimishwa au shinikizo lisilostahili.

Saini (Mtafiti).....

Tarehe.....

Appendix III: Questionnaire

EXPERIENCES OF CAREGIVERS AND CARE NEEDS OF CHILDREN WITH CONGENITAL HEART DISEASE AT KENYATTA NATIONAL HOSPITAL

Questionnaire

Section A: Caregiver characteristics

1. Gender

Male [] Female []

2. Age (in years):

3. Residence

Urban [] Rural []

4. Educational level

No formal education [] Primary level [] Secondary level [] Tertiary level []

5. Employment status

Employed [] Unemployed []

6. Average monthly income? (Ksh).....

7. Parity:

8. Number of ANC visits?.....

9. Presence of comorbidity

Yes [] No []

10. If yes, which one?.....

11. Place of Delivery:

12. KNH []

13. Home []

14. Other health facility []

15. Mode of Delivery:

Spontaneous Vertex Delivery [] Breech vaginal []

Cesarean Section []

Section B: Patient's data:

16. Sex:

Male [] Female []

- 17. Birth order
- 18. Age at diagnosis of CHD (years).....
- 19. Symptoms experienced prior to diagnosis
 Fast breathing [] Cough [] Fever [] Fatigue [] Rapid heartbeat []
 Fainting [] Bluish color []
- 20. Were you referred out of KNH?
 Yes [] No []
- 21. What treatment modality was adopted?
 Medication [] Catheter procedures [] surgery [] Heart transplant []
- 22. What is the type of congenital heart disease?
 Atrial Septal Defect [] Atrioventricular Septal Defect []
 Coarctation of the Aorta [] Double-outlet Right Ventricle []
 Others (specify).....

Section C: Healthcare needs of children

- 23. Does the child have insurance?
 Yes [] No []
- 24. Have you received any support from the government or any organization?
 Yes [] No []
 24a. If yes, which organization?.....
- 25. Is your child enrolled in any social protection program?
 Yes [] No []
- 26. If yes, Which one?.....
- 27. Is your child attending school?
 Yes [] No []
- 28. If no, why?
 Too weak to go through education system []
 Lack of enough finances to allow schooling []
 I am afraid to take him to school []
 Others (specify)
- 29. Does your child perform physical activities?
 29a. if yes, how many hours per day?.....
- 30. Was your child admitted in the first one year after birth?
 Yes [] No []

Section D: Impact on caregiver mental wellbeing

Patient Health Questionnaire (PHQ-9)

Patient Health Questionnaire (PHQ-9)				
Over the last 2 weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things				
2. Feeling down, depressed, or hopeless				
3. Trouble falling or staying asleep, or sleeping too much.				
4. Feeling tired or having little energy.				
5. Poor appetite or overeating.				
6. Feeling bad about yourself or that you are a failure or have let yourself or your family down				
7. Trouble concentrating on things, such as reading the newspaper or watching television				
8. Moving or speaking so slowly that other people could have noticed? Or the opposite—being so fidgety or restless that you have been moving around a lot more than usual.				
9. Thoughts that you would be better off dead or of hurting yourself in some way				

Section E: The Maslach Burnout Inventory

Indicate how frequently the following statements apply to you and add the points indicated on top of the respective box:

0 = Never

1 = At least a few times a year 2 = At least once a month

3 = Several times a month 4 = Once a week

5 = Several times a week 6 = Every day

	Never						Every day						
	0	1	2	3	4	5	6						
01 – I feel emotionally exhausted because of caring for my child													
02 – I feel worn out at the end of the day													
03 – I feel tired as soon as I get up in the morning and see a new day stretched out in front of me													
04 – I can easily understand the actions of my others													

05 – I get the feeling that I treat some people impersonally, as if they were objects										
06 – Caregiving the whole day is stressful for me										
07 – I deal with other people’s problems successfully										
08 – I feel burned out because of my caregiving										
09 – I feel that I influence other people positively through my caregiving										
10 – I have become more callous to people since I have started doing this										
11 – I’m afraid that my caregiving makes me emotionally harder										
12 – I feel full of energy										
13 – I feel frustrated by my caregiving										
14 – I get the feeling that I work too hard										
15 – I’m not really interested in what is going on with many of my										
16 – Being in direct contact with my child is too stressful										
17 – I find it easy to build a relaxed atmosphere in my caregiving environment										
18 – I feel stimulated when I been caregiving with other caregivers										
19 – I have achieved many rewarding objectives in my caregiving										
20 – I feel as if I’m at my wits’ end										
21 – In my caregiving I am very relaxed when dealing with emotional										
22 – I have the feeling that my family members blame me for some of their problems										

Appendix IV: Consent for focus group discussion
Introduction

My name is Dr. Abdirahman, a student at University of Nairobi, Department of Paediatrics and Child Health. I am carrying out a study on **Experiences of Caregivers and Care Needs of Children with Congenital Heart Disease at Kenyatta National Hospital**. Your participation in this study will be on a voluntary basis, and you may decide to withdraw from the study at any stage without any penalty. The study is purely descriptive, non-invasive, and will not attract any cost to your part.

I, the moderator and principal investigator, will give you a full explanation of the procedure before you participate in this study. You will be required to answer the questions as asked in the questionnaire. The research assistants will help in making any clarifications regarding the questions. The completion of this questionnaire will take approximately 10 minutes of your time.

Your identity will be protected with utmost confidentiality during the study. There are no identifiers that you will provide. There is no direct harm for participating in this study. This discussion will be recorded for research purposes. No personal information will be documented. I will give you a unique ID which will be your identity through out the study. If you accept the terms of this focus group discussion please sign this form.

I confirm that I have clearly explained to the participant the nature of the study and the contents of this consent form in detail, and the participant has decided to participate voluntarily without any coercion or undue pressure.

Signature (Researcher).....Date.....

Kiambatisho V: Kukubaliana kwa majadiliano ya kikundi cha kuzingatia Utangulizi

Jina langu ni Dr. Abdirahman, mwanafunzi katika Chuo Kikuu cha Nairobi, Idara ya Paediatrics na Afya ya Watoto. Ninafanya utafiti juu ya Uzoefu wa Watunzaji na Mahitaji ya Utunzaji wa Watoto wenye Magonjwa ya Moyo ya Congenital katika Hospitali ya Kitaifa ya Kenyatta. Ushiriki wako katika utafiti huu utakuwa kwa hiari, na unaweza kuamua kujiondoa kutoka kwa utafiti katika hatua yoyote bila adhabu yoyote. Utafiti huo ni wa maelezo tu, usio wa uvamizi, na hautavutia gharama yoyote kwa sehemu yako. Mimi, msimamizi na mchunguzi mkuu, nitakupa maelezo kamili ya utaratibu kabla ya kushiriki katika utafiti huu. Utahitajika kujibu maswali kama ilivyoulizwa katika dodoso. Wasaidizi wa utafiti watasaidia katika kutoa ufafanuzi wowote kuhusu maswali. Kukamilika kwa dodoso hili itachukua takriban dakika 10 za wakati wako. Utambulisho wako utalindwa na usiri mkubwa wakati wa utafiti. Hakuna vitambulisho ambavyo utatoa. Hakuna madhara ya moja kwa moja kwa kushiriki katika utafiti huu. Mjadala huu utaandikwa kwa madhumuni ya utafiti. Hakuna taarifa binafsi itakayotolewa. Nitakupa kitambulisho cha kipekee ambacho kitakuwa utambulisho wako kupitia utafiti. Ikiwa unakubali masharti ya majadiliano haya ya kikundi tafadhali tia saina fomu hii. Ninathibitisha kuwa nimemwelezea wazi mshiriki asili ya utafiti na yaliyomo kwenye fomu hii ya idhini kwa undani, na mshiriki ameamua kushiriki kwa hiari bila kulazimishwa au shinikizo lisilostahili.

Saini (Mtafiti).....Tarehe.....

Appendix VI: Focus group discussion guide

1. Do you know the medical condition your child is having?
2. When did you know that your child had a medical problem?
3. How did you feel?
4. What was your reaction after your doctor told you that your child has congenital heart disease?
5. Did you receive any counselling from hospital professional?
6. How would you describe your journey so far?
7. Have you been receiving enough support from?
 - i. Spouse
 - ii. Family
 - iii. Friends
 - iv. Government
 - v. Healthcare providers
8. Do you think your child will lead a normal life?
9. What are the major challenges that you have been facing in your journey raising a child with this medical condition?
10. What do you do to cope with challenges of raising a child with congenital heart disease?

Appendix VII: KNH – UoN ERC Approval



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Ref: KNH-ERC/A/279

Dr. Mahad Abdirahman Mohamed
Reg. No. H58/38041/2020
Dept. of Paediatrics and Child Health
Faculty of Health Sciences
University of Nairobi



20th July, 2022

Dear Dr. Mohamed,

RESEARCH PROPOSAL: EXPERIENCES OF CAREGIVERS AND CARE NEEDS OF CHILDREN WITH CONGENITAL HEAR DISEASE AT KENYATTA NATIONAL HOSPITAL (P250/03/2022)

This is to inform you that KNH-UoN ERC has reviewed and approved your above research proposal. Your application approval number is **P250/03/2022**. The approval period is 20th July 2022 – 19th July 2023.

This approval is subject to compliance with the following requirements;

- i. Only approved documents including (informed consents, study instruments, MTA) will be used.
- ii. All changes including (amendments, deviations, and violations) are submitted for review and approval by KNH-UoN ERC.
- iii. Death and life threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to KNH-UoN ERC 72 hours of notification.
- iv. Any changes, anticipated or otherwise that may increase the risks or affected safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH-UoN ERC within 72 hours.
- v. Clearance for export of biological specimens must be obtained from relevant institutions.
- vi. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. Attach a comprehensive progress report to support the renewal.
- vii. Submission of an executive summary report within 90 days upon completion of the study to KNH-UoN ERC.

Protect to discover

Prior to commencing your study, you will be expected to obtain a research license from National Commission for Science, Technology and Innovation (NACOSTI) <https://research-portal.nacosti.go.ke> and also obtain other clearances needed.

Yours sincerely,



DR. BEATRICE K.M. AMUGUNE
SECRETARY, KNH-UoN ERC

c.c. The Dean, Faculty of Health Sciences, UoN
The Senior Director, CS, KNH
The Assistant Director, Health Information Dept., KNH
The Chairperson, KNH- UoN ERC
The Chair, Dept. of Paediatrics and Child Health, UoN
Supervisors: Prof. Fredrick N. Were, Dept. of Paediatrics and Child Health, UoN
Prof. Dalton Wamalwa, Dept. of Paediatrics and Child Health, UoN

Protect to discover