AN INVESTIGATION OF THE SYMPTOM BURDEN OF PAEDIATRIC CARDIOLOGY OUTPATIENTS IN BLANTYRE, MALAWI: THE PATIENT PERSPECTIVE

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DECLARATION

I, CORNELIUS KONDWANI HUWA, hereby declare that the work on which this thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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I took responsibility as a student to formulate my research question and objectives. My supervisors guided me as to how the question could be answered using qualitative methods. The final copies of the proposal were submitted to University of Cape Town Ethics Committee and College of Medicine Research and Ethics Committee (COMREC). Final approval was granted by both committees.

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Table of Contents

LIST OF ABBREVIATIONS AND ACRONYMS

APCA – African Palliative Care Association
COMREC – College of Medicine Research and Ethics Committee
CRF – Case Report Forms
HIV – Human Immunodeficiency Virus
MRI – Magnetic Resonance Imaging
MOH – Ministry of Health
QECH – Queen Elizabeth Central Hospital
WHO – World Health Organization
UCT – University of Cape Town
PI – Principal Investigator
POS – Palliative Outcome Scale
COM – College of Medicine
AVSD – Atrial-ventricular septal defect
RHD – Rheumatic Heart Disease

ABSTRACT

Introduction

Children suffering from cardiac disease present with an increasing burden of symptoms throughout the trajectory of their disease. There is little research describing symptom burden among children with cardiac disease in resource-limited settings in general and looking particularly from the patients' perspective. Social, spiritual and psychological symptom burden and challenges are rarely examined in literature.

This study was designed to explore the symptom burden of children with cardiac disease by engaging the children in a discussion about their illness with reference to their social (family and school), physical, spiritual and psychological lives. This was done with the understanding that palliative care improves quality of life through alleviation of distressing symptoms.

AIM

To determine symptom burden and palliative care needs of paediatric cardiology outpatients from the perspective of the patient.

OBJECTIVES

1. To describe the common physical symptoms of the children coming to cardiology clinic
2. To describe the psychosocial burden of paediatric cardiology patients in outpatient clinic
3. To describe the spiritual symptoms burden of paediatric cardiology patients in outpatient clinic

Methods

This was a cross-sectional descriptive study, using qualitative methodology with semi-structured interviews. The study had twelve participants (aged between 8 years and 18 years) and was conducted at Queen Elizabeth Central Hospital (QECH)'s Paediatric Cardiac Clinic.

Findings

Pain was a common physical symptom in all the participants. Only 2 participants received analgesia aimed at treating the pain. Other common physical symptoms were breathlessness, fatigue, vomiting and insomnia. Schooling challenges were common with 7 of the participants either repeating a class or starting school at an older age. Availability of a loving and caring family provided an enabling environment.

Schools which had been informed of the cardiac condition of the participants were found to be helpful in supporting the children. Faith and religion were found to be important to most of the participants in coping with the disease.

Conclusion

Children with cardiac disease have physical, social, psychological and spiritual challenges and symptoms. To alleviate the burden of symptoms, health workers must pay attention and aim to treat all possible reported symptoms and provide support to families. Living with a chronic cardiac condition affects the whole being of a child including relationships, schooling, family and faith.

1. INTRODUCTION

Cardiac disease, in general, has a high symptom burden as has been described in the literature (1-3).In children, both congenital and acquired cardiac disease come with symptoms that require good quality diagnostic and treatment protocols which are not as readily available in the developing world(4-7). Rheumatic and non-rheumatic valvular heart diseases are still major diseases in Africa with a significant burden on resources (2).

No comprehensive studies of both congenital and aquired cardiac disease in African children exist. We know more about cardiac disease in African children from studies examining paediatric rheumatic heart disease. Rheumatic heart disease remains the most common cardiac disease among children and is the major cause of morbidity and mortality in developing countries. Sub-Saharan Africa is known to have higher rates of rheumatic heart disease (8). Rheumatic heart disease prevalence has fallen sharply among the developed countries. Nevertheless, there are still about 15.6 million people with rheumatic heart disease in the world and the majority are in the developing nations with Africa bearing a major burden (4, 8, 9). Researchers also agree that the burden could be even higher as many prevalence epidemiological studies have been conducted based on clinical evidence which largely underestimates the problem by a margin of 10 fold compared to when echocardiographic screening is used (9). This means that there is a significant cardiac disease burden among children in Sub-Saharan Africa that is undetected.

Findings of a study of rheumatic heart disease in school going children in Mozambique showed that the prevalence of rheumatic heart disease was 30 per 1000 population which was significantly higher than what was previously estimated at 5.7 per 1000 population (10). This also agrees with an analysis of rheumatic and non-rheumatic valvular cardiac disease in Africa in a study by Essop et al. (2). With the advent of echocardiography, what was clinically silent rheumatic heart valve involvement is now detectable (8). There still remain human resource and diagnostic equipment challenges in Africa in general and Malawi in particular. Malawi has only one center with dedicated echocardiography for children found at QECH (11).

It is estimated that by 2030, cardiovascular diseases will contribute significantly to mortality in low-income countries in Africa (12). It is already known that rheumatic heart disease contributes the higher rates of deaths in the developing world (12).There is no specific literature describing the symptom burden of the children with cardiac disease or how they die and how they are taken care of during the development and progression of the disease.

Understanding the burden of symptoms in an individual or a population can help clinicians to alter their treatment and engage the sick in an ongoing treatment process. It has been proven that involvement of the patient in conversations about their disease improves the quality of the communication between the health teams and the patient and their families (13). No randomised controlled clinical trials exist to help with the understanding of paediatric symptom burden measurements and treatment benefits. Adult data, however, has shown increased improvement in patient outcomes over time when the patients are engaged in a health-related Quality Of Life (QOL) measure to describe their own symptoms; or just by having the patient-physician open outcome discussion(14).

Children with cardiac disease have significant symptom burden and require chronic care for a significant part of their lives. Most of the acute cardiac disease cases, unlike chronic cases, may present to the hospital with the symptoms that largely mimic other diseases (1).Where good quality diagnostic equipment is present, the diagnosis of cardiac disease is made and patients are referred to cardiac clinics for continuum of care. Continuum of care for such patients requires medical and surgical interventions which are largely palliative in nature. Many surgical interventions are unavailable to children who need them in developing countries(4).

It has to be mentioned that survival for children with chronic disease, including cardiac disease, has improved over the years throughout the world but the quality of life of these children is reduced and sometimes get worse with time (15, 16). Palliative care provides home based care and symptom management that most of the children with cardiac disease need(15, 17).

Corrective cardiac surgical interventions have improved around the world over the years. Despite such surgical improvements, children who undergo surgical corrections require long-term post-surgical care as they also continue to be burdened by distressing symptoms(18). Other studies have shown that quality of life is compromised in children with cardiac conditions even after successful surgeries(19). With prolongation of life, especially in the developed countries, there is now a shift toward improving the quality of life of these children and their families using approaches that are holistic in nature with good outcome success (3).For these children, prolonged life would also mean prolonged symptom burden and suffering. In Malawi, only a handful of children are selected for corrective surgery outside the country with funding support from Ministry of Health (MOH) and a few philanthropists (11). Unpublished cardiac clinic data shows that at QECH about 12 children on average per year are sent for corrective cardiac surgery outside of Malawi (clinic data). The long-term impact of symptom burden after surgery is unknown for Malawian children.

With limited options for the management of cardiac disease in children, it is parents and guardians who bear the burden of such prolonged care at home. It is not known how many of these children benefit from home-based care provided by palliative care services in Africa or

Malawi. It is, however, known that palliative care improves the quality of life through alleviation of distressing symptoms (17, 20-26). Using pharmacological, surgical, psychosocial and spiritual interventions, quality of life has been seen to improve in those with chronic illnesses in general and can also apply to paediatric cardiac disease (17, 20-26).

Palliative care has been defined by World Health Organization (WHO), as “An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO 2002) (27, 28). WHO in its guiding principles of palliative care for children argues that palliative care in children should “start from the moment a diagnosis of a life threatening/limiting illness is made to the end of life regardless of either child will receive care aimed at the cure of the disease or not” (29). Most childhood cardiac illnesses, (acquired and congenital), do fall within the definition of life-threatening and life-limiting illnesses.

The sad part of palliative care for children in Africa is that not all children who need palliative care actually get the service (30). In a study which was undertaken in three African countries, (South Africa, Kenya and Zimbabwe), only 5% of the children who needed palliative care actually received it (30). Reasons for such a large unmet need included a lack of policies and poor integration systems into the mainstream health systems (30). Children with cardiac disease are a large part of such unmet need for palliative care. Children with cardiac disease, present with physical problems, social problems, psychological problems and spiritual problems which can be managed by a holistic approach(31-35).

Queen Elizabeth Central Hospital (QECH) is a 1300 bed referral and teaching hospital. It is in the southern part of Malawi and is the teaching hospital for the only medical school in Malawi (11, 36). QECH is also a national referral hospital for specialised services like paediatric oncology, paediatric surgery, and others.

QECH has a number of outpatient clinics with the paediatric cardiology clinic being in operation since 2008. In the period between January 2009 to December 2011, the cardiac clinic saw 250 children of which 56% had congenital cardiac disease while 44% had acquired cardiac disease. In that population, ventricular septal defect (24%), Tetralogy of Fallot (10%) and patent ductus arteriosus (7.2%) were the most common congenital defects. Rheumatic heart disease (22.4%) and dilated cardiomyopathy (13.6%) were the most common acquired diseases (11). Echocardiogram screening was used to diagnose cardiac disease (11). Many of the cases seen in the clinic are largely being managed symptomatically due to late presentation and little or no corrective surgical options (11). It has to be mentioned, however, that 80% of the patients seen at the cardiac clinic come from the 10 Km radius from the clinic at QECH (11).

The cardiology clinic for children at QECH sees about 15 to 25 children every week as recorded in patient register book. The clinics take place on Tuesdays from 9 am to 12 o'clock noon. There are different age groups of children coming to this clinic.

Since 2001, Queen Elizabeth Central Hospital (QECH) in Malawi has been providing an inpatient children palliative care service under Umodzi Children Palliative Care clinic(36). The service which at first was largely for HIV affected children was extended to include all children with palliative care needs. In the first 4 years of the start of the service, 574 children had been referred to Umodzi Children Palliative Care from different paediatric wards. The main reasons for referral were symptom control and counselling(17, 36).

2. LITERATURE REVIEW

Developing countries face several challenges that start with late diagnosis, lack of diagnostic equipment and a lack of human capacity to deliver much-needed services for children with cardiac disease (5-7, 11). Apart from low investment in medical science, poverty and poor hygiene, have contributed to an increased incidence of cardiac disease especially rheumatic heart disease, in the developing nations (4). Rheumatic heart disease has remained the leading acquired childhood cardiac disease in developing countries while the same has significantly reduced in developed countries(4). Despite secondary prevention of rheumatic heart disease using penicillin, children who are diagnosed live longer but present with valvular complications that lead to significant symptoms (4). Even in developing nations, where corrective cardiac surgical interventions are available, there still is significant symptom burden to deal with and ongoing follow up visits years after surgery(37-39).

There is an urgent need to provide cardiology services to improve access and care for cardiac patients in Africa as one other review observes (37). As access to cardiology services is improving, there is also need to improve the understanding of the symptom burden of cardiac disease so as to provide the care needed for these children. With the knowledge that there is a large unmet need for the diagnostics and care, there also is a gap in the understanding of the actual symptom burden amongst this population. To date, there is no data from Malawi to describe the symptom burden of cardiac disease in children, especially from the patient perspective.

Home-based care has been used as a follow-up mechanism after surgical heart corrections in other countries in both adults and children (18, 39, 40). This requires resources and education and demands a more symptom based management approach with special attention being paid to psychological, spiritual and social needs for sustainability of the families (18, 39, 40). In the USA, home-based care has been employed as an effective mechanism for the provision of a continuum of care for cardiac disease patients(41). In a randomised controlled trial by McAlister et al, a disease management programme for cardiac disease in the USA, it has been shown that when people with the cardiac disease are followed up and cared for at home, there is an improvement in the quality of life and saving on resources which might have been used up on medical care (41). In Africa and Malawi in particular, palliative care programmes could provide this care.

A significant number of children die from undiagnosed cardiac disease in many developing countries(37). Whilst ways need to be found to improve the management of cardiac disease and to increase availability of scarce surgical resources in these settings, palliative care may be the only sustainable way of improving quality of life in this population (11). This is true for many developing countries especially in Africa (37). A study in Sudan showed that there is still high fatality rate in children with cardiac disease even for those with cardiac surgery (23.8%) (37). It is yet to be established what the success rates of such external surgical interventions are in Malawi. It is also not known how many children with cardiac disease get external corrective surgical intervention compared to those who need it in Malawi.

In a meta-analysis study that looked at common symptoms for cancer, AIDS, Heart disease and other common chronic illnesses, pain and breathlessness and constipation ranked among the most frequent symptoms in cardiac disease (42). Nausea, anorexia, insomnia, and diarrhoea were also reported symptoms in cardiac disease, though these did not feature highly(42).

Breathlessness is one of the common symptoms and physical activities are limited due to fatigue in children with cardiac disease (43). Such children will miss out on the learning and development that exists during play and interactions with friends(43).

Congenital cardiac disease diagnosed in children is known to cause family stress (43). Families and especially parents use several coping mechanisms and social support helps to bridge the gap between stress and well-being for families (43). Children with cardiac disease are likely to miss school classes due to illness or hospital appointments.

A study of the psychological and cognitive functions of children with congenital heart diseases concluded that there is impairment psychologically and cognitively especially in children with the severe congenital cardiac disease(43). The study recommended intervention specifically targeting perceptual organisational abilities, such as visual–spatial abilities. Older children were found to be more likely to externalise behavioural problems due to the cardiac disease(43).

There is limited data available to describe the spiritual symptoms specifically in cardiac disease. It is known, however, that question of the meaning of life has been associated with life-threatening illnesses even in children despite receiving little to no attention (44). Even though children may not be able to express much, they do tend to have spiritual reactions to what is happening to them (44). Children, just as adults, especially when faced with death and dying, need an in-depth exploration of their spirituality (44). Facing death can be a source of deepening or questioning one’s spirituality.

Palliative care has been asserted as a universal human right(45, 46). Despite the fact that the voice of palliative care advocacyis on the rise, there still remain disparities in the provision of and availability of palliative care in different parts of the world (45). Brennan in his special article asserts that “The majority of countries have neither formal palliative care policies nor integrated palliative care services, do not meet basic international guidelines in the provision of palliative care, and have legislation or policies whose effect restricts the availability of opioids for medical purposes”(45).

WHO has advised that palliative care can be provided through three main strategies using a public health approach. These strategies are education, government policies and drugs accessibility (47). A 2002 Cape Town Palliative Care Declaration stands out as a homegrown initiative for Sub-Saharan Africa. The Declaration asserts that: “1. Palliative care is a right of every adult and child with a life-limiting disease. 2. Appropriate drugs, including strong opioids, should be made accessible to every patient requiring them in every sub-Saharan African country and at all levels of care, from hospitals to community clinics and homes. 3. There should be establishment of education programs at all levels of the learning continuum (i.e., undergraduate, graduate, postgraduate, preregistration, and post registration) for all formal and informal caregivers, including medical and nursing trainees, community workers, volunteers and informal caregivers. 4. Palliative care should be provided at all levels of care: primary, secondary and tertiary. While primary care is emphasised, secondary and tertiary level teams are needed to lead and foster primary level care. This necessitates career opportunities for secondary and tertiary-level palliative care professionals”(48).

The definition of palliative care for children, as endorsed by WHO, is said to be a special but closely related field to adult palliative care. The following have been listed as principles under the definition(29, 49).

- “Palliative care for children is the active total care of the child's body, mind, and spirit, and also involves giving support to the family.
- It begins when the illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.”

Research has proven that early integration of palliative care in children with life threatening illnesses has positive outcomes in terms of parental acceptability, good symptom control and good preparation for the end of life care by the families (50). There are still barriers to access to palliative care services for children. Among them are; lack of training and education, communication and time constraints as alluded to in one study(51).

Families of children with palliative care conditions have unmet needs as they care for their children. An American study shows how families have had to give up certain things just to live with a child with a life-threatening illness (52). Depressing symptoms weighed heavily on the families.

Children’s palliative care was first established in Malawi, in the year 2001 under the name Umodzi (meaning togetherness). In a study by Bunn et al. at QECH, Malawian parents were found to have difficulties to disclose the details about the illness to the sick child. Cultural beliefs and traditional practices of nondisclosure result in a restricted impact of psychological or spiritual care that could otherwise be made available to the child (53). Palliative care remains a significant part of care for families and children faced with life-limiting and life-threatening illnesses. In Malawi, cardiac disease is among the life limiting illnesses affecting children with heavy symptom burden requiring palliative care intervention especially at community level.

Patients with chronic life-threatening illnesses and their families experience other barriers to care. A study in Malawi by Israels et al. discovered that there were high default rates amongst patients with chronic illness.

Looking at what palliative care can achieve, as alluded to above, children with cardiac disease are among chronically sick children stand to benefit from early palliative care intervention and follow-up in their homes. Nevertheless, in the absence of data concerning symptom burden of cardiac disease plus social and spiritual challenges, interventions can fall short of meeting the holistic needs of these children. Research has shown that children as young as 4 can provide vital information about their own health conditions (54). Hence the need to establish the symptom burden of cardiac disease from the patient perspective.

3. AIMS AND OBJECTIVES

AIM

To determine symptom burden and palliative care needs of paediatric cardiology outpatients from the perspective of the patient.

OBJECTIVES

1. To describe the common physical symptoms of the children coming to cardiology clinic
2. To describe the psychosocial burden of paediatric cardiology patients in outpatient clinic
3. To describe the spiritual symptoms burden of paediatric cardiology patients in outpatient clinic

4. RATIONALE FOR THE STUDY

With the opening of the cardiac clinic for children at QECH there is now an increase in the understanding of the disease among children. As Malawi is growing in its understanding of the burden of cardiac disease through the introduction of echocardiography there is a growing need to map the way forward for children who will be diagnosed with cardiac disease and will live with an increased symptom burden. Understanding the symptom burden of cardiac disease among children is a sure way to developing population-specific home-based and palliative care services to reach these children. This study also provides an opportunity for personal stories to be told to inform programs which are designed for children with cardiac disease, be it at home, at school or at the hospital. This research is working to understand the symptom burden of this special group of children with cardiac disease from the patients themselves.

5. METHODOLOGY

STUDY DESIGN

This was a cross-sectional descriptive study, using qualitative methodology with semi-structured interviews.

SITE

The study was conducted at the paediatric cardiac outpatient clinic at Queen Elizabeth Central Hospital in Malawi.

STUDY POPULATION

Children aged 8-18 years with confirmed diagnosis of a cardiac disease attending the cardiac outpatient clinic at Queen Elizabeth Central Hospital.

INCLUSION CRITERIA

The inclusion criteria were as follows:

1. Patients coming to paediatric cardiac outpatients clinic
2. They should have a confirmed diagnosis of a cardiac condition
3. They should be aged between 8 years and 18 years and are able to communicate verbally and have come to the clinic for a review
4. Guardian should have read and understood the research information and given informed consent
5. Patient should have signed the assent form
6. Participant should have been well enough to withstand the interview

EXCLUSION CRITERIA

The exclusion criteria were as follows:

1. Patients who could not communicate by themselves
2. Patients who were acutely ill.
3. Children who had been admitted less than 2 weeks prior to date of data collection.

SAMPLE SIZE:

A total number of 12 participants were interviewed.

TWO STEP CONSENTING PROCESS

The parents/primary guardian of the child was told about the study and the information sheet was given to them to read or was read to them where they did not know how to read

(Appendix 1(a)). They were allowed to ask questions and when satisfied they were asked to sign the consent form as legal guardian of the child. The child was given age-appropriate information concerning the study. The child was also made to understand what the study was all about as described in information sheet for patient Appendix 1(b). The child was given a chance to say whether they were comfortable to speak to the interviewer or not. Upon agreement, they were given a chance to sign or write their name on the assent form. This was done in the presence of the guardian before releasing the guardian out of the room.

The parent/guardian was then asked to wait outside the room where the interview was taking place. At the end of the whole interview which took on average 20 minutes each, the guardian was asked to come back into the room. Special thanks were given and an MK500 was given to them to add to their transport money as a thank you for participating in the study and for the inconvenience caused during the interview.

SUBJECT RECRUITMENT AND SAMPLING

Paediatric cardiology patients and primary caregivers

Convenience sampling was used. After each interview, the next sequential patient who was eligible to participate was invited.

THE PROCESS

The proposed process was that the researcher would invite the potential participant and a study information sheet given to them after formal introductions (Appendix 1(a) & 1(b)). An individual consenting process would then commence if participant and guardian agree that they have read and have understood what the study was all about. Information sheets were both in English and Chichewa for participants to choose by themselves the language of choice (Appendix 2). If they could not read, the information sheet was read aloud to them so they would understand the consenting process. Before signing a consent form, the researcher would make sure he answered all questions and concerns coming from the participants and their primary caregivers. Ethical clearance letters from the ethical boards (UCT - HREC and COMREC) were made available to participants as evidence that they were protected by ethics institution and that they could report to ethics authorities in case of any violation of the agreed protocol of the study.

All English and Chichewa versions of the consent forms are captured in Appendix 2, 3, 6 & 7. The children were taken through the assenting process. After signing or putting a mark with a thumb, the data collection would commence.

DATA COLLECTION

1. Time Frame
   The whole data collection took one month from the initial date of start.
2. Data collection tools
   a. Semi-Structured Interview Guide (Appendix 8)
   b. Demographic data collection sheet (Appendix 9)
   c. Health Passport Book data collection sheet (Appendix 10)
3. Piloting
   The piloting of the semi-structured interview questions to be used was done on 15thNovember 2016. No changes were made to the questions set for the data collection.

   A recorder was used to collect the information from the interviews.

4. The researcher, Dr Cornelius Huwa, was directly responsible for data collection (interview). Dr Cornelius Huwa is a child palliative care doctor working in paediatrics at Queen Elizabeth Central Hospital. He has worked as a medical officer for 6 years three of which he has spent doing palliative care for children at the same facility. He is a holder of post graduate diploma in palliative medicine from the University of Cape Town apart from holding a fellowship in HIV Leadership and Management and a medical degree from the College of Medicine, University of Malawi.

5. The interviews were conducted with the children in the absence of the guardian. The cardiology clinic had a spare room which they had allowed the research team to use for interviews. The room was comfortable and was private enough to allow the participants to communicate effectively.

6. Demographic data plus disease information was obtained from the health passport books of the participants. All participants had their health passport books with them.

7. Data Storage and Confidentiality
   a. All data collection tools and forms were stored in a securely lockable cupboard. Electronic data was kept on a password protected computer and also on an external hard drive.

b. Participants’ IDs were not disclosed. Only code numbers were used. Anonymized data will be kept for 5 years after the study for any unforeseeable need for accountability.

DATA ANALYSIS

The interview transcripts were analysed using thematic framework analysis. The researcher with the support of the supervisor (JB) read and re-read the interview transcripts to become immersed in the data. Codes were generated from the data through an inductive process. These codes were then grouped into sub-themes and themes. Thematic analysis is method of choice for interviews.

The Consolidated Criteria for Reporting Qualitative Research (COREQ) Checklist was used to assess the data collection and analysis procedure(55). COREQ examines the three categories of qualitative research. The first category is Research Team and Reflexivity. This category looks at personal characteristics of researchers. The second category of COREQ checklist looks at the study design. This examines the theoretical framework of the research. The last category looks at analysis and findings. This last category examines the data analysis and procedures(55).

ETHICAL CONSIDERATIONS

The recruitment of the participants waited for the approval by the UCT-HREC. The protocol was concurrently submitted to local IRB, College of Medicine Research and Ethics Committee (COMREC) since the study was to be conducted in Malawi.

The study followed the principles of the Declaration of Helsinki, 2008(56).

The children who were acutely sick and or had been hospitalised in the last two weeks before the interview were not recruited in the study. The guardians signed a consent form after they had read and understood the study and its involvement. They were given the chance to ask questions and clarifications were given. The children/participants underwent accenting process to participate.

The personal information belonging to the patients and their families was to be kept confidential and not to be disclosed to anyone except study team responsible for collecting and managing the data. The data was kept in lockable cabinets for safekeeping and confidentiality. The same will be kept for 5 years as part of the data that can be used should need arise.

Participants were allowed to withdraw from the study at any point they felt like leaving and their views were to be respected. It has to be mentioned that there was no participant who opted to withdraw from the study during the data collection time. Emphasis was made that even after withdrawing from participation, there would be no disadvantage by any means in terms of receiving their usual treatment at the clinic.

Those in need of immediate palliative care interventions were to be linked to the service providers within QECH.

Distress protocol was put in place for any child who would show signs of distress during the interview. A well-trained palliative care nurse was assigned to care for any patient who would need help due to distress and was within reach in any case of the available need.

6. FINDINGS (RESULTS)

All the participants and their guardians gave assent and consent respectively to be interviewed.

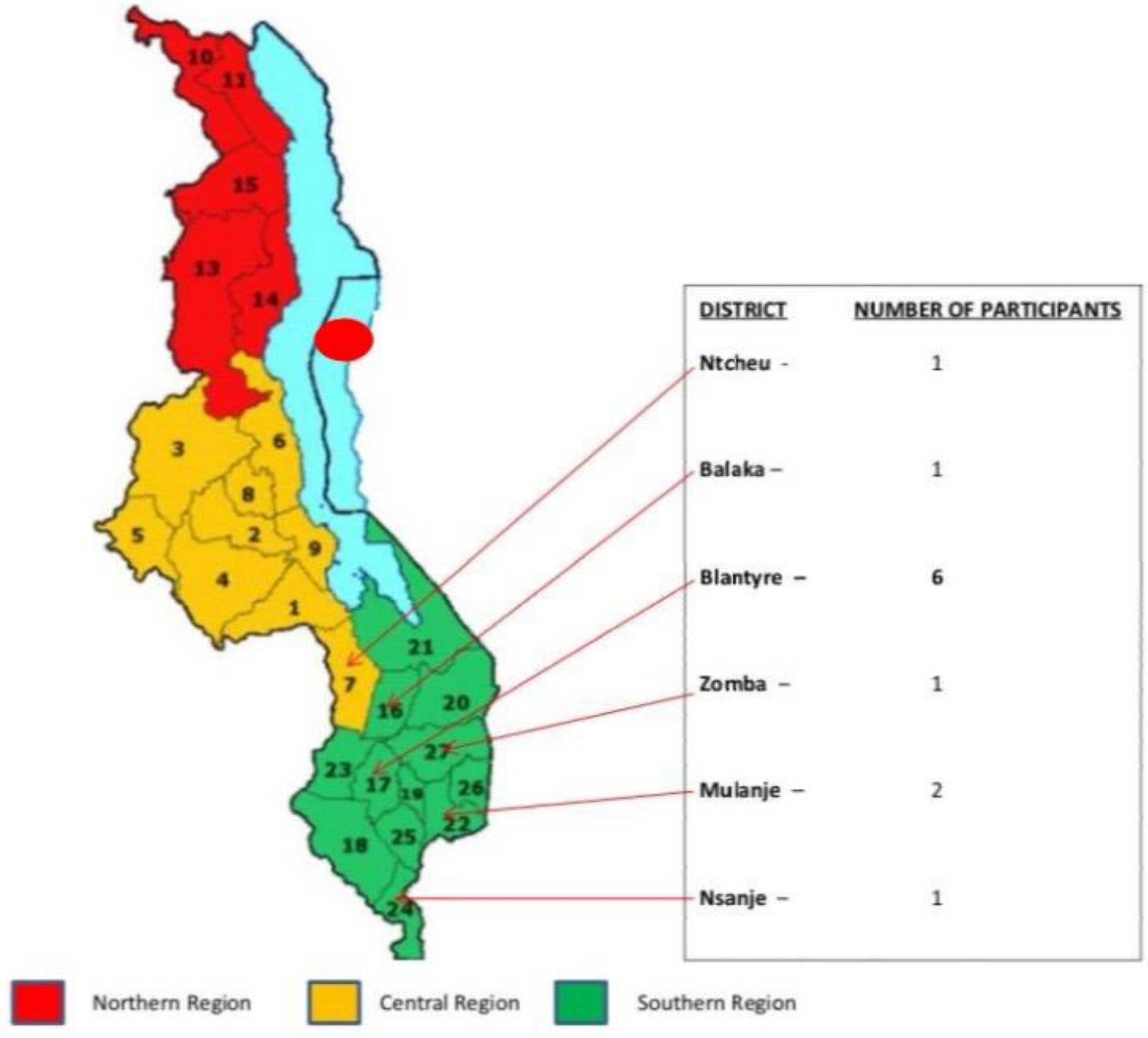
Demographic findings

Table 1. Summary of participants' features

Participant	Sex	Age	Academic Status	Cardiac Diagnosis	HIV Status	Religion	Place of stay	Approx. Distance From QECH to Home
P.001	F	18	Secondary school dropout	Tricuspid Regurgitation	Negative	Muslim	Blantyre	12km
P.002	M	14	Primary school	Dilated Cardiomyopathy	Positive	Christian	Blantyre	12km
P.003	F	12	Primary school	AVSD	Negative	Christian	Zomba	40km
P.004	F	15	Primary school	RHD	Negative	Christian	Mulanje	50km
P.005	F	17	Secondary school	RHD + Mitral Regurgitation	Negative	Christian	Blantyre	12km
P.006	M	9	Primary school	RHD + Mitral Regurgitation	Negative	Christian	Ntcheu	200km
P.007	M	14	Primary school	RHD + Severe Mitral Regurgitation	Negative	Christian	Nsanje	250km
P.008	F	14	Secondary school	RHD	Negative	Christian	Blantyre	12km
P.009	M	14	Secondary school	RHD	Negative	Christian	Blantyre	12km
P.010	M	11	Primary school	RHD + Severe Regurgitation	Negative	Christian	Mulanje	50km
P.011	F	8	Primary school	RHD + Mitral Regurgitation	Negative	Christian	Blantyre	12km
P.012	F	13	Secondary school	RHD + Dilated Cardiomyopathy	Negative	Christian	Balaka	180km

The most common diagnosis was RHD representing 75% of all participants. Mitral valve regurgitation was the common complication in the RHD patients. Only one patient had a congenital heart disease. One patient had HIV and was on antiretroviral drugs with up to date medical review and good drug compliance. The rest were HIV negative.

Figure 1. MAP OF MALAWI SHOWING DISTRICTS WHERE THE PARTICIPANTS CAME FROM



DISTRICT	NUMBER OF PARTICIPANTS
Ntcheu -	1
Balaka –	1
Blantyre –	6
Zomba –	1
Mulanje –	2
Nsanje –	1

Eleven participants came from the southern region of Malawi. Only one participant was coming from Ntcheu district, a central region district. He was at first staying in Blantyre and started coming for clinic then until one year prior to this interview when he moved to stay with grandparents in Ntcheu. Two participants came from very far districts. One came from Ntcheu district, about 200 km from Blantyre city and one came from Nsanje district about 250 km from Blantyre City.

<u>Table 2. SCHOOL PROGRESS AGAINST AGE</u>

DESCRIPTION	**NUMBER OF PARTICIPANTS**
RIGHT AGE FOR CLASS	4
OVERAGE FOR CLASS	7
UNDERAGE FOR CLASS	0
DROP OUT	1

Table 3. PHYSICAL SYMPTOMS DISTRIBUTION

PHYSICAL SYMPTOM	**NUMBER OF PARTICIPANTS REPORTING THE SYMPTOM DURING THE INTERVIEW PROCESS**
Pain	12
Breathlessness	7
Vomiting	1
Insomnia	1
Fatigue	3

Table 4. Medication prescribed in last clinic review

Medication	**Number of participants who received**
Paracetamol	1
Aspirin	3
Ibuprofen	1
Digoxin	1
Furosemide	9
Spironolactone	5
Lisinopril	8
Amoxyl	1
Benzine penicillin	7
Hydrocortisone	1
Morphine	0

Thematic analysis

After analysing the data from the semi-structured interviews, themes and sub-themes were identified. Four major themes emerged from the analysis and these were as follows:

1. Living with the disease
2. Life at School
3. Family relationship
4. Other coping strategies

These themes also were followed with subthemes or minor themes as shown in the table below:

Table 5. Themes and sub-themes

	MAJOR THEMES		**MINOR THEMES**	
1	Living with the disease	1.1	Impact of Physical Symptoms of daily life	
		1.2	Impact of disease in general on daily activities	
		1.3	Understanding disease-modifying interventions	
		1.4	Letting others know about disease	
2	Life at school	2.1	Impact of school on disease	
		2.2	Impact of disease on school	
		2.3	Academic performance	
3	Family relationships	3.1	Positive attributes of family relations	
		3.2	Negative attributes of family relationship	
		3.3	Loss of parents	
4	Other coping strategies	4.1	Spiritual support	
		4.2	Playing with friends	
		4.3	Chatting with family members	

THEME ONE: LIVING WITH THE DISEASE

1.1 Impact of Physical Symptoms on daily life

All participants reported to having one type of physical symptom or another. Pain was the commonest symptom reported by the participants. Pain was present in different sites and in varying degrees. Pain was associated with many difficulties in either going to school or doing any household related chores. The common pain-related symptoms were headaches and chest pain (heartache). Abdominal pain was mentioned by one participant while another participant mentioned having severe menstrual pain. One participant complained of the pain of the extremities (both arms and legs).

Some of the participants said the following:

"*I experience chest pains and get tired easily especially when walking on a sloped road.*" P.009

"*I don't often get chest pain, but when I do, it is severe and piercing in nature. It (pain) is worse at night at times and sometimes during the day*." P.005

"*My heart and chest give me problems (pains) a lot*." P.011

One of the participants indicated that she had the pain in both the legs and her arms.

"*Apart from my headache, I also get pain in my legs and arms*." P.011

One participant associated pain and breathlessness to her reaction over emotional distress. She had this to say:

"*When I am upset with something or someone, I easily get angry and that causes me a lot of headache and breathlessness*." P.003

Breathlessness was one of the major physical symptoms that were reported by 7 of the 12 participants.
One participant had this to say about breathlessness:

"*I struggle with breathlessness which gets worse when I walk a long distance and when I am talking with friends or when I am running.*" P.004

One participant reported that she struggles to sleep due to breathlessness. She experiences orthopnea and normally uses two to three pillows to sleep comfortably every night.

One participant reported that she sometimes vomit when she is eating. It is not a common symptom but it does come especially when she is also coughing.

1.2 Impact of disease in general on daily activities

The participants reported various degrees to which the disease impact their daily activities. Most of them reported on reduced activity in relationship to walking, talking, doing household chores, running, concentrating in class and other things.

One participant said:
"*I easily get tired when I am running or playing with friends at home or at school.*" P.003

One participant had this to say: *"When I am playing, I fail to jump and I struggle to ride a bicycle.*" P.012

One participant, who had undergone cardiac corrective surgery in India reported improvements in managing her physical activities including walking, running and doing household chores. She had one fear though. She was 18 years old and dropped out of school. She mentioned that she was told that she will never be able to conceive and carry a baby in pregnancy. She had this to say:

"*When they discovered my heart condition, being a girl, they (doctors) said that I might have difficulties in the future when giving birth.*" P.001

1.3 Understanding disease-modifying interventions

The participants had varying knowledge of the availability of disease-modifying interventions. All of them appreciated that they continue to come to QECH to receive drugs that help them to be healthy. One participant had this to say:

"*I have heard that others do not get better when they have an illness like mine. I am happy to be one of those receiving medication here. I also hear these drugs are difficult to find*." P.010

One of the participants had previously underwent cardiac surgery in India with the help of QECH doctors. She testified that the surgery improved her life and modified the way she felt. This is what she had to say:

"*I was told that I had a heart problem and that the problem needed an operation for me to be better. They (doctors) helped me to go to India.*" P.001

All of the participants have been coming to the cardiac clinic every two to three months for reviews. Medications are given for the maintenance of their well-being while others come to get check-ups and treatment for other illnesses.

1.4 Letting others know about disease

Living with the disease to many of the participants means constantly having to make a choice of whom to tell about their illness and whom not to tell. All of them had their immediate family know about their disease. Friends and teachers, however, were among the major groups where a choice had to be made.

Three of the participants were able to tell both friends and teachers at school. One of them said the following:

"*Mr C. my teacher knows about my heart disease,*" she said, "*and my friends Comfort and Gladys also know. I told them about my heart disease*." P.004

Two of the participants did not want any of their teachers to know about their heart disease. One of the two specifically said she had problems with the teachers. She felt they do not understand her well. She would rather keep the information to herself rather that telling it to the teachers. She said the following:

"*My teachers want me to work just like the other girls in school. When I took a letter from the Hospital (QECH) explaining my condition, they hated me for it. They thought I am trying to be lazy. I hate them and will not talk about my disease with them.*" P.003

She continued to say: "*There is one teacher I have confided in. She is our social science teacher. She understands me unlike the other teachers.*" P.003

The other participant felt she was ok having teachers not know her heart disease. She only told her friends. She only mentioned the condition to the boarding mistress because she has to get her permission every time she is coming to the hospital.

Ten of the participants had at one point told their close friends about the cardiac disease . Two of the participants, however, felt not ready yet to tell their friends about their cardiac disease. One of them had this to say:

"*I don't have any reason but I just feel it is not proper to tell my friends*." P.010

It was clear from the conversation, however, that the issue of who to tell was entirely in their hands. They were not asked by the hospital or felt obliged to do so by anyone. One participant had this to say:

"*Only Mr C. knows about my condition. He is just a teacher. The head teacher does not yet know. It is because he is new in our school. I will tell him (new head teacher) at some point*." P.004

THEME TWO: LIFE AT SCHOOL

2.1 Impact of school on disease

All participants come from homes who do not own cars and who walk to school. 11 of the 12 participants expressed challenges with walking to school. In some of the instances, the participants had to miss school classes because the distance was far and it was hard for them to walk to school. Breathlessness was one common symptom reported as the first to appear when they walk a long distance to school.

Here are some of the quotes from the participants:

"*I easily get tired when I walk a long distance*." P.003

"*My school is a little far. I pass through some high and low places. Walking up the slope is difficult for me*". P.009

One participant expressed that she had difficulties understanding the teachers when learning in class. She mentioned that she sometimes experiences headaches that are so bad that she starts crying while in class. She said she sometimes struggles to look and see the blackboard when the teacher is teaching.

One participant expressed concern that she does not manage to do quite a lot of physical activities as required by the school authorities. At first the teachers thought she was just being lazy until when she was taken to the hospital one morning after collapsing in the school campus. It was during that hospital admission that a diagnosis of cardiac disease was made. The school teachers now accept her condition and accommodate her by giving her light physical assignments to do.

Playing with friends is one activity they all seemed to express that they enjoyed most. However, one of the participants expressed difficulties in playing as she becomes breathless so easily. This is what she had to say:

"*I get shortness of breath when I am running, playing with friends and when talking with friends*." P.004

One other participant said: "*When I am quarrelling with someone at home or at school, or when a person is accusing me of things I did not do, I feel bad and this leads to me having a headache and breathing fast.*" P.003

Others expressed different levels of discomfort with varying degrees of exertion especially running.

One participant had a good relationship with her school teachers. This came about when the girl was diagnosed with the heart condition and the school authorities were notified. Teachers started putting money together to support the family to go for clinical check-ups at QECH. The participant comes from Mulanje district which is about 50 km from Blantyre. It takes about MK3000 for a round trip per person. The family is poor and the school authorities thought of supporting the child and her family every time they are coming for clinic visits. The teachers had been doing that at least for the last two visits prior to the recent visit

"*My teachers, after learning about my sickness started helping me and my aunt with transport money to come to the hospital*." P.004

2.2 Impact of disease on school

Missing classes due to illness was a common finding. All the participants reported having missed school days at one point or another due to the illness. The degree of severity of the illness differed with each participant. One participant, who had to undergo cardiac surgery in

India, missed almost a whole academic year as she had to recover from the wound caused by the surgery. Others would miss school for a day or two at a time. Missing classes was noted to be a significant concern. Below are some of the spoken concerns:

"*I started school when I was 9 years old. I was not allowed to start at that (earlier) age because I was looking young*." P.004

"*I have missed a lot in my studies because this whole term I did not go to school due to my illness*." P.009

Another participant had this to say: "*I stopped going to school in standard 6. I missed the whole term (due to the illness).*" P.007

The cardiac clinic takes place every Tuesday from 9:00 am to 12:00 o'clock noon. Patients are requested to come at 8:00 am to have their biometric measured done by the patient attendants. Patients in this clinic, who are mostly school going children, would have to miss classes when they are coming for reviews. Patients miss different amounts of class depending on how frequently they visit the cardiac clinic, that only takes place during school hours.

Two of the participants were coming from the furthest districts in comparison to the rest of the participants. One of the participants was coming from Nsanje which is about 250 Kms from Blantyre and another from Ntcheu about 200 Kms away. A minimum of three days needs to be planned for the patient from such a distance to successfully attend the clinic. This is because transport networks are unpredictable especially in the rainy season in Malawi. Communities use bicycle transportation to take them from the village to the nearest connecting road where they catch buses or other local transport systems. Such travels have a direct impact on the school attendance especially if the frequency of such visits is increased.

Half of the study participants had reported to have repeated a class at some point in their school journey. One participant said the following:

"*I am now in standard 6 but I repeated standard 5 because I missed one whole term due to my illness*." P.004

2.3 Academic performance

Performance in class was another challenge with the participants. Due to illness and constant missing of classes, most of the participants lag behind and struggle to catch up with friends in class.

"*Sometimes I have to come to the hospital while my friends are learning in class. This affects my studies and I don't pass well in class*". P.005

Apart from just missing classes, three participants reported having missed writing end of term exams at some point due to illness. Two of the participants had just missed the most recent exams. This has contributed to failure and repeating of classes. As the simple rule is that, one cannot go to the next level until one has sat for and passed exams. Unfortunately, some of the exams missed were a final term and very crucial in deciding whether one repeats or proceeds.

One participant said "*I sometimes do fail to go to school due to illness. My friends have now known about my heart condition because I did not write my end of term exams with them recently*. I *have missed a lot in my studies. This whole term I did not attend classes due to this disease*." P.009

THEME THREE: FAMILY RELATIONSHIP

3.1 Positive attributes of family relations

Family play a major role in providing an enabling environment for learning for the participants. One participant who stayed in the tea estates with her family had struggles walking to and from school in that area. The school was far from home. One participant's aunt volunteered to keep the participant at her home because it was closer to the school. The girl was able to continue with her studies without difficulties because a family member offered an enabling environment.

She had this to say:

"*I now stay with my aunt despite the fact that I still have both parents. School here (aunt's place) is closer to home than where my mother is*." P.004

The majority of children in the study were brought to the cardiac clinic by their mothers. Just a few are accompanied by their fathers. 2 of our participants were brought by uncles and 2 were unaccompanied as they were older and managed to come to the clinic on their own (17 and 18 years).

One participant said the following:

"*He (the uncle) is not my father, he is my uncle. My father stays in Chirimba. Him (father) and my mother divorced. My uncle brings me here (hospital)*." P.009

One participant mentioned that her sister who is currently working in the Republic of South Africa has been instrumental in sending money to her which she has been using to buy books, pens and other school related items. She appreciated the support that her sister was offering.

The family was also seen as a source of hope and encouragement. One participant who mentioned that she gets depressed at times but that her mother has been helping her to get over it by telling her that things will be alright one day. The mother has been providing spiritual guidance and encouragement to her.

When it comes to financial support, the family was found to be the main financier for the participants' financial needs. One participant from Nsanje district, when asked about how he finds transport money to use when coming the hospital for clinic reviews, he had this to say:

"*My family has been selling goats every time I am coming for the visits. That is the money we use for transport fare*." P.007

The family, especially the mother, was seen as a role model for prayer and spiritual satisfaction. In one instance, one participant said her mother always ask her to pray when she is in trouble or she is depressed. She said prayer helps her to deal with her challenges and face the positively.

"*I had a bad dream the other day. When I woke up I told my mother and my mother encouraged me to continue praying*." P.003

3.2 Negative attributes of family relationship

Not all family relationships, however, were as good as one would hope. In some instances, there were rivalries within the family. Siblings were noted to be causing trouble in some relationships with the participants. One participant mentioned how she is no longer interested in chatting with the younger siblings except one. This was due to what she referred to them as "*backbiters*". (P.004)

"*I don't play with them (young siblings) because they speak lies*." P.004

Two participants were living without one parent. One had lost a mother and another had lost a father. The one without a father was living with a stepfather after the mother had remarried. She described her relationship with her siblings which came into the house with the stepfather to be rather cold. She was usually in conflict with step sisters over petty issues. She sometimes leaves the house and goes to her grandmother's house, which is nearby, to avoid these conflicts. She sometimes spends days at her grandmother's home. The mother always encouraged her to connect with the siblings but she finds it difficult since there has been ongoing friction among them.

"*I sometimes don't live well with my siblings. So, I sometimes just go to my granny's place. Like what happened this week, I have just come back last Saturday from my granny's home*." P.004

One participant expressed that her relationship with her parents was poor. Her parents are pastors and they are usually busy. She found it hard to chat and connect with them.

"*I do not chat with my mother or my father. I don't have any particular reason but I just don't feel connected to them. That's all*". P.005.

On further enquiry, one participant felt her parents did not support her adequately and felt they did not believe in her since she was sick.

"*Though I wrote my last exams while I was sick, I managed to pass that exam. My parents though did not pay for my school fees in the following year because they had already told me that since I was sick, they will just be wasting money on me. When I asked this year again for school fees, they just told me they had no money. It could be due to the national-wide hunger maybe*." P.001

3.3 Loss of parents

As alluded to, two participants had lost one of the parents. The rest had both parents alive. Three were not living with their own parents despite the fact that their own parents were alive.

The gap created by the departing parent seemed to affect the two participants in varying degrees. One participant was living with the mother and stepfather. The other participant was living with her grandparents after the father married another wife when the mother died. She was not happy living with the grandparents but it seemed that was the tradition of the Lomwe culture. The children belonged to the mother by tradition and when the mother is dead, the parents or relative of the mother have to take care of the children. There was not much support coming from the father.

One participant's parents were divorced. The father had left home and he was staying in another township away from where the participant stays. The uncle, the brother of the mother, has assumed the responsibility of taking care of the participant. The participant seemed to be fine with the arrangement of the biological parents. The participant mentioned that the parents had their own difficulties and decided to part ways. The father has since remarried and the mother is still staying by herself. The participant, however, mentioned that he does not think their divorce had anything to do with his illness. He said this:

"*No. I don't think they divorced due to my illness. They parted ways before I was diagnosed with the illness of the heart*". P.009.

He, however, appreciated the support he gets from his uncle who usually accompanies him to the hospital.

One participant lives with grandparents despite having both parents alive. She said she likes living with the grandparents. She has other siblings who stay with the parents but she lives with the grandparents. She mentioned that she started living with the grandparents when she was young and has gotten used to it. She sometimes goes to see her parents for few days but she has to come back home. She, however,said it is her mother who escorts her to the hospital when she has to come for clinic reviews. Her grandparents are old. She is the one who helps the grandparents with household chores.

THEME FOUR: OTHER COPING STRATEGIES

4.1 Spiritual support

Eleven of the participants are Christians. There was only one from the Islamic faith. Faith seemed to take a major role in coping with the illness in most of the participants. More than half of them quoted prayer as one way of coping with the illness. Others quoted prayer and Bible verses as a way of getting encouragement and cope with the illness.

"*I get encouraged when we make mention of the things of God even verses of the Bible."* Said one participant. P.004.

One participant said:

“*My faith has changed for the better. I am always happy when I have been prayed for at church*.” P.009

One other participant said:

“*My faith helps me. I pray a lot that God should remove this disease*.” P.010

One participant found participating in church activities to help her in coping with the illness. She is Roman Catholic and is involved in the youth of the church. She is part of the active girls who go to church to either sing or arrange things in the church. Being allowed to participate in church business without any discrimination was an encouragement to her.

One participant mentioned that her Sunday school teacher helps her a lot to cope with her illness. The Sunday school teacher knows about her condition and he usually encourages her with verses from the Bible.

There was not much mention of the church being generally involved at home in managing the illness. One participant mentioned that her church members come to visit especially when she has fallen sick. They are, however, not as directly involved in the care.

Talking to God was one way of getting encouraged throughout the illness trajectory for most of the participants. They had all learned how to pray through parents or church or mosque.

One participant said: “*I believe I will be healed. I believe that as I am praying, one day I will get healed*.” P.008

4.2 Playing with friends

All of the participants found chatting or playing with friends to be helpful. They all had between 2 to 5 trusted friends. Playing ranged from simple to high energy types of children play. All in all, playing provided hope to the participants.

One participant said, “*I like playing bila and mila with my friends*”. P.003
She continued to say, “*My best friend is Natasha. I like playing with her because she does not like fighting*” P.003

Playing also provided accepting environment for the participants. One participant did not want her friends to know about her illness because she felt they will not accept her back into their circles. She enjoyed playing with them and felt accepted. She was worried that if they knew, they would abandon her since she was sick. To her, being accepted by her friends was everything she counted on. She did not say whether she knew of any friend or person who was ever abandoned by friends because they were sick.

Playing also provided to some participants a way of distraction from thinking about the disease. Playing made them to think about friends and other things.

Interestingly, one participant found being alone to be of much help when distressed or worried. He had this to say:

"*When I am distressed, sitting quietly alone and doing nothing helps.*" P.007

4.3 Chatting with family members

Family members played a role in helping the participants cope with the illness. One participant mentioned her older sister as a source of inspiration and encouragement throughout her illness. The elder sister is supportive and helps her to face challenges in life including working hard at school. Such support helps her cope with the illness.

One participant talked about her fears over the disease being incurable but finds courage in her siblings.

"*I sometimes worry because I have heard people saying that no one gets cured of this disease. My chat with my siblings and others helps me to manage my condition.*" P.010

One participant said she enjoyed chatting with one of her younger siblings.
"*I don't chat well with the other siblings except for Natacha. Natasha is 9 years old and we get along very well. When I chat with her it helps me to be strong*."

7. DISCUSSION

Cardiac disease is known to present with several symptoms and challenges regardless of the age at presentation (42). Many studies have been done among the adult cardiac population to quantify the symptom burden. There are few studies on the symptom burden among children with cardiac disease especially considering the patient perspective and understanding.

This study examines the symptom burden of cardiac disease among children looking at patient perspective as they interact with day to day activities in their environment and in their families. Four major themes were identified from analysing the interview data as reported in the Findings section. These themes are: living with the disease, life at school, family relationship and other coping strategies.

Palliative care for children, among other guiding principles, "is the active total care of the child's body, mind, and spirit and also involves giving support to the family" (29, 49). Cardiac disease in children is among the reasons for referral to palliative care services in the world at large and Malawi in particular. From January to December 2016, there were 45 children with cardiac disease referred to palliative care out of 540 child patients seen in palliative care in the same year (clinic data). This figure represented 8.3% of paediatric palliative care patients. Less than 20% of these referrals came from the cardiac clinic. The majority had come from in-patient referrals. With the knowledge of palliative care needs in children with cardiac disease, it was not clear how cardiac outpatients were being served. This unanswered question motivated this study to be initiated with the aim, among others, to understand the services and support that the patient and family would require and to define key and common challenges or symptoms that the patients themselves face in the quest for an improved quality of life.

Most qualitative studies that have been done among children with cardiac disease have looked at the outcomes from the guardian's perspective. Few qualitative studies, like that of Elizabeth Tong et al, have been done among children to report on the experiences with chronic disease in general and cardiac disease in particular (57).

The population in this study was drawn from a wide age range and a well-balanced representation of both female and males. Most of the patients in the population of this study were coming from rural or peri-urban poor communities. They represented a Malawian population from a diversity of cultural and traditional backgrounds. There was only one participant of Islamic faith while the rest were Christians. In general, the group of participants represented a picture of the people that frequent the attendance of government health services in general and QECH in particular. Among them were children who were in primary and secondary schools. The participants also came from diverse family units. There were children from homes where both parents are alive, while others came from homes where one parent had passed away, or they lived with grandparents while others we coming from homes where they lived with extended family. The researcher also appreciates that there are some children who come from child-headed homes in Malawi (58), but this study did not have any participant from such a home.

This is the first study in a palliative care setting, to interview children with cardiac disease on a face to face setting in Malawi.

There are many physical, social, psychological and spiritual issues that concern chronic illnesses in general and cardiac disease in particular. Studies have shown that children suffer from so many discomforting symptoms as they go through various treatments in their illnesses. It has been found in adult studies that patients with cardiac disease would generally present with pain, breathlessness and constipation among other physical symptoms(42). This study, however, looked beyond physical symptoms. The physical symptoms in this population under study were studied using the less structured system as it relied on information obtained from the interviews. The participants were asked using a semi-structured questionnaire which incorporated physical symptoms, social interactions, psychological symptoms and spiritual relationships.

The family is a major part of every child's life. It is not surprising that other studies have associated increased family stress in families where a child has a cardiac disease(43). How children with cardiac disease interact with their families on a day to day basis in a Malawian setting had not been established. In general terms, however, Caring for the sick, in an African setting, is the role of the entire family as described in a study by Geoff Foster (59). This is not different from the findings of this study. The interaction of family and community at large has been highlighted and shown to be of great value among the population of the participants in this study.

The participants showed diverse understanding of the physical symptoms that were affecting them on a day to day basis. Pain was among the common finding where all the participants reported to have the pain of one kind or another. Solano et al. in their meta-analysis on symptom prevalence in far advanced diseases which included cardiac diseases, pain was found to be a common symptom of cardiac disease in adults (42). In this study, pain was reported as originating from different parts of the body, headache and chest pain being the commonest complaints.

Pain, as a symptom, is majorly underestimated in children. Neil L Schechter in his article emphasises how pain is less vigorously treated in children compared to adults. He asserts that myths, attitudes, lack of information and complexity in the assessment and treatment of childhood pain areat the main reasons for the lessvigorous treatment of pain in children (60). This study found 100% of the children had reported to having pain of one kind or another since their most recent hospital visit but yet only two children had pain medication prescribed to them in the last clinic visit. The experience of the researcher, having worked in children palliative care for four years at QECH, agrees with the statements made by Neil Schechter that pain is less vigorously treated in children. With high doctor-patient ratio in Malawi in general, (61), certain symptoms, like pain are easily left untreated especially in children.No patient was on outpatient morphine to treat pain or dyspnea which was present in 58% of the participants.

QECH, however, has made positive strides in the treatment of pain for children under the guidance of Umodzi Children Palliative Care for inpatients. Morphine is made available in all the children admission wards at QECH. There is an ongoing interaction between the palliative care team and the clinicians in the Department of Paediatrics which has promoted the diagnosis and treatment of pain. More still needs to be done as more and more new health workers come to the Department of Paediatrics and may need to be oriented to symptoms management of patients including pain management. In this study, only two patients were prescribed pain medication in the last clinic visit.

Seven of the twelve participants said breathlessness was their other common symptom. The breathlessness was associated with exertion in most of the participants while one participant complained that she gets breathless when she is angry. This is not a surprising finding as most of the participants had RHD with mitral valve regurgitation as the common complication. Dyspnoea and orthopnoea are associated with the left heart failure. Solano et al. also recognised breathlessness as one common finding among patients with cardiac disease (42). Some participants pointed out that breathlessness seemed to limit the way they would fulfil the chores or participate in various activities including playing with friends and sleep.

As children grow, they are expected to engage in various life skills development activities. Having cardiac disease affected the participants in varying degrees as regards to life skills developmental activities. All of them reported a level of decrease in activity. Some of them reported being affected in their walking, talking, doing household chores, running, concentrating on class lessons and other things.

One participant, who had undergone cardiac corrective surgery in India reported improvements in managing her physical activities including walking, running and doing household chores though this was still not as good as one would compare with the other normal children in her area. This agrees with the study that has shown that there is still need for long-term management of the children with cardiac illnesses even after corrective surgery has successfully been done (39).

Older participants faced different challenges than their younger counterparts. One of the participants mentioned that her fear was her future childbearing potential. At the age of 18 years, she had been hoping to get married and have children like most girls in the future. She was, however, told by her doctors that she will not be able to give birth due to her illness. Not being able to give birth to her was same as not being able to marry. In Malawi, the age of sexual debut has been estimated at 15 years for girls (62).The minimum legal age for marriage in Malawi is 18 years but girls, due to socioeconomic circumstances, have gotten married before the legal age and mostly to men significantly older than them (63).

Samuel et al. in their prospective multicenter study confirmed that "pregnancy in women with heart disease is associated with significant cardiac and neonatal complications"(64). This was found to be true even in countries where they have "state of the art obstetric and cardiac care"(64). This makes the concern of the adolescent valid and calls for continued counselling and advice. This kind of concern is not uncommon from an adolescent who is transitioning into adulthood. Another study agrees with the concerns above and elaborates how the adolescents with cardiac disease saw the disease as a hindrance to their many future dreams (57).

The participants had varying degrees of knowledge and understanding of the availability of disease-modifying interventions. All participants showed knowledge that their coming to QECH for medication and review was helping them to stay well. There was a general sense of understanding that the continued clinical and medical care was generally not aimed at a cure but rather to keep them stable. All of the participants do come to the clinic every two to three months for reviews ad clinical check-ups and for medication.

Corrective cardiac surgery is not available in Malawi. This is true in most developing countries as also confirmed by other literature sources (5-7). In Malawi, those who are assessed by doctors and seen to be candidates who can benefit from corrective surgery maybe supported by the MOH to go to India or other countries to get their cardiac corrective surgery. It must be said that this support is limited by the availability of government funds and well-wishers donations(11). Only a handful of people have benefitted from this initiative in Malawi.

Living with the chronic disease is in itself a stressful life for family and the patient. Nevertheless, the stress is ameliorated by having a supportive and accommodative environment. Support from the family and community does depend on how much information the family and patient are willing to share with the rest of their community. Participants to this study had to make deliberate choices on who should know about their disease among friends, teachers and other family members. All of them had their immediate family made aware of the cardiac disease diagnosis. Other participants went as far as telling friends about the disease while other participants found it helpful to let their teachers know about the disease.

While other participants did seem not to mind about who knows about their illness, there were other participants who felt that telling friends about the illness would compromise the relationship they had worked hard to develop over years with those friends. Cultural barriers have been explored in the area of HIV and cancer concerning disclosure of one’s illness among children and their families in a Malawian context (53). Family feelings, even when it comes to letting the child (patient) know about diagnosis, differ hugely with the majority thinking it would do much harm to disclose than to keep a secret over a life-threatening illness diagnosis (53).Disclosure of one’s illness, even in children, however, has shown to help in the management of the overall disease process. My experience working with children has taught me that when the parents allow their children to know the truth about their illness, it liberates both the parent and the child. There is an immediate reaction which usually is part of the grief process and requires management, but the overall outcome, in general, is good. Age appropriate open discussion is fruitful in our setting for children and their guardians and agrees with literature in promoting the understanding of disease and planning of appropriate interventions (23, 50, 65). Disclosure to friends and school authorities, however, depends largely on the level of awareness of the friends and teachers being told.

There is limited data available describing what the experiences are like for children or adolescents with cardiac disease. Tong et al. published an enlightening study of their findings among a population of adolescents with cardiac diseases. In their article about the dilemmas that adolescents face in many areas including disclosure, they found that it is not easy to deal with realities of life including disclosure among adolescents especially as they become aware of their many limitations due to their cardiac disease. This study by Tong et al. concluded that good understanding of the adolescent dilemmas by health workers is important in helping the patients and their families (57).

Three of the participants were able to tell both friends and teachers at school. They felt telling gave them some kind of freedom to interact with their peers and teachers.

One participant had a negative reaction from the teachers after she had told the school authorities that she had been diagnosed with a heart disease and that her involvement in otherextracurricular activities would be limited. It was not clear whether this was just a misunderstanding or intentional reaction, but the class teacher thought the child just wanted to run away from extracurricular activities according to the participant. Other studies, however, have shown that school authorities are very crucial in the support that a child may receive when suffering from the chronic illness at school. In a study by Olson et al. educators were interviewed to determine their perceptions over having a pupil who has a chronic illness including HIV, cardiac disease and asthma. The study found that education professionals had positive perceptions. There were concerns and fears, however, over what to do when an emergency occurs and even feared death might happen on their watch (66).

School formed a greater part of almost all the study participants' lives. There was much interplay between the participants' disease condition and the schooling itself. Missing school due to illness was not uncommon in the population under study. Distances from home to school vary. Most of those from rural areas stayed a considerable distance away from school. It has to be mentioned that primary school in Malawi is free. Like many resource-limited settings, schools are far apart and distances considerably high for small children to walk (67). The effects of such distances are worse when a cardiac disease is involved like in the lives of this study's participants especially those whose main symptom is breathlessness. The frequency of hospitalisations and distance to school might also explain why some participants started school at an older age than is expected apart from looking small for age.

Missing classes was found to be a common occurrence in the population under study. Among many reasons for missing school classes, were ongoing medical struggles. Apart from being in poor health, the participants were made to miss school when they were required to go for appointed medical review at the cardiac clinic. The clinic takes place on Tuesdays and this is a school day. For participants who were coming from Blantyre city, they only had to worry about one school day for the clinic. For participants from outside Blantyre city, however, two to three days had to be planned as days that a child will be away from school. This is so because they have to travel on Mondays and sleep over in Blantyre, at the hospital, so that they can attend the clinic on the morning of Tuesday. Others from far districts have to sleep over in Blantyre before they start off on Wednesday morning going to their homes. Missing classes have a direct bearing on the overall performance in class.

It was not surprising to hear most of the participants expressing concerns over their academic performance. Keeping pace with the other peers in class was difficult as they were required to write the same exams everyone else in their class writes. They are assessed on the same platform with the other well able students. Illness and clinic visits were among the reasons they gave for failing to keep up with their academic work. Other participants repeated their classes after they had failed to seat for their exams due to their illness.

On the positive side, however, the family was a key to the success of the participants in different areas of their lives including school. All participants had something to say about family. Involvement of the family in the lives of the participants and their disease or lack thereof had a direct impact on the participants. The mere fact that the families were involved seemed to encourage the participants in one way or the other.

In an African setting, looking after the sick is a family and community responsibility (68). It should, however, be mentioned that such families need support and continued help as they go on helping their loved ones. One such area of empowerment is information sharing. Early palliative care involvement in the lives of children with cardiac disease has proven, in the western world, to improve the choices that families can make concerning interventions that such children should undergo (69). It would appear that the participants in this study would benefit from similar interventions though they are from a different background.

A major part of the lives of the participants was spent in school regardless of the challenges they faced. It was discovered in this study that the family played a major role in providing an enabling environment for learning for the participants. Some of the participants benefitted a lot from the extended family support. In this study, four of the participants were staying with other relations other than their own biological parents. All participants, except one, were going to school with the support of their families. The family also provided resources for the needs of the participants. Household worth like goats was sold to provide transportation money in some instances.

There were also instances, however, where family relationships were not all that good as described by some of the participants. Where mixed families existed, instances of family quarrels among siblings were common. In the presence of burden of symptoms of the cardiac disease and unstable relationships, the environment would be psychologically and physically challenging for the development of a child. Such families can benefit from continued support and counselling.

Life is more complicated for the children who were living without parents or living with one parent. Losing a biological parent or both can be one challenge in itself and worse when a chronic illness is in the picture. Two of the participants expressed how they lived in the absence of one parent. One participant lived in the grandparents’ home and was satisfied with the care though the grandparents are older and growing weak as time goes. The question that one would ask now is about the continuity of care once the grandparents are no longer strong to carry on with the responsibility of looking after the sick child. Literature, from an African context, explains the difficulty that grandparents go through when they look after the orphaned sick grandchildren (68).

Divorce was one reason why some parents were not living together. The study had one participant whose parents had divorced. He was quick to point out that he did not think he was the reason for the separation of the parents. He was able to note that the illness came later on in life after the divorce of his parents. Nevertheless, the literature shows that children who are dealing with the divorce of their parents compared to children from intact families exhibit more behavior problems, lower academic performance and poor self-image among many things (70).

One major theme that was identified was how the participants coped with the disease using various ways. Faith was one major area where the participants found refuge. They all expressed involvement in faith-related activities and getting encouragement from church leaders and other elders. It is not uncommon that faith has played a major role in helping people cope with situations that are hard for them. Narayanasamy in a study found that faith-related search for meaning and purpose appear to be an important coping mechanism in chronic patients(71).

Play therapy has been widely accepted as an effective psychotherapy in dealing with children especially those with chronic illnesses (72, 73). Other hospitals have adopted play therapy as part and parcel of the treatment offered to children with chronic illnesses. Participants in this study found playing and chatting with friends to be very helpful as they were helped to forget their illnesses. The play is one important language of children. Umodzi Children Palliative Care at QECH has a play room and play leaders that help inpatients to find a place to relax and play when in the hospital. Continuity of play after discharge is left to the family and the surrounding social system. Playing provides an environment of acceptability and accommodation. All participants to this study had friends. The fewest number of friends the participants had was two. Umodzi Children Palliative Care has a play room within the hospital at QECH. All children admitted at QECH, who are able to walk, are encouraged to come to the playroom to play and watch movies.

Apart from friends, spending time with family and siblings was seen as one of the coping mechanism for the participants.

STUDY LIMITATIONS

The study was carried out in a cardiac clinic in a hospital setting. According to Allison Tong et al, studies done in the hospital setting would not yield the same exact results as done in a home setting (55). Hospital in itself gives more power to the doctor than the patient. Nevertheless, the researcher, who was collecting the data is an experienced children palliative care provider and doctor with four years of experience in managing children and making them comfortable. The applicability of the results may be done in most settings with the similar demographics,especially in Sub-Saharan Africa. Affluent societies may not experience the similar challenges especially on the social dimension of the findings.

Another limitation of this study is interviewing children from the age of 8. This study may miss out on the experiences of children with cardiac disease who may not live up to 8 years. Nevertheless, a child who is able to provide insight into their disease condition can relate also to what has been happening even years before they were 8 years old. The choice of the age of the participants is in itself a limitation as the study has ended up self-selecting for Rheumatic heart disease. Most of the children with congenital heart disease may have been missed as many of them would not survive to 8 years in the setting of the study.

Interviewing 12 children only was another limitation of this study. Nevertheless, saturation of the data had been reached as there were no new themes being explored from the conversations as the same themes kept on coming up repeatedly. The length of the interview per participant was also limited. The maximum of time was 25 minutes and minimum of 18 minutes. Since these children had come for their periodic clinic review, and were expected to be seen by a cardiac doctor, the researcher had to restrict the time so that the children could also spend time with their doctors and get home in time.

The study was done in the month of December, which is rainy season in Malawi. Those that came to the clinic during this period were those who stayed in places where the rains do not cause transportation challenges. This brings in a limitation in the type of participants that could be recruited. Though this is not verified, it is worth mentioning.

Since the study is done in Malawi, a resource-poor nation, the burden of symptoms may be overestimated due to other factors connected to poverty. The same may be different in resource-rich populations.

8. CONCLUSIONS AND RECOMMENDATIONS

This is the first study to look at the symptom burden in paediatric cardiac disease in an African setting. Symptoms reviewed were not just physical, but clearly demonstrated the impact that living with a chronic cardiac condition has on the child's whole being, including relationships, schooling, family- life and faith.

Physical symptom burden was high with 100% of the participants reporting pain and 58% breathlessness. Only 2 out of 12 of the participants were prescribed analgesics and there was no morphine prescribed for breathlessness.

This study looked at the symptom burden of children who are seen at the cardiac clinic from the ages of 8 years to 18 years. The study was conducted at QECH in Blantyre city in Malawi. Literature findings have documented paediatric cardiac symptoms mainly from the physical point of view. Apart from physical symptoms, this study examines social interactions, spiritual relationships and psychological symptom burden in the children with cardiac disease in an African setting.

The study participants came from a wide background and from different districts of the southern region of Malawi with one from Ntcheu district in the central region of Malawi.

There was wide understanding of the issues that they participants face on a day to day basis. Living with the cardiac disease means constantly living with a good number of physical symptoms that range from pain, breathlessness and lack of sleep. All participants exhibited a level of knowledge when it comes to the copingstrategies for the challenges that they face due to the disease.

Social challenges that are compounded by the burden of symptoms of the cardiac disease and general household poverty were isolated from the participants. Family life and school attendance formed a backbone of what constitutes a social life. The interplay between the family, school and the disease itself creates either an enabling environment for learning and development or creates a challenging environment for learning and development. A loving and caring home and the school authorities that understand the cardiac disease provided comfort and support while the hostile homes and schools that were not well informed created an unpredictable conflict zone which played negatively on the overall disease management.

The social system proved supportive where family break-up was seen through divorce or death of a parent. The role of the grandparents, the uncles and aunties were seen to provide the parental cover where one has no parents.

The sample in itself was small to make general conclusions about the population under study though certain themes kept reappearing confirming that there was a pattern that could identify with the population.

The following recommendations have been drawn from this study:

1. **For Cardiac Clinic**
    - Increased referrals from cardiac clinic to palliative care for children with cardiac disease. This recommendation is to create an enabling environment for a continuum of care and support for the family and the patient.
    - The Clinic should have a way of identifying those patients who are coming from a considerable distance so that they can be seen earlier to give time for them to travel back home in good time.
    - To develop a symptom inventory and palliative care management guidelines for children with cardiac disease.
    - Writing of reports to schools, with the consent of families. This will help schools to provide a conducive learning environment.

2. **For Family**
    - Guardians should be in constant communication with school authorities to find out how the child is doing in school
    - Promoting open discussion about disease as the child grows and possibility of forming parents support groups to help parents understand the issues with their children

3. **For School Authorities**
    - School teachers and authorities should learn more about the disease and how they can manage the child in case of emergency in school
    - School friends should be encouraged to accommodate the sick child in their school activities according to the flexibility of the sick child
    - Champion general awareness campaigns for cardiac disease in communities

4. **For Further research**
    - In-depth parents/guardian interviews to determine the level of symptom burden from the guardian perspective.
    - Barriers to successful implementation of corrective cardiac surgeries in Malawi.

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10. APPENDICES

APPENDIX 1 (a) – INFORMATION SHEET

INFORMATION SHEET (GUARDIANS)

SYMPTOM BURDEN OF PAEDIATRIC CARDIOLOGY OUTPATIENTS IN MALAWI; THE PATIENT PERSPECTIVE

Thank you for taking your time to read through this information sheet which is giving information about the study to be conducted by Dr Cornelius Huwa. The study forms part of his Master Degree in Palliative Medicine offered by the University of Cape Town in South Africa.

World health Organisation (WHO) has defined palliative care as a way of treating patients and their families together. This approach touches on all aspects of the patient who is suffering from a disease that has been declared by medical people as incurable or one that has prolonged burden. The treatment touches on the social, spiritual and psychological aspect of the both patient and family. WHO also recognises that children are a special group of people and their care must be given to them from the point of discovering the disease (diagnosis) regardless of whether or not they are receiving care aimed at acure for their problem.

This study has been considered to find out the extent of the burden of problems experienced by the children (symptoms) with heart problems (cardiac conditions) as seen at the cardiology clinic here at QECH. The study will examine the burden of the problems and try to establish whether the children are able to recognise and describe the problems being faced.

The researcher seeks to:

i) Conduct an interview with the child (patient). When the interview is done, the researcher will record the information as a way of learning more on how the patient has been progressing as described by the patient.

ii) Some information concerning the illness will also be taken from the health passport book. The number of previous admissions, exact name of the disease and other relevant information will be taken from the health passport book and the file if separate one exists.

If you agree to let your child/ward participate, you will be asked to sign a consent form, which shows that you have agreed to the review of the patient’s information and that you will let the child respond to the questions that will be asked.

The whole process is expected to take not more than 30 minutes of your time.

Be assured that all information gathered in this exercise will be kept safe and confidential. No one, other than the research team, will have access to your information or that of your child. Your names will not be disclosed at any point during or after the study.

You or child will be allowed to withdraw from the study at any point you feel like it and there will be no repercussions to you or your child under QECH care.

The distress protocol has been made available so that should there be any sign of distress, the child can get the necessary attention needed. Beatrice Man'ganda, a trained children palliative care nurse, with more than 8 years of experience in child care will take responsibility for any issues that may arise from the distress of the child during and or after the interview.

There is no procedure that involves injections or skin cutters to be carried (like drawing blood for samples etc) during this study.

The patients who may need attention to the doctor or referral to palliative care will be assisted. No material benefit to you or your child will be given by participating in this study. What the researcher expects is that the findings of this study would help to pave way for improvements in the care offered to these children in the near future.

The feedback or findings of the study will be made available to you if you so wish to get in touch and will also be made available to the management of QECH. These findings will also be presented at research meetings and conferences as a way of adding knowledge to the larger community. These findings may eventually be published in a medical journal so that the future generations may make reference to the same findings.

Contact details:

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APPENDIX 1 (b) – INFORMATION SHEET

INFORMATION SHEET (PATIENT)

SYMPTOM BURDEN OF PAEDIATRIC CARDIOLOGY OUT-PATIENTS IN MALAWI; THE PATIENT PERSPECTIVE

Thank you for taking your time to read through and or listened to this information sheet which tells you about the study to be conducted by Dr Cornelius Huwa. The study forms part of his Master Degree in Palliative Medicine offered by the University of Cape Town in South Africa.

World health Organisation (WHO) has defined palliative care as a way of treating patients and their families together. This approach touches on all aspects of the patient who is suffering from a disease that has been said by medical people as without treatment or one that has increased problems over a long period of time. The treatment of this kind does not aim at treating or removing the source of problems but helps to reduce the problems which are faced socially, spiritually and psychologically. Both family and patient are supported through this treatment approach. WHO also recognises that children are a special group of people and their care must be given to them from the point of discovering the disease (diagnosis) without looking at whether the person is receiving care aimed at treating the disease or not.

The questions in this study have been selected to find out how far these problems cause challenges in the children with heart problems (cardiac conditions) as seen at the cardiology clinic here at QECH. The study will try to establish the extent of suffering and see whether you are able to recognise these problems as they occur on you.

The researcher is looking to:

iii) Conduct an interview with you (the child and patient). The information will be recorded so that the researcher does not forget anything that is said in the interview. The questions will be the day to day questions.

iv) Some information will be taken from your health passport book and file.

If you agree to participate in this research, you will be asked to sign a consent form, which shows that you have agreed to the interview and review of your health information from your health passport.

The whole process is expected to take not more than 30 minutes of your time.

Be assured that all information gathered in this exercise will be kept safe and confidential. No one, other than the research team, will see or listen to the information being discussed. Your name will not be opened or disclosed at any point during or after the study to anyone.

You are allowed to withdraw from the study at any point you feel like it and there will be no problems to you in line with your usual care here at QECH.

A way of helping you with any distress or problems arising from the questions (distress) protocol has been put in place to make sure that you are protected from unnecessary stress that can come now or after the interview. Our palliative care Nurse by name of Beatrice Man'ganda, a trained children palliative care nurse, with more than 8 years of experience in child care will take responsibility for any issues that may arise from the distress. Beatrice is an experienced nurse and will help answer any other questions you may have.

There is no procedure that involves razors, injections or skin cutters to be carried (like drawing blood for samples etc) during this study.

Should you as the patient need attention to the doctor or referral to palliative care we will assist you to get to that help quickly. There is no special payment to you for participating in this study. What is expected is that the information collected will help us to understand the challenges that you and many other children with the similar disease go through. This may, in turn, help us to advise the hospital and other doctors in Malawi and all over the world on how they can help better.

The feedback or findings of the study will be made available to you if you so wish to get in touch and will also be made available to the management of QECH. These findings will also be presented at research meetings and conferences as a way of adding knowledge to the larger community. These findings may eventually be published in a medical journal so that the future generations may make reference to the same findings.

Contact details:

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APPENDIX 2 – CONSENT FORM

CONSENT FORM (GUARDIAN)

SYMPTOM BURDEN OF PAEDIATRIC CARDIOLOGY OUT-PATIENTS IN MALAWI; THE PATIENT AND GUARDIAN PERSPECTIVE

I confirm that I have read the study information or the study information has been explained to me and I have had an opportunity to ask questions.

1. I understand that my child's answers will remain confidential.
2. I understand that neither my and my child's name nor identity will be made public or shared with anyone outside the study team.
3. I understand and appreciate that my child's/ward's participation is voluntary and I and child are free to withdraw at any time during the study without giving any reason.
4. I understand that the child's participation or not participating in the study has no direct benefit or risk to the care my child/ward will receive from this hospital.
5. I understand that there will be no injections used or any skin cutting procedure done on me or my child during the process of the study.
6. I understand that the health passport of the child will be looked into and some information taken as part of the research.
7. I have been provided with a telephone number of a person to contact should I need to speak about any issues that may arise whilst I am going through this interview.
8. I agree to take part in this study.

____

Participant's name

_______________________ ______________________

Signature of Participant Date

____

Signature of Researcher

APPENDIX 3 – ASSENT FORM

ASSENT FORM (CHILD PARTICIPATING IN THE STUDY)

SYMPTOM BURDEN OF PAEDIATRIC CARDIOLOGY OUT-PATIENTS IN MALAWI; THE PATIENT PERSPECTIVE

I confirm that I have read the study information or the study information has been explained to me and I have had an opportunity to ask questions.

1. I understand that my answers will remain hidden from other people (confidential).
2. I understand that neither my name nor my identity will be made public or shared with anyone outside the study team.
3. I understand and appreciate that my participation is without force (voluntary) and I am free to withdraw at any time during the study without giving any reason.
4. I understand that my participation or not participating in the study has no direct benefit or risk to the care I will receive from this hospital.
5. I understand that there will be no needle or razor(invasive) procedure done on me during the process of the study.
6. I understand that some of theinformation will be taken from my health passport book.
7. I agree to take part in this study.

____

Participant’s name

________________________ ________________________

Signature of Participant Date

____

Signature of Researcher

Appendix 4 – DISTRESS PROTOCOL

DISTRESS PROTOCOL

SYMPTOM BURDEN OF PAEDIATRIC CARDIOLOGY OUT-PATIENTS IN MALAWI; THE PATIENT PERSPECTIVE

The following will be followed as and when any sign of distress in the research participants is noted:

1. The participants will be informed of the issues to be discussed in the interview
2. When a participant shows signs of distress, the interview will immediately be stopped
3. The interview may restart after some time or on another day when the distress has resolved
4. A nurse or social worker may be contacted, at the request of the interviewee or family to help with the problem at hand
5. If the patient/family feels the distress is too great to continue with the study, withdrawal from the study will be permitted without any further impact on the patient's care.
6. Confidentiality will be observed at all times with all information shared
7. Beatrice Mang'anda, a Children Palliative Care Nurse, with more than 8 years of experience as palliative care nurse and more than 20 years of experience as a community nurse will support any participant who will need help.
8. Beatrice's phone number is +265 888 529 639. She can be contacted anytime.

APPENDIX 5(a) – INFORMATION SHEET: CHICHEWA VERSION

(Chichewa Version of Information sheet)

NKHANI YOKHUDZA KAFUKUFUKU (KEPELEKEDWA KWA WOYANG'ANIRA MWANA)

(SYMPTOM BURDEN OF PAEDIATRIC CARDIOLOGY OUT-PATIENTS IN MALAWI; THE PATIENT PERSPECTIVE)

Tikukuthokozani potenganthawiyanukuwelengankhaniyokhudzakafukufukuyu amene akuchitikandiDr. Cornelius Huwa. A Cornelius Huwaakuchitakafukufukuyungatimbaliimodzi ya maphunziroawoa ukachenjedemdela la Palliative Care omweakuchitirakusukulu ya University of Cape Town mdzikolija la South Africa.

Oyang'anira za umoyo m'dziko lonse la pansi a World Health Organisation, pomasulira nkhani ya Paliyetivi Keya adanena motele: Palliative care ndi njira yomwe imapelekedwa kwa odwala matenda amgogona kapena osachizika kuti akhoze kuchepetsa mavuto ena omwe amabwera kaamba ka matendawa. Zoterezi zimachitika popewa kuzunzika kwa odwalayo komanso a pa banja lake pamene akhudzika ndi matendawa. Iwo amalimbikitsa kuzindikira zovutazi mwachangu, komanso kupeleka mankhwala oletsa ululu omwe umadza chifukwa cha ululu wa pathupi, ululu wa mmalingaliro komanso mmoyo wa uzimu wa munthu.

A bungwe la za umoyowa amazindikiranso kuti ana ndi anthu apaderadera amene ayenera kulandira thandizo lawo la palliative care angakhale kuti akulandiranso chithandizo chofuna kuchiza matendawa kapena ayi.

Kafukufukuyu wakhazikitsidwa kuti afufuze zovuta zomwe ana amene ali ndi nthenda ya mtima amakumana nawo m'moyo wawo wa tsiku ndi tsiku. Izi zichitika pufunsa mafunso kwa mwana odwalayo.. Mwanayu akuyenera kukhala yemwe amalandira chithandizo cha nthenda ya mtima pa chipatala cha Gulupu (Queen Elizabeth Central Hospital). Kafukufukuyu akufuna kupeza mavuto odza kaamba ka matendawa ndikupeza ngati anawa angathe kufotokoza bwino lomwe za mavutowa.

Kafukufukuyu akufuna kupeza zinthu izi:

i) Kufunsa mafunso kwa mwana ngati momwe akhalira macheza ofunika. Zokambiranazo zidzaikidwa malo osamalitsa ngati njira imodzi yophunzilira momwe odwalayo akuvutikira kapena kukhalira tsiku ndi tsiku.

ii) Zofufuza zina zidzatengedwa pa buku lakuchipatala kapena chikalata cha kuchipatala.

Ngati mudzavomera kuti mwana wanuyu akhale nawo mu kafukufukuyu, mudzafunsidwa kuti mu saine pa chikalata cha umboni kuti inuyo mwamvetsetsa zifukwa zokhalira mkafukufukuyu. Komanso umboniwu udzakhala wotilora ochita kafukufuku kufunsani mafunso omwe aikika kwa mwanayu.

Nkhani yafunsa mafunsoyi idzatenga mphindi makumi atatu basi.

Khalani wolimbikitsika kuti zonse zomwe tidzalankhulana zidzasungidwa mwa chinsisi. Palibe munthu wina kupatulako iwo ogwira ntchito mu kafukufukuyu amene adzawone kapena kumvetsera nkhani zimenezi. Dzina lanu kaya la mwana wanu silidzalembedwa pena paliponse komanso silidzatchulidwa paliponse mu nthawi yonse ya kafukufuku kapena kupambana apo.

Ngati mkatikati mwa zokambirana zathu inu mwafuna kusiya kupanga nawo kafukufukuyu, muli ndi ufulu kutelo. Ndipo simudzakakamizidwa kutenga mbali ina iliyonse. Palibe choopsa chilichonse chidzachitike ku moyo wanu kapena wa mwana wanu mukatelo. Pakakhala zovuta zina zomwe zadza kaamba kokhala nawo mu kafukufukuyu, mwanayu adzathandizidwa ndi a nesi odziwa bwino ntchito yawo, a Beatrice Man'ganda. Iwowa nambala yawo ya foni ndi +265 888 529 639.

Mu kafukufukuyu palibepo zobayana ma jekeseni kapena kutnega magazi antundu uliwonse.

Phindu lomwe mungayembekezere ndi lakuti pamene tidzawona kuti mwana wanu akufunika chithandizo chansangansanga, tidzathamanga kutelo. Palibe kulandira zina zosiyana ndi ena pokhala nawo mu kafukufukuyu. Ofufuzawa akuyembekeza kuti zotsatira za kafukufukuyu zidzathandiza kusintha mmene ana odwala matenda a mtima adzathandizidwira mtsogolomu.

Zotsatira za kafukufukuyu zidzapelekedwa kwa inu ngati mutafuna kudziwa mwa njira iliyonse. Zotsatirazinso zidzapelekedwa kwa akuluakulu a chipatala cha gulupu kuti ngati mpofunika kusintha zinthu zina, atero. Zotsatirazi zidzapelekedwanso ku mikumano ina ya anthu a ukachenjede wa kafukufuku. Chiyembekezo china ndi chakuti zotsatirazi zidzapelekedwe ndikusindikizidwa mmabuku okhudza kafukufuku kuti anthu obwera mtsogolo adzakhale akuphunzira zoterezi.

Mungatipeze bwanji?

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APPENDIX 5(b) – INFORMATION SHEET: CHICHEWA VERSION

(Chichewa Version of Information sheet)

NKHANI YOKHUDZA KAFUKUFUKU (KEPELEKEDWA KWA MWANA WODWALA)

(SYMPTOM BURDEN OF PAEDIATRIC CARDIOLOGY OUT-PATIENTS IN MALAWI; THE PATIENT PERSPECTIVE)

Tikukuthokozani potenganthawiyanukuwelengankhaniyokhudzakafukufukuyu amene akuchitikandiDr. Cornelius Huwa. A Cornelius Huwa akuchitakafukufukuyungatimbaliimodzi ya maphunziroawoa ukachenjedemdela la Palliative Care omweakuchitirakusukulu ya University of Cape Town mdzikolija la South Africa.

Oyang'anira za umoyo pa dziko lonse la pansi a World Health Organisation, pomasulira nkhani ya Paliyetivi Keya adanena motele: Palliative care ndi njira yomwe imapelekedwa kwa odwala matenda amgogona kapena osachizika kuti akhoze kuchepetsa mavuto ena omwe amabwera kaamba ka matendawa. Zoterezi zimachitika popewa kuzunzika kwa odwalayo komanso a pa banja lake pamene akhudzika ndi matendawa. Iwo amalimbikitsa kuzindikira zovutazi mwachangu, komanso kupeleka mankhwala oletsa ululu omwe umadza chifukwa cha ululu wa pathupi, ululu wa mmalingaliro komanso mmoyo wa uzimu wa munthu.

A bungwe la za umoyowa amazindikiranso kuti ana ndi anthu apaderadera amene ayenera kulandira thandizo lawo la palliative care angakhale kuti akulandiranso chithandizo chofuna kuchiza matendawa kapena ayi.

Kafukufukuyu wakhazikitsidwa kuti afufuze zovuta zomwe ana amene ali ndi nthenda ya mtima amakumana nawo m'moyo wawo wa tsiku ndi tsiku. Izi zichitika pufunsa mafunso kwa mwana odwalayo.. Mwanayu akuyenera kukhala yemwe amalandira chithandizo cha nthenda ya mtima pa chipatala cha Gulupu (Queen Elizabeth Central Hospital). Kafukufukuyu akufuna kupeza mavuto odza kaamba ka matendawa ndikupeza ngati anawa angathe kufotokoza bwino lomwe za mavutowa.

Kafukufukuyu akufuna kupeza zinthu izi:

iii) Kufunsa mafunso kwa iweyo ngati mwana za momwe ukukhalira ndi matenda ako. Zokambiranazo zidzaikidwa malo osamalitsa ngati njira imodzi yophunzilira momwe iwe umavutikira kapena kupewa kuvutika tsiku ndi tsiku.

iv) Zofufuza zina zidzatengedwa pa buku lakuchipatala kapena chikalata cha kuchipatala.

Ngati udzavomeleza kutenga nawo mbali mu kafukufukuyu, udzafunsidwa kuti usonyeze chivomelezo pa chikalata cha umboni kuti iweyo wamvetsetsa zifukwa zokhalira mkafukufukuyu. Komanso umboniwu udzakhala wotilora ochita kafukufuku kufunsani mafunso omwe aikika kwa iwe.

Nkhani yafunsa mafunsoyi idzatenga mphindi makumi atatu basi.

Khala wolimbikitsika kuti zonse zomwe tidzalankhulana zidzasungidwa mwa chinsisi. Palibe munthu wina kupatulako iwo ogwira ntchito mu kafukufukuyu amene adzawone kapena kumvetsera nkhani zimenezi. Dzina lako kaya la makolo ako silidzalembedwa pena paliponse komanso silidzatchulidwa paliponse mu nthawi yonse ya kafukufuku kapena kupambana apo.

Ngati mkatikati mwa zokambirana zathu inu mwafuna kusiya kupanga nawo kafukufukuyu, muli ndi ufulu kutelo. Ndipo simudzakakamizidwa kutenga mbali ina iliyonse. Palibe choopsa chilichonse chidzachitike ku moyo wako kapena wa makoro ako ukatero. Pakakhalanso mavuto ena amene adza chifukwa cha kukhala nawo mbali ya kafukufukuyu, mukhoza kulankhula ndi a Beatrice Man'ganda, omwe ndi a nesi a palliative care pachipatala cha gulupu. Iwo nambala yawo ya foni ndi +265 888 529 639.

Mu kafukufukuyu palibepo zobayana ndi ma jekeseni, ma lezala kapena kutenga magazi antundu uliwonse.

Phindu lomwe mungayembekezere ndi lakuti pamene tidzawona kuti ukufunika chithandizo chansangansanga, tidzathamanga kutelo. Palibe kulandira zina zosiyana ndi ena pokhala nawo mu kafukufukuyu. Ofufuzawa akuyembekeza kuti zotsatira za kafukufukuyu zidzathandiza kusintha mmene ana odwala matenda a mtima adzathandizidwira mtsogolomu.

Zotsatira za kafukufukuyu zidzapelekedwa kwa inu ngati mutafuna kudziwa mwa njira iliyonse. Zotsatirazinso zidzapelekedwa kwa akuluakulu a chipatala cha Gulupu kuti ngati mpofunika kusintha zinthu zina, atero. Zotsatirazi zidzapelekedwanso ku mikumano ina ya anthu a ukachenjede wa kafukufuku. Chiyembekezo china ndi chakuti zotsatirazi zidzapelekedwe ndikusindikizidwa mmabuku okhudza kafukufuku kuti anthu obwera mtsogolo adzakhale akuphunzira zoterezi.

Mungatipeze bwanji?

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APPENDIX 6 – CONSENT FORM CHICHEWA VERSION

(Chichewa version of Consent form)

CHIVOMELEZO CHOPANGA NAWO KAFUKUFUKU (KUCHOKERA KWA WODWAZIKA MWANA)

Ndikutsikimiza kutindawerengankhaniyokhuzakafukufukuyukapenenaandiwerengerandipondamva. Ndakhalanso ndimwayi wofunsa mafunso.

9. Ndamvetsetsa kuti mayankho a mwana wanga ndi achinsinsi
10. Ndamvetsetsa kuti dzina langa kapena la mwanayu kapena chizindikiro sizidzasindikizidwa pa malo okhalapo anthu ena kuti awerenge. Kupatulako iwo opanga kafukufukuyu.
11. Ndamvetsetsa komanso kuzindikira kuti kulowa mkafukufukuyu mkosakakamizidwa. Tikhoza kutuluka mkafukufukumo opanda vuto lililonse ine ndi mwanayu.
12. Ndamvetsetsanso kuti palibe chopindura chopatsidwa pamanja pamene ndidzatengapo mbali mu kafukufuku ameneyu. Komanso kuti palibe chowopseza chowoneka chilichonse cholunjika mwana kapena ine mwini pochita nawo kafukufuku ameneyu.
13. Ndamvetsetsa kuti sipadzakhala zogwilitsa ntchito ma jekeseni kapena kutenga magazi aliwonse kwa mwana wanga nkafukufukuyu.
14. Nda mvetsetsa kuti zofufza zina zidzatengedwa m'buku la kuchipatala la mwanayu.
15. Ndapatsidwa nambala ya lamya ya ochititsa kafukufukuyu kuti patakhala vuto lililonse ndingathe kuyimba foni yodandaula.
16. Ine ndavomera kutenga nawo mbali mu kafukufuku ameneyu.

____

Dzina la Otenga nawo mbali mu kafukufuku

________________________ ________________________

Saini ya otenga nawo mbali mu kafukufuku Tsiku

____

Saini ya ochita kafukufukuyu

APPENDIX 7 – ASSENT FORM CHICHEWA VERSION

CHIVOMEREZO CHA MWANA - KULOWA NKAFUKUFUKU

(SYMPTOM BURDEN OF PAEDIATRIC CARDIOLOGY OUT-PATIENTS IN MALAWI; THE PATIENT PERSPECTIVE)

Ndikutsikimiza kuti ndawerenga kapena kuti andiwerengera zonse zokhudza kafukufukuyu. Ndakhalanso ndi nthawi yofunsa komanso kuyankhidwa mafunso anga.

1. Ndamvetsetsa kuti mayankho anga adzasungidwa mwa chinsisi.
2. Ndamvetsetsa kuti dzina langa komanso zizindikiro zanga sizidzawonetsedwa kwa wina aliyense kupatula iwo amene akupanga kafukufukuyu.
3. Ndamvetsetsa komanso kuzindikira kuti kutenga nawo gawo nkaundulayu ndi chisankh changa osati mokakamizidwa ndipo ndili ndi ufulu kutulukamo nthawi iliyonse opanda kupeleka chifukwa.
4. Ndikumvetsetsanso kuti kutenga mbali kapena kusatenga mbali kulibe phindu la pa ine kapena chiwopsezo chilichonse cha pa in kuchokera ku chipatala chino cha gulupu.
5. Ndamvetsetsa kuti sipadzakhala kugwiritsa ntchito ma jekeseni kapena zobaya zilizonse pa thupi langa nkati mokhala nawo nkaundulayu.
6. Ndamvetsetsa kuti zina zokhudza matenda anga zidzatengedwa m'buku langa la ku chipatala.
7. Ine ndavomeleza kutenga nawo gawo nkaundulayu.

____

Dzina la otenga nawo mbali nkaundula

________________________ ________________________

Saini/Chidindo cha otenga nawo mbali nkaundula Tsiku

____

Saini ya Ochititsakafukufuku

APPENDIX 8 – THE SEMI-STRUCTURED INTERVIEW QUESTION GUIDE

QUESTION GUIDE

(SYMPTOM BURDEN OF PAEDIATRIC CARDIOLOGY OUT-PATIENTS IN MALAWI; THE PATIENT PERSPECTIVE)

Introduction

This is a qualitative study which is set to interview children of 8 years and above up to 18 years old. The information about the study has been made available in the information sheet provided (appendix 1(a) and 1(b).

Beginning

1. Setting the room, interviewer and research assistant inviting the potential participants in, greetings
2. Introduction of the interviewer – (Dr Cornelius Huwa, palliative care doctor)
3. Talking more about the information sheet for guardian and for thechild. Answering any questions
4. Talking about the distress protocol and how the patient will be able to use the set protocol (Beatrice Man'ganda, children palliative care nurse to be responsible for distressed child when need arise)
5. Signing of consent form
6. Signing of assent form
7. Starting interview with demographic questionnaire (appendix 9)

Physical

1. Have you had pain lately due to your heart problem? (probe – when and where exactly in the body? How often and when is it more prominent, night or day or same? What worsens the pain, movement, sleep or none?
2. Other problems? (breathlessness, diarrhoea, cough) explain more. How often? How do you make the breathlessness or any other problem go away?
3. Feeding problems? (specify… appetite, food availability, vomiting, choking, getting tired when eating…?
4. Sleep problems? Probe…… possible sleep disturbances, waking up in the middle of thenight with breathlessness or pain ….?

Social

1. School – missed classes (Why ?….probe – how many times in a normal school week would class be missed due to illness?
2. Do you talk to the teacher, friends or anyone else at school about your problem? Who is a close confidant at school in terms of illness..?
3. How has to live with a heart condition affected you socially? School, church, friends etc? Probe – how do you cope with such problems at school, church/religious meeting place and when with friends…?
4. How has to live with a heart condition affected your family? Probe – are parents/guardians worried, family members talking about it to friends etc..?
5. Who stays with you at home? An adult, older or younger sibling?
6. Playing and mixing with siblings…Who do you like staying around with among your family members? And why do you like those?

Psychological

1. What kind of things do you think about when you think about your heart condition?
2. Have you been worried lately? Explain what makes you worry.
3. Have you had feelings of depression lately?
4. **Has your condition changed your feelings toward your family? The way you chat or interact with them?**
5. **Do you experience any distress? How do you cope or deal with thedistress of any kind when it occurs?**

Spiritual

1. **Do you have any religious affiliation? If yes what religion is that?**
2. **Does your religion/belief help you cope with your current illness?**
3. **Has the illness affected your beliefs?**
4. **Do you have any cultural belief that may be helping you cope with illness or make the situation worse?**
5. **How has to live with a heart condition affected your faith and beliefs? Probe..**

APPENDIX 9 – DEMOGRAPHIC DATA COLLECTION SHEET

(SYMPTOM BURDEN OF PAEDIATRIC CARDIOLOGY OUT-PATIENTS IN MALAWI; THE PATIENT PERSPECTIVE)

Study Number:

Age:

Sex:

Tribe:

Place of stay:

School Class:

Religion/Belief:

APPENDIX 10 -HEALTH PASSPORT BOOK INFORMATION DATA COLLECTION SHEET

From Health Passport book and or file

Study Number: ……………………….

Diagnosis:

1. **Date made**
2. **Investigations done**
3. **Investigations not done**

Management

1. **Current medication**
2. **Any other interventions**
3. **Planned intervention but not undertaken**

Previous hospital admissions

1. **How many admissions in last one year?**
2. **Diagnoses on each admission**
3. **Where was anadmission (Central, district/mission hospital or health centre)?**

Any other matters to note:

APPENDIX 11 - REQUEST LETTER OF PERMISSION TO CONDUCT STUDY

Head Of Paediatric Department
Queen Elizabeth Central Hospital
P.O. Box 95
Blantyre
Malawi

21stMarch 2016

Dr Cornelius Huwa
University of Cape Town
Faculty of Family Medicine
C/O Palliative Care Support Trust
P.O. Box 32625
Chichiri, Blantyre 3

Dear Sir

SYMPTOM BURDEN OF PAEDIATRIC CARDIOLOGY PATIENTS IN MALAWI: THE PATIENT PERSPECTIVE

I am writing to request your office to grant me permission to conduct the study entitled "Symptom burden of paediatric cardiology patients in Malawi: Patient perspective" at Queen Elizabeth Central Hospital. The study is being conducted as part of my fulfilment of a master of Philosophy in Palliative Medicine being undertaken at the University of Cape Town.

The Study will be a qualitative study with semi-structured interviews being conducted on children with theconfirmed cardiac disease being seen at theCardiacclinic within paediatricoutpatients clinics. These patients will be from the age of 8 years to 18 years. I have planned to interview at most 10 patients.

The recruitment will be taking place on the day of clinics and expect the interview to take not more than 30 minutes of the patients time.

My study supervisors are Dr Michelle Meiring (UCT) and Dr Jane Bates (CoM).

I have attached the study protocol as presented to University of Cape Town health Ethics Committee and College of Medicine Research and Ethics Committee (COMREC).

Yours Faithfully

Signed by candidate

Signature removed

Dr Cornelius Huwa (Student)

Cc: UCT’s Human Research Ethics Committee (HREC)
College of Medicine Research and Ethics Committee (COMREC)

APPENDIX 12 – LETTER FROM HUMAN RESEARCH ETHICS (UCT)

UNIVERSITY OF CAPE TOWN
Faculty of Health Sciences
Human Research Ethics Committee

Room E53-46 Old Main Building
Groote Schuur Hospital
Observatory 7925
Telephone [021] 406 6492
Email: sumayah.ariefdien@uct.ac.za
Website www.health.uct.ac.za/fhs/research/humanethics/forms

12 October 2016

HREC REF: 594/2016

Dr M Meiring
Division of Palliative Medicine
C/o Naomi Fray
Level 2, Rm2.23, Entrance 5
Falmouth Building FHS

Dear Dr Meiring

PROJECT TITLE: SYMPTOM BURDEN OF PAEDIATRIC CARDIOLOGY OUT-PATIENTS IN MALAWI: THE PATIENT PERSPECTIVE (MPhil-candidate- Dr C Huwa)

Thank you for submitting your study to the Faculty of Health Sciences Human Research Ethics Committee (HREC) for review.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

Approval is granted for one year until the 30 October 2017.

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.
(Forms can be found on our website: www.health.uct.ac.za/fhs/research/humanethics/forms)

Please quote the HREC REF in all your correspondence.

We acknowledge that the student; Dr C Huwa will also be involved in this study.

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval before the research may occur.

Yours sincerely

Signed

PROFESSOR M BLOCKMAN
CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE

Federal Wide Assurance Number: FWA00001637.

HREC 594/2016

APPENDIX 13 – APPROVAL CERTIFICATE FROM COMREC (MW)

CERTIFICATE OF ETHICS APPROVAL

This is to certify that the College of Medicine Research and Ethics Committee (COMREC) has reviewed and approved a study entitled:

P.05/16/1947 – Symptom burden of paediatric cardiology out-patients in Malawi: The patient perspective by Dr. C. Huwa

On 24th June 2016

As you proceed with the implementation of your study, we would like you to adhere to international ethical guidelines, national guidelines and all requirements by COMREC as indicated on the next page

Signed

Dr.C. Dzamalala Chairperson (COMREC)

Approved by
College of Medicine
(COMREC)

24th June 2016
Date