



Kamuzu College of Nursing

**EXPERIENCES OF CAREGIVERS OF CHILDREN RECEIVING
PALLIATIVE CARE AT MZUZU CENTRAL HOSPITAL, MALAWI**

By

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**A Research Dissertation Submitted to the Faculty of Nursing in Partial Fulfilment
of the Requirements for the Award of the Masters of Science Degree in Child Health
Nursing**

DECEMBER, 2015

Declaration

I, Bertha Mwandida Chaputula, hereby declare that this study is a true reflection of my own work, and has not been submitted for a degree at any other institution of higher learning. Acknowledgement has been done where other people's work has been used.

Bertha Mwandida Chaputula

.....

Signature

.....

Date

Certificate of Approval

We, the undersigned, hereby certify that this study is Bertha Mwandida Chaputula's own work and effort, and has been submitted with our approval.

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Dedication

This dissertation is dedicated to my husband, Aubrey, for his love, encouragement, support and contributions. To my children, Brian and Dalitso, for persevering during my absence from home, and to all my wonderful family members for being there for me.

Acknowledgement

I would like to express my deepest appreciation to the main supervisor, Professor Ellen Chirwa, for the strong support, quick feedback and contributions. All her encouragement provided valuable experience to me throughout the process of coming up with this thesis. I would also like to thank Mrs Lucy Kachapila, the second supervisor, for her support.

I extend my special thanks to Mrs Jeany Chawinga, the palliative care nurse provider at Mzuzu Central Hospital, for her warm welcome and assistance in identifying participants for the study.

I would also like to thank the study participants for their time and information for without them the study could not have been possible. More thanks should go to all library staff of Kamuzu College of Nursing, Blantyre Campus, for their untiring support.

Abstract

The number of children with life threatening and limiting illnesses requiring children palliative care is increasing each and every year. In response to the rising number of children requiring palliative care, family involvement in care giving has expanded. Caregivers play a major role in caring for children with life-limiting or threatening illnesses on palliative care at home as well as in hospital. However, for them to adequately provide the care, they require adequate support. This study reports on the caregivers' experiences of caring for children receiving palliative care at Mzuzu Central Hospital Palliative Care Clinic. The study was aimed at exploring the caregivers' experiences of caring for children receiving palliative care. A descriptive qualitative research method was used. The target group was caregivers of children with life threatening or limiting illnesses receiving palliative care at the clinic. A total of 30 caregivers were recruited for the study using purposive sampling technique. Qualitative data was collected using semi-structured interview guide for in-depth interviews and a tape recorder while analysis was done using thematic analysis. Findings revealed that caregivers play a major role in caring for their children receiving palliative care. They provide assistance with activities of daily living and health care management in addition to their usual daily chores. The needs of the children receiving palliative care included transportation, finances, information, health care and daily needs. Family members and community members formed part of the caregivers' support systems. Caregivers of children receiving palliative care reported facing financial, social, physical,

and psychological and health service challenges. Proper assessment and availability of adequate support would positively influence the caregiver's experiences of caregiving and the child's quality of life. Hence, there is need to develop practical interventions that will lessen the caregivers' challenges.

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List of acronyms and abbreviation

AIDS	Acquired Immune Deficiency Syndrome
APCA	Association of Palliative Care in Africa
COMREC	College of Medicine Research and Ethics Committee
HIV	Human Immune-deficiency Virus
PACAM	Palliative Care Association of Malawi
PPC	Paediatric Palliative care
UNAIDS	Joint United Nations Programme on HIV/AIDS.
WHO	World Health Organisation
PC	Palliative Care

Operational definitions

Child: Any person below the age of 18.

Caregiver: Any person or family member who assists with the general care of the sick child.

Caring: Provision of what is necessary for health, welfare maintenance and protection.

Experiences: Something personally encountered or lived through.

Palliative care provider: Health professionals who have been trained to provide palliative care services.

Life threatening illness: Illness in which curative treatment is feasible but can fail, such as cancer.

Life limiting illness: An illness in which there is no hope for cure and gives limits on a child's quality of life.

CHAPTER ONE

INTRODUCTION AND BACKGROUND

Introduction

The number of children with life threatening and limiting illnesses requiring children palliative care is increasing each and every year. Palliative care for children has been defined by World Health Organization as “the active total care of the child's body, mind and spirit which also involves giving support to the family,” and begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease (Benin, Spizzichino, Trapanotto, & Ferrante, 2008). Diseases that require palliative care in children include cancer, cardiovascular diseases, congenital anomalies, neurological disorders, neonatal conditions such as spinal bifida, hydrocephalus, extreme prematurity and HIV and AIDS (Conor & Bermedo, 2014). However, HIV and AIDS and Cancer are the major conditions that have increased the need for palliative care (Amery, 2009).

Globally, it is estimated that 1.2 million children are in need of palliative care (Conor & Bermedo, 2014). Each year, approximately 166,000 children under the age of 15 are diagnosed with cancer worldwide. By 2030, the developing world is expected to bear 70% of the global cancer burden (Harding, Sherr, & Albertyn, 2010). Joint United Nations Programme HIV/AIDS [UNAIDS] report on the global AIDS epidemic (2012) indicates that an estimated 3.1 million children under the age of 15 were living with HIV:

350,000 were newly infected, and 230,000 had died of HIV and AIDS in Sub-Saharan Africa in 2010. According to the World Health Organisation [WHO] 2008 report, HIV and AIDS was the leading cause of deaths among children below the age of five in six Sub-Saharan African countries. These include Botswana, Lesotho, Kenya, Zambia, Zimbabwe and Malawi.

In Malawi, heart conditions, the HIV/AIDS pandemic and the spread of cancer have increased the need for children palliative care (Palliative Care Association of Malawi[PACAM], 2012). A total of 18,946 new cases of cancer were registered in Malawi from 2007-2010. Out of these cases, 55.9% were females, 7.2% were children aged less than 15 years, and 76.5% were adults aged 15-59 years (Malawi Cancer Registry, 2010). There is an estimated 930,000 children living with HIV in Malawi (UNAIDS, 2011). Statistics at Queen Elizabeth Central Hospital Umodzi Palliative Care shows that 367 children were enrolled for palliative care from January 2013 to mid-May 2014. This high incidence indicates the extent at which children palliative care is needed, and will potentially be needed for all of these children.

In response to the rising numbers of children requiring palliative care, family involvement in care giving has expanded. A caregiver is any person or relative who voluntarily assists with the general care of the sick child. Caregivers of children with life threatening or limiting illnesses take care of their children in the home and continuously come to the hospital for medical reviews. Caregivers are central to the care that a child with life-limiting illness may receive at home or in the health care setting regardless of diagnosis or prognosis. Many life limiting conditions experienced by children are extremely rare, and while diagnosed in childhood, they may survive into early adulthood

(Malcom, Forbat, Knighting, & Kearney, 2008). The duration of palliative care in a child is hard to predict. In some cases, such as congenital diseases, it is mostly limited to the early years of life. In others, it may be needed for far longer such as neurological, cardiological and autoimmune diseases, whilst in others it may be concentrated in a brief period before death (Benin et al., 2008) hence, bringing up children who are receiving palliative care is a lifelong responsibility that needs support and encouragement.

Caregivers are significant in the well-being and quality of life of the children receiving palliative care. They are a source of support to the child because they are the ones who spend more time with the child than the palliative care providers. Fisher, Briggs and Carers Association of Australia said that caregivers manage and coordinate medical care, administer medication, assist with personal care and provide emotional support (cited in Gigis, Lamberts, Johnson, Waller, & Currow, 2013). They also provide expenses that are needed to access professional help (Mawani, et al., 2013).

To ensure that they are providing adequate care for the health and wellbeing of the child and to maintain their functioning and wellbeing, palliative care providers need to provide attention to the caregivers' needs for information, resources and support. According to a study by Rodriguez and King (2009), caregivers go through a full emotional struggle which involves the inner drive, feeling responsible, psychological effects, threatened self- image, social withdraw and fear of death. Provision of emotional, psychological and social support is inadequate, and from experience, it has been observed that minimal or no attention is given to caregivers as palliative care providers mostly focus on the problems of the child. This arises due to shortage of staff which contributes to inadequate contact time for the caregiver and the palliative care provider.

Most facilities in Malawi provide in-patient, out-patient and home-based palliative care services. Children once diagnosed, depending on the condition, may be admitted for stabilisation. Caregivers are counselled on the child's condition, and are registered for palliative care services in which they are expected to come back with the child every month for medical follow-up. However, some caregivers default follow-up care, and are no longer traced. In a study conducted by Sitaesmi, Mostert, Schook, and Veerman (2010) which was aimed at analysing parents' reasons for abandoning treatment, it was found that transportation and financial constraints were not the main reasons for abandoning care but they were not satisfied with the health care providers. This shows the need to understand the caregivers' unmet needs. Many of them experience a lot of challenges with respect to their physical, psychological well-being, economic circumstances, social and personal relationships (Gilgis, et al., 2013). Hence palliative care providers need to support them directly or by referring them to appropriate services to ensure that their needs are met.

Background

Children palliative care is a newly formed sub-specialty of medicine that focuses on achieving the best possible quality of life for children with life-threatening conditions and their families (Liben, Papadatou, & Wolfe, 2008). The concept of palliative care originally evolved from the hospice philosophy of meeting gaps in care for seriously ill and dying patients (Morgan, 2009). During the second half of the century, Fabiola opened a hospice for pilgrims and the sick which was being used for the dying, and later became hospitals. According to Ministry of Health (2011), Jean Garnier was the first person to open a hospice for the dying in 1842 after losing her two children in France. In 1897 and

1905 the Irish Sisters of Charity started hospice for the dying at Dublin and St Joseph hospice in London. In 1957, St Christopher Hospice in London was established by Cicely Saunders. It was research and training at this hospice that led to the hospice and home care teams in United Kingdom, Canada, Europe and United States. In 1967, Cicely Saunders also set up a modern hospice movement which is being practiced worldwide. In 1982, the first children's hospice Centre opened in England (Foster, 2007).

In the Sub-Saharan Region, the first hospice started in Harare, Zimbabwe in 1979, South Africa in 1980, Nairobi in 1990 and Uganda in 1993 as a role model hospice for Africa palliative care services. In Malawi, Palliative care was unknown until Dr. Anne Merrium visited the country and introduced the concept in 2002. The first palliative care team was set up in Paediatric Department at Queen Elizabeth Central Hospital.

Gradually, the concept was grasped and embraced in HIV and AIDS care and treatment. Palliative care providers studied for post-graduate qualifications, health care workers gained extra skills, and national voice for stakeholders was established in 2005 (Mackriel & Hunt, 2008). Thereafter, palliative care services in Malawi were significantly increased. In 2010, 25 sites were recognised as palliative care providers by Ministry of Health which consisted government and private facilities, and were delivering different components of care with varying levels of resources, medication and training (Mackriel, 2011). According to PACAM (2012) the sites include Light House, Kamuzu Central Hospital and Nkhoma in Lilongwe, Ndi Moyo in Salima, St Gabriel in Namitete, Dowa, Ntchisi and Nkhotakota District Hospitals. All these sites are in the Central Region. Palliative care centres in the Southern Region are located in Bangwe, Tiyanjane and Umodzi in Blantyre, Mulanje Mission Hospital, Mwanza, Machinga and Zomba Central

Hospital whilst in the North the centres are located at Ekwendeni Mission Hospital, Mzimba District Hospital and Mzuzu Central Hospital.

Previously, the lives of many children with life-threatening and terminal illnesses were dominated with pain, severe sickness and hopelessness (Grant, Brown, Leng, Bettega, & Murray, 2011). Children were being referred to a tertiary hospital for assessment and treatment as general medical patients. Treatment was also being sought from traditional healers, and in case of treatment failure, children were being supported in the communities. According to Israels, Ribeiro, and Molyneux (2010) management of terminal diseases faced the challenges of late presentation and misdiagnosis such that children presented with advanced stage disease. Currently children with terminal diseases need to be adequately palliated.

For many years, palliative care was not offered to paediatric patients, and even today, only a minority of children with incurable conditions benefits from palliative care services. Many Malawian children requiring palliative care die without receiving proper care, mostly in the hospital setting within the care and support of their family. The 2011 survey by Palliative Care Association of Malawi revealed that children are neglected, and do not receive the intended holistic care due to inadequate trained and confident professionals to provide palliative care to children, limited knowledge, availability and use of palliative care drugs for children which affects the control of pain and other distressing symptoms (PACAM, 2012).

Challenges in providing children palliative care in Malawi represent those of many other African countries which are high child morbidity and mortality, and poor availability and accessibility of health services. Despite the challenges, children palliative

care is just developing in Malawi. There is Umodzi Children's Palliative Care based at Queen Elizabeth Central Hospital in the southern part of Malawi which pioneered the development of children palliative care. The services have also been introduced at Zomba, Kamuzu and Mzuzu Central hospitals and other district hospitals with support from the Palliative Care Association of Malawi (PACAM). Paediatric palliative care is concerned with the medical, psychosocial, spiritual and economic needs of patients and their families from hospital to community and home, and it involves an interdisciplinary team of caregivers (Benin, et al., 2008).

The care for children with life limiting and life threatening conditions has moved from hospital-based to family or community-based role. In hospital, care is being delivered through specialised clinics. Improvements in medical technology and as a way of reducing congestion in hospital wards, children with life limiting and threatening conditions are being managed in the community (Rodrigue & King, 2008). Most children are looked after by their family members. Family caregivers provide support to children that extend across physical, psychological, emotional and spiritual support. According to Nicholl and Begley (2012), caregivers meet the needs of their children which involve feeding, mobility, personal hygiene, bladder and bowel management, ongoing care related to symptom management, the promotion of wellness and management of progressive deterioration.

The role of caregivers continually changes depending on the child's condition since other children rely solely on the caregiver for all personal needs where as others can render children completely dependent on their caregiver for communication and mobility. Thus being a parent of a child with life limiting or threatening illness carries with it a

significant burden. Parents may make adjustments in their lives that have a broader effect, and touch every member of the family, for instance, change of employment. The environment of care can have a profound impact on the caregiving experiences of families caring for their child (Penlod, Baney, Loeb, Peggy, & Shipley, 2012). Hence, healthcare professionals need to come up with interventions and a model for family caregiving that is directly applicable to understanding the family caregiver experiences so that they should be applying a suitable framework for guiding their decisions of care (Hudson, Arandam, & Kristjanson, 2004). In Malawi, there is an information gap on what caregivers of children who are on palliative care go through as they provide care to their children at home and in hospital. Therefore, there is need to understand the caregivers' experiences in order to come up with interventions that will provide adequate care, support and meet their needs.

Background of the study site (Mzuzu Central Hospital)

Mzuzu Central Hospital is a government funded referral hospital located in Mzuzu city in the northern part of Malawi. The hospital is located at a walking distance to some caregivers while others use public transport. It provides secondary and tertiary services to patients and clients within Mzuzu City and all districts in the region. The services provided include children palliative care services which started in November 2011 with support from PACAM. It operates at no fee as an outpatient clinic but children who are very ill are admitted in the paediatric ward for stabilisation. The clinic provides palliative care services to children with sickle cell disease, cerebral palsy, rheumatic heart disease and various types of cancers which are some of the conditions that constitute children palliative care.

Currently, the clinic has an enrolment of 211 children with life threatening and limiting illnesses. Out of this number, 124 stay within Mzuzu City, 22 come from Nkhatabay, 13 from Mzimba, 38 from Erukweni, Ekwendeni, Mpherembe and Enyezini, and 9 from Karonga, 4 from Rumpi and 1 whose place of residence was not documented (Clinic Register, January 2014). Caregivers have a 1 to 2 monthly role of taking the child to the clinic for review. The palliative care services are provided by nurses and clinicians who are trained in children palliative care. Services offered involve counselling of caregivers and patients, assessment and management of patient's symptoms on their monthly review visits and follow up of in-patients and out-patients who fail to come for the clinics for a long time. Home follow-ups are rarely done due to inadequate financial resources and shortage of staff. They also facilitate teen club meetings where children and their guardians meet for updates.

Statement of the problem

Palliative care is provided alongside treatment that is aimed at prolonging life and cure (Association of Palliative Care in African, 2010). Children who receive palliative care services and their families need continuous clinical reviews and care, and may need palliative services for months or years in order to improve their quality of life which is the main goal of children palliative care. To achieve this goal, guidelines for comprehensive palliative care services delivery include access to care in which the patients and their families accesses holistic palliative care which aims at meeting their physical, psychosocial and spiritual needs within their cultural context (National Palliative Care Guidelines, 2011). The need to support caregivers who care for a patient

requiring palliative care have been emphasized in the national guidelines as well as the APCA standards.

Despite the emphasis on the need to support caregivers in Malawi, there is scarcity of information on the physical, psychosocial, spiritual, emotional needs and concerns of the caregivers as they provide long term care within the home. According to Mok, Chan, Chan, and Yeung (2003) caregivers are faced with the physical challenges of direct care such as activities of daily living, preparation of treatment and medication regimes, accompanying patient for follow-ups and transportation. Emotional challenges such as dealing with concerns of patient and own distress and psychological challenges such as anxiety, fatigue depression and reduced self-esteem. Unfortunately, such challenges and unmet needs create a gap in the provision of children palliative care which affects the caregivers' compliance to the services. This compromises the care and affects the quality of life of the child. Therefore, there is need to explore caregivers' experiences because this information will assist in devising measures that will help to improve care of caregivers, quality care for these children, the existing guidelines and the policy that is being developed.

Justification of the study

Most parents of children with life limiting or threatening illnesses take part in the care of their children. However, these parents have their own experiences in caregiving and responses to patients' diagnosis and prognosis, and may require coaching and emotional support for them to maintain their wellbeing and their role as a caregiver. This study will give information on what caregivers encounter when caring for children with

life threatening and limiting illnesses on palliative care, and how they can be supported in order to provide adequate care to their children. The findings from the study will assist palliative care providers in developing tools for providing care and understanding caregivers.

Children palliative care is a new concept being advocated for in Malawi hence the researcher did not find any study conducted to explore the experiences of parents of children with life limiting or threatening condition. This study will contribute to knowledge in the fields of paediatric palliative care, family care giving, nursing education, practice and research. Furthermore, the study will also provide an insight in the palliative care services provided at Mzuzu Central Hospital, and the recommendations made may help to improve service delivery.

Objectives of the study

Broad objective

To explore the caregivers' experiences of caring for a child with life limiting or threatening condition receiving palliative care at Mzuzu Central Hospital.

Specific objectives

1. To describe the role of caregivers in caring for children who are on palliative care.
2. To explore the care needs of children with life threatening or limiting illnesses when they are at home.
3. To assess the support services that are provided to caregivers and children within their community.

4. To describe the challenges that caregivers' face while caring for children who are on palliative care.

Conclusion

This chapter described palliative care and the prevalence of children with life-limiting and threatening conditions requiring palliative care. It has also stated the aims of the study, study problem, objectives and justification for the study. Literature shows that the care of children with life-limiting and threatening conditions requiring palliative care has moved from hospital-based to family-based role. Care is now being provided through palliative care clinics, hence, children requiring palliative care are being managed in their homes by family members who assume the caregiving role and are taken to hospitals on a monthly basis for follow up care. Despite the emphasis on the need to support caregivers, in Malawi, there is scarcity of information on the physical, psychosocial, spiritual, emotional needs and concerns of the caregivers as they provide long term care within the home. Therefore, there is need to explore caregivers' experiences because this information will assist in devising measures that will help to improve care of caregivers, quality care for these children, the existing guidelines, and the policy.

CHAPTER TWO

LITERATURE REVIEW

Introduction

This section aims at describing and understanding thoroughly the studies that explored the experiences of caregivers of children with life limiting illnesses receiving palliative care. A variety of sources were reviewed which included journal articles, government publications, and books as well as policy documents. Review of literature in this chapter has been organized in accordance with the study objectives. The review covers the roles of caregivers in the care of children receiving palliative care, the existing support system, the care needs of children requiring palliative care, and the challenges that caregivers encounter while caring for their children. Literature search was done through various academic databases (EBSCOHOST, CINAHL, PUBMED and MEDLINE) in order to find out what is known about caring for a child who is on palliative care.

The search was done by running search words on the academic databases and the criteria for the academic search engines were based on the nursing, medical and scientific journals. The literature review focused on studies that were done in 2005 to 2014, however few relevant studies done before 2005 were incorporated. This was done to ensure that relevant and current literature was reviewed and also to offer good overview of the research that has been done so that the relevance of the present study can be

determined. The search words used included, paediatric OR children OR child* AND palliative care, children palliative care AND life-limiting or threatening illnesses, caregiver OR guardians experiences of caregiving, informal caregiving, caregiving role, caregiver supportive care ,in hospital and home caregiving, caregiver challenges and coping mechanisms, and palliative care.

Roles of caregivers in the care of children receiving palliative care

Caregivers are essential in healthcare systems as they collaborate with healthcare providers in the care provision. They have a major responsibility of providing care to children who are on palliative care. Caregivers provide the majority of physical, emotional and psychological support for individuals with life-threatening and limiting conditions at home as well as in hospital (Joad, Mayamol, & Chaturvedi, 2011; Skilbeck et al., 2005). Studies on in-hospital caregiving have been done mostly in developed countries. In the USA, Morrow-Howell and Proctor (1998) conducted a study at a Geropsychiatric unit of a large urban hospital in which in-hospital medical information was collected from medical records, and telephone interviews with 45 older adults with depression were done. Another quantitative study was conducted by Sapountzi- Krepia et al. (2008) in Greece in which a 30 item questionnaire was used to collect data from 140 nurses at a Greek oncology hospital. Despite the two studies being done in two different settings (USA and Greece) and within a ten year difference, they both revealed that the majority of the patients had the assistance of the caregivers, and agreed on the importance of informal caregivers in the provision of care.

Studies on in-hospital caregiving are scarce in Malawi. The researcher only came across one study which was done by Hoffman et al. (2012) at Kamuzu Central Hospital in

which seventy three qualitative surveys and nineteen in depth interviews with hospital administrators, guardians, physicians and nurses were done. The findings of this study were consistent with those made in studies done by Morrow-Howell and Proctor (1998) and Sapountzi- Krepia et al. (2008) in that, caregivers were all relatives of the patients who performed a wide range of daily tasks in patient care from wound dressing to advocacy.

Similarly, other studies conducted focusing on the caregiving role done in the home setting indicates that caregivers provide most of the care. For instance, Lindsey, Hirschfeld, Tlous, and Neube (2003) conducted an exploratory, descriptive and qualitative study that investigated the experiences of young girls and older women caring for family members with HIV and AIDS, and other chronic and terminal illnesses at home in three districts of Botswana. Seventy (70) interviews with family caregivers, community home-based care team and government officials were conducted. Findings also revealed that the majority of the care was provided by relatives that included older women who reported feeling overwhelmed with the magnitude and loads of tasks which they had to perform. In addition, a Statistics Canada (2012) report indicated that over 8 million informal caregivers provide care to family members or friends with chronic conditions, disabilities, and other health needs in their home setting in Canada whereas the National Alliance for Caregiving (2009) report revealed that 65.7 million people have served as informal caregivers to an adult or a child in United States.

In summary, studies reviewed across the world show that caregivers provide care to a wider range of patients that include the elderly, children and adults with life-limiting/threatening illnesses both at home and in hospital setting. However, studies done

in the USA indicate that the majority of the caregivers provide care to elderly patients. The studies have shown the magnitude of work caregivers undertake in providing care to adults as well as children with various conditions. Thus, it can be concluded that caregivers play a crucial role, and are of paramount importance in caring for children and adults with life threatening and limiting illnesses. It is, therefore, important to understand what the caregivers go through especially those whose children are receiving palliative care.

Most studies on informal caregiving have qualitatively described the tasks involved in caregiving. These tasks include: administration of drugs, wound care, dressing, laundry, seeking alternative medicines, bathing, feeding, ambulating, toileting, medication management and administration, provision of nutrition support, physical care and emotional and spiritual support (Buchanan, Radin, Chakravorty, & Tyry, 2009; Doris, 2007; Emmanuel et al., 2008; Sawatzky & Fowler – Kelly, 2003). However, Plank, Mazzon, and Cavada (2012) argued that caring involved much more than this, and hence included keeping and organizing appointments with physicians, transporting patient to hospital, and assistance with social activities, ensuring appropriate environment, constant supervision, making decisions, managing patients' difficult behaviours and care of financial matters. In addition, multiple patients' symptoms such as pain, fatigue and dyspnoea were found to be another caregiver's responsibility especially in caregivers whose children had lung cancer (Ferrel & Mazanec, 2009; Grant et al., 2013). However, Gilgis and Lamberts (2009) and Zapart, Kenny, Hall, Servis, and Wiley (2007) in their studies conducted in Australia, agreed with some of the mentioned care giving roles which shows that the tasks could be different depending on the age of the patient,

condition, geographical location, and ethnic group. In addition, other tasks mentioned in literature on care giving tasks for older patients may not be similar since some tasks may be specifically for children. However, most studies reviewed have focused on the tasks of caregivers for adult patients than children which are the focus of the present study.

Hence, it should not be taken for granted that the tasks could be similar.

Key providers of the caregiving role

Studies have identified the key providers of the caregiving role as family members (Emmanuel et al., 2008; Kneipp, Castleman, & Gailor, 2004). Focusing on caregiver relationship with the patient, Mawani, et al. (2013) in Morocco, and Monterosso, Kristjanson, Aoun, and Phillips (2007) in Western Australia agreed that the patient's mother was the primary caregiver but differed in that the patient's mother was not the only primary caregiver in all the patients. Monterosso, et al. (2007) argued that some patients were being supported by immediate and extended family members. On the contrary, a cross sectional survey describing the extent of informal care giving unit for older people done in England involving 650 people found that spouses, daughters, sons, daughter in-laws and other relatives and friends were the key supporters in the provision of care (Bond et al., 1999). Thus it appears that all family members are involved in care giving but they differ on the extent of care provided depending on the person receiving the care.

Notable key issues pertaining to the caregiving role

Studies have noted that most relatives or family members become caregivers abruptly and are mostly not aware of the extent of the role when they become caregivers.

Assuming the caregiving role is influenced by several factors, Emmanuel, et al. (2008) in a study on the challenges faced by informal caregivers of hospice patients in Uganda revealed that the most common reasons reported by family caregivers were family expectations, closeness to the patient and their religion; where as in Turkey, Kusgu, Dural, Yasa, Kiziltoprak, and Onen (2009) study results on decision pathways in informal care giving indicated that individual decision, social and family network decision and role dependent obligation as the decision pathways of becoming an informal caregiver. Despite agreeing on one factor, it is evident that influencing factors are different across Africa and Europe as well as in different countries. In addition, both were qualitative studies that used convenience samples which is unlikely to be representative of all the caregivers. Gilgis, Lamberts, Johnson, Waller, and Currow (2013) reported that majority of caregivers took on the role of caring because of the family responsibility, with little choice and no one else to provide care and as an obligation or duty that they must uphold for their loved ones with minimal or no preparation. However, Foreva and Assenova (2014) argued that in Bulgaria, caregiver's participation in care was solely due to the lack of organised services for palliative care. Thus, it can be concluded that becoming a caregiver is closely connected with individual experiences and social and cultural factors (Kusgu et al., 2009).

Lack of choice and preparedness in assuming the care giving role has also been investigated (Scherbring, 2002; Schulz et al., 2012). A national telephone survey with 1397 caregivers aimed at identifying predictors, lack of choice and consequences in taking on the caregiving role revealed that 44% of the caregivers reported lack of choice in taking on the caring role (Schulz et al., 2012). The study further noted that lack of

choice was associated with high levels of emotional stress, physical strain and negative health impacts. Likewise, Brazil, Thabane, Foster, & Bedard (2012) in their study observed that lack of preparation, knowledge and inadequate experience of caregiving, along with numerous tasks required of the caregiver, poses a threat to the health and well-being of the care recipient as well as the caregiver.

A correlation, cross sectional study involving 125 family caregivers of patients with life threatening and limiting illnesses found that preparedness was significantly associated with high levels of hope, reward and lower levels of anxiety and that relationship to the patient was significantly associated with preparedness (Henrikson & Arestedt, 2013). These studies clearly indicate that lack of caregiver preparation is associated with negative outcomes of caregiving. On the contrary, Archbold, Stewart, Geenlick, and Harvath (2007) in their study which determined whether mutuality and preparedness for caregiving were related to lower levels of caregiving role strain, indicated that preparedness improves some but not all aspects of role strain. Thus, it can be suggested that some negative effects would still be experienced despite preparations. Therefore, a longitudinal study would be necessary to investigate and determine the impact of unpreparedness of caregivers of children on palliative care in Malawi. However, it is not surprising that the literature reports of lack of caregiver preparation considering how the diagnoses of life threatening and limiting illnesses are made. There is little time for preparation from the time of diagnosis to time the caregiving role is assumed.

Whilst much of the literature points out that the caregiving role is rewarding, most studies still believe that caregiving is a demanding role. Buchanan et al. (2009),

Blindhein, Thorsnes, Brataas, and Dahl (2012) and Plank, et al. (2012) researched on the caregiving role. They all found that the caregiving role was demanding, time consuming and challenging. In addition, Navab, Negarander, and Peyrovi (2012) noted that caregiving despite being a rewarding experience, can also create a range of physical, emotional and financial demands that places caregivers at risk of negative outcomes.

Some studies have been conducted to determine the relationship between the caregiving role and the risk of negative outcomes. An exploratory study on the caregivers' perspective of health implications of long term informal caregiving for children with disabilities, involving forty caregivers in Utah, USA, indicated that caregiving negatively impacted on the caregivers' health. It was noted that their physical and emotional health was negatively affected by the demands of caregiving (Murphy, Christian, Caplin, & young, 2006). Similarly, Robison, Fortinsky, Kleppinger, Shugrue, and Porter (2009) in a state wide survey involving 4041 caregivers examined six health and psychosocial outcomes of caregiving. They found that caregivers with inadequate income, unmet needs for long term services and those living with the care receiver relate to multiple negative outcomes. Studies reviewed show that the caregiving role affects the health of the caregivers, and affects greatly those with inadequate support. However, it can be concluded that caregiving can be rewarding or demanding with negative effects depending on the caregiver's support systems and perception. Since all these studies were done in other countries, their relationship to the Malawian situation is not known. This study hence presents an opportunity to determine the perception of the caregivers in a Malawian context.

Not only does the literature agree that acceptance of the role is important in care giving, some literature suggest that acceptance may in fact play a crucial role in their ability to cope and look forward. A qualitative study conducted by Blindhein, et al. (2012) on the role of next of kin of patients with cancer, learning to manage unpredictable care situations involving nine next of kin revealed that acceptance of the care giving role played a crucial role in their ability to cope and look forward. The study further noted that support, knowledge and guidance is important to caregivers as it helps them to understand and cope with the situation and reduce the extent of strain experienced in the care giving role. Similarly, Calvete and Lopez De Arroyabe (2012) in a cross sectional study of primary caregivers of individuals with traumatic brain injury which included 223 caregivers indicated that secondary control coping such as acceptance and positive thinking was associated with less grief and depressive symptoms. The two studies have associated acceptance with positive caregiving role outcomes. Therefore, it can be deduced that acceptance has an impact on the outcome of the caregiving role. However it can be argued that it is not the only factor that would help caregivers to cope. As it was found by Whittier, Coon, and Aaker (2003) and Major (2003) there are several factors for coping with the caregiving role. Among others, caregiver coping could depend on the extent of the burden, diagnosis of the child, place of caring, and support. With the availability of positive social and emotional support, care giving can be a fulfilling experience for the caregivers. Considering this, it can be suggested that there is need for palliative care providers in Malawi to understand the roles that caregivers play and the impact on their wellbeing as it may help them in supporting

caregivers to cope, and come up with applicable interventions. Patient's wellbeing may be greatly enhanced when the caregivers are well supported.

The needs of children receiving palliative care at home

Family caregivers are of importance in meeting the child's physical and psychosocial needs, and in achieving treatment goals. In order to provide complete and effective care to children with life-limiting and life-threatening illnesses, caregivers need to clearly understand the child's needs and what is expected of them. Children with life-limiting and threatening illnesses need physical, emotional, social, spiritual elements and enhancement of quality of life and support for the family (Docherty, Thaxton, Allison, Barfield, & Tamburro, 2012). In addition, Geere et al. (2012) and Superlveda, et al. (2003) in their study findings specifically highlighted the main needs to be relief of pain, accessible and affordable drugs, suitable equipment such as wheel chairs or calipers or shoes to facilitate the child's mobility and reduce the need for carrying them, food, and income. The main sources of such assistance are health professionals who work in collaboration with caregivers on the provision of care at home. The caregivers of these children require adequate information from health professionals since they are constantly challenged to solve problems and make decisions throughout the progression of the child's illness. However, lack of information and skills to perform their tasks adequately have been reported (Schubert, et al., 2012; Selman, et al., 2009; Superlveda, et al., 2003).

In a study conducted in four palliative care services in South Africa and Uganda found that lack of information from health care providers led the caregivers and patients to draw information from alternative sources. The caregivers reported needing more information in the key areas of the causes, progression of the disease, its symptoms and

treatment, and financial and social support (Selman, et al., 2009). Understanding the child's illness and needs is essential for the caregivers as it helps them in coming up with unique plans and prioritization of care which may help to lessen the care burden. The burden of caring for children with life-limiting and threatening illnesses adversely affect the caregivers who lack adequate resources, planning or are ill prepared for the new role (Mc Corkle & Pasacreta, 2001). In Malawi, the provision of adequate resources and information has been affected by shortage of health care providers and inadequate resources. However caregivers need to be provided with adequate information and resources for them to effectively care for their children at home.

Despite being diagnosed with life-limiting or threatening illnesses, children are naturally dependent. As they are physically, mentally and developmentally unable to perform many tasks associated with their care, hence, their family members assume this responsibility. In addition to these tasks caregivers are responsible for administering medications, getting their children to clinic appointments. They are also responsible for providing special diets and nutritional supplements. They also need to help children to cope with their own burden (Gayomali, Sutherland & Finkelstein, 2008).

Children with life-limiting or threatening conditions are at risk for adverse psychosocial outcomes, such as fear of rejection, low self-esteem, anxiety and fear of restrictions as a result of the illness that may become barriers to optimal coping (Creedy, et al., 2004). However, psychosocial support programs have been reported to be effective strategy in improving a range of outcomes for children. Creedy, et al. conducted a pre and post intervention study in which they evaluated a psychosocial program for children with chronic condition that aimed at enhancing coping abilities. They observed that there was

significant increase in self-esteem of children, reduction in anxiety, symptoms and improved perception of family support at 3 months post group assessment. This study highlighted the need to identify and help children to cope with the illness. It could be necessary to adopt such intervention in supporting children receiving palliative care in Malawi.

Children with life-threatening or limiting illnesses have a major challenge to health development which lies in the education area. These challenges arise due to frequent absences which compromise the acquisition of skills that lead to advanced mastery of subject materials, and place the children at a distinct disadvantage compared to other children without life-limiting illnesses (Martinez & Erickson, 2009). Hence caregivers need to discuss with the school authorities on how the children could be accommodated to catch up with their friends so that they should be able to achieve their academic success. Palliative care providers are well positioned to advise the caregivers on accomplishing the child's education need. However, the caregivers need to take the leading role.

While assessing the needs of the children has been described as essential, the needs for caregivers have not been left out. Multiple studies have identified other needs, in addition to information, for caregivers caring for patients with chronic illnesses, such as, social and psychological support, financial concerns and the need for choice and information in key areas of the condition, free medication, opportunities for income and caregiver training (Emmanuel et al., 2008; McIlfatrick, (2007). A study conducted in Neno district, Malawi found that caregivers reported the need for food and wide

availability of palliative care services. Poverty and lack of food were noted as their important barriers to their wellbeing (Herce, et al., 2014).

Despite the identification of the caregivers needs in care, studies examining the needs of caregivers have shown that caregivers providing support to individuals receiving palliative care report unmet needs for information, communication, service provision and support from health and community services, psychological, social and financial support (Aoun, Kristajanson, Currow, & Hudson, 2005; Hudson, et al., 2011; Joad, et al., 2011; Ventura, Brooker, Burney, Fletcher, & Ricciardelli, 2013). However, some care needs have been mentioned consistently in palliative care studies, for instance, patient comfort, information and practical needs, and emotional support. Caregivers require practical information on how they can provide care for a patient, how to ease patient's discomfort, preparation for patient's and caregiver's emotional response to illness and how and where to acquire practical assistance (Aoun, et al., 2005). Aoun et al. (2005) argued that such care needs are not met due to barriers to seeking help, scarcity of research based intervention focusing on reducing the negative aspects of caring and the number of challenges to effective policy and service development for family caregivers. In agreement, Hodgson et al. (2014) also argued that unmet needs arise from lack of knowledge about the disease process and lack of psychosocial support resources. The reviewed literature, dominated by qualitative studies, has shown that most caregivers reported psychosocial support as their unmet needs, this could lead to a suggestion that their physical care needs were being achieved although it can also be argued that caregivers tend to focus on the needs for children while neglecting their own needs (Schubert et al., 2008) hence the under-reporting of the physical needs. Understanding

the needs of children receiving palliative care and their caregivers is vital as it forms a basis on which palliative care interventions for children receiving palliative care and their caregivers can be formed and evaluated.

Caregivers support systems

Support for family caregivers is a core function of palliative care. Examples of support systems that have worked well for caregivers and how much they have relied on that support have been given. They include support from various individual members, friends, neighbours, and from the community including home care services, and caregiver support groups (Sawatzky & Fowler-Kelly, 2003). It is often the family and friends who play a crucial role in providing support regardless of whether the patient is at home or in hospital. Plank, Mazzoni, and Cavada (2012) in a study comprising of eight caregivers in individual interviews and ten caregivers in focus-group discussion aimed at gaining the understanding of new informal caregivers' lived experiences in Italy, found that nearly every caregiver named other family members as essential resources when reflecting on the support they required. It was further noted that the family gave important psychological and organizational assistance, and close friends did the same in some cases. Similarly, an exploratory study on comprehensibility and manageability in palliative home care conducted by Milberg and Strang (2004) involving 19 adult informal caregivers of cancer patients in three hospital-based home care teams in Sweden found that support came from family, friends, hospital-based home care or other community service organizations. Despite the two studies being conducted in two different time frames and places, they both emphasise on the important role family members play in supporting caregivers. This echoes sentiments made by Benin, et al. (2008) who had

pointed out that family members and friends play a significant role in creating a supportive, sharing, and effective network during the child's illness as well as after its death.

Lack of support as well as limited support to caregivers has also been reported in the literature. A systematic review of qualitative literature in sub-Saharan Africa by Gysels, Pell, Straus, and Pool (2011) on the end of life care in which 51 articles were synthesized, found that informal caregivers were women, the elderly, and children who provided total care in the home while lacking support from professional or extended family. Similarly, qualitative exploratory studies conducted in Namibia (Amakali & Small, 2013) and Switzerland (Inglin, Hornug, & Bergstraesser, 2011) to describe the caregivers' experiences of providing care to children with heart disease and other life limiting diseases revealed lack of support from the family, lack of organized forms of support from societal organizations, lack of support concerning practical issues of care and psychosocial aspect. As already indicated, both of these studies were qualitative in nature which means that they were specific to their context of study. However, most of the studies done in Africa appear to highlight lack of support from family and organisations than those done in Europe, and there are variations in the type of support needed. Overall, the availability of caregiver support and support systems is inconsistent between the studies. Hence, it can be suggested that the presence, lack or effectiveness of caregiver support is dependent on the caregivers' specific needs, values and perception.

Caregivers of children receiving palliative care need support in various aspects of their lives. Availability of support has been shown to help caregivers cope with the daily stresses of caregiving. Social, emotional, practical and financial support has been seen to

promote caregivers' health, and positive experiences. Shirai, Koerner, and Kenyon (2009) indicated that social-emotional support from family members was an important resource for caregivers' feelings of gain. They further noted that the mechanism by which social-emotional support influences the caregiver's feelings of gain varied depending on its source; be it family member, friend or partners. They observed that when caregivers are supported in the care of their children with life limiting or threatening illness, they are encouraged to care. Even if the health status of the child worsens, caregiving experience remains positive as their coping abilities are improved. On the contrary, a study conducted by Amakali and Small (2013) in Namibia observed that lack of support from families and societal organizations seem to increase the caregivers' poor coping experience. The common factors in connection with overall poor coping by caregivers were emotional disturbance, disruptive social functioning and social relations, lack of support from family, and lack of organised forms of support from societal organisations. On the other hand, factors that contribute positively to the caregivers' quality of life were having a good relationship with the patient, good friendship in their marital status, and social support they receive from family members (Francis, Worthington, Kypriostakis, & Rose, 2009). Considering that coping abilities of caregivers differ according to context, it is important to determine the factors that promote coping abilities of caregivers in the Malawian context, particularly those involved in caregiving to children with life limiting conditions at Mzuzu Central Hospital.

Some studies have been conducted to determine the effects of support intervention on caregiver outcomes (Henrikson, Arrestedt, Benzein, Ternestedt, & Andershed, 2012; Hudson & Aranda 2014; Northouse, Katapodi, Song, Zgang, & Mood,

2010). Northouse et al. (2010) in a study on ‘intervention with family caregivers’ of cancer patients which analysed 29 randomised clinical trials published from 1983 to March, 2009 indicated that the three types of interventions offered, that is, psycho-educational, skill training and therapeutic counselling, significantly reduced caregiver burden, improved their coping ability and increased self efficacy and improved aspects of their quality of life. Henrikson et al. (2012) Hudson and Aranda (2014) and Thurman, Jarabi, and Rice (2012) in their qualitative and quasi- experimental studies evaluated psycho-educational support intervention and support groups. They all found statistically significant outcomes which included improvement in family caregivers’ preparedness, competence, positive emotions, more favourable level of emotional well- being, and reduction in unmet needs. Despite variation in support interventions and methodology used, it appears that the support interventions result into positive outcomes in caregivers in all these studies.

Another study conducted by Candy, Jones, Drake, Leurent, and King (2011) consisting of a review of 11 Randomised Control Trials on interventions for supporting informal caregivers of patients involving 1836 caregiver participants, found that interventions that directly support the family or friends help them to cope emotionally and may also help them to cope with the caring role, and improve their quality of life. However, the researchers argued that there is low quality evidence that interventions that directly support the caregiver significantly reduces psychological distress in the short term, and that coping skills and quality of life may be improved. This implies that the support intervention, though effective, might be specific to a section of caregivers depending on the type of illness, level of burden, and stage of the child’s condition. In

spite of this, it can be deduced that caregivers' support interventions have an impact on caregivers' quality of life and experiences.

Supportive counselling, expressive therapies, social networks and support groups have been mentioned as the most common support or resource needs for families and caregivers who face challenging situations. Such psychosocial factors are helpful because they act as coping resources since they positively affect coping behaviours which directly influences stress and depression (Calvete & Lopez De Arroyabe, 2012). Supportive counselling helps to encourage caregivers to identify positive impacts that are associated with their children's illness (Knapp et al, 2010). In addition, individually targeted support and education intervention such as home visits, messages or phone calls from health professionals result in minimized feeling of burden and physical pain. Social networks are potential sources of instrumental, informational and emotional support, and are made up of family members and friends.

Support groups are also an important resource as they provide caregivers a chance to meet others who are in similar situations, obtain information, and discuss matters with professionals (Henrickson, Ternstedt, & Andershed, 2011). Amakali and Small (2014) in a study on "support programs for caregivers of children with heart conditions in rural Namibia" indicated that caregivers' knowledge of the child's condition, skills for providing care at home and information about community based resources that could provide them with support to cope, increased. The participants valued the positive impact the support programs had on their lives. Therefore, it can be suggested that if similar support programs are initiated in Malawi, caregivers of children receiving palliative care might similarly benefit from them. Palliative care providers need to interact with

caregivers so they should be able to appreciate their challenges. Within the challenges that exist in the provision of paediatric palliative care in the country, provision of support groups for children and caregivers in a non-threatening environment may be useful. Thus, palliative care services need to be perfectly developed and placed to provide support to family members and caregivers of children with life threatening or limiting illnesses in order to reduce the effects of the challenges that they face.

The challenges that caregivers encounter while caring for their children

Caregivers perform a significant role in the care of patients with life threatening and limiting illnesses. Despite the intensity of these conditions, the majority of these patients receive treatment as outpatients at home, and their caregivers are expected to cope with the demands of caring at home. The diagnosis of a life-limiting or threatening illness in a child result into various changes in family structure, routines, and functioning. Caregivers have limited time to socialize with others hence feelings of isolation are experienced, and sometimes the extent of care needs increases and disrupt the daily routines of the caregiver. Mawani, et al. (2013) and Houldin (2007) indicated that caregivers are totally disrupted in their life with the presence of their loved one's illness. They struggle with caring as they assume increased household, family and financial responsibilities and cope with the personal effects while attempting to meet their own needs and maintain normal family routines. In addition, complex needs result in giving things up, altered priorities and inability to plan. Knapp, et al. (2010) looked at how families are impacted by their child's illnesses. He noted that 71% of the parents indicated that their families have to give things up as a result of their children's illnesses.

Additionally, caregivers make significant adjustments in their lives that affect every member of the family. For instance, one or both parents might have to reduce work hours or give up employment if the caring demands surpass the benefits of employment (Cadell, Kennedy, & Hemsworth, 2012; Glajchen, 2004; Knapp, et al., 2010).

The large body of literature on caregiving demonstrates that caregivers suffer adverse health, psychosocial, and financial effects because of the caregiving role (Abernethy, Wheeler, & Currow, 2009; Cadell, et al., 2012; Helbert & Schulz, 2006; Lund, Ross, Petersen, & Groenvold, 2014). Caregiving is demanding, overwhelming and a stressful experience that may affect the economic, physical and psychological health of the caregiver. Studies suggests that caregiving can place extensive demands on the caregiver in the physical, emotional, financial, existential and social domains and can negatively impact on the caregivers health and life expectancy. A study titled “supportive and palliative care needs of families of children with life threatening illnesses: evidence to guide the development of a palliative care service” conducted by Monterosso, et al. (2007) in Western Australia revealed that many families are affected emotionally, financially and physically by the burden of caring for children with life threatening or chronic conditions requiring complex care at home. This study noted that the complexity and long term duration of care provided contributed to a number of problems which included physical exhaustion, neglect of other children’s needs, general health problems that included musculoskeletal problems, social and physical isolation strain on spousal relationships, and inability to take holidays. Other studies (Lund et al. 2014; Ogce, Ozkan, Okcin, Yaren, & Demiray, 2013; Ugur, Elcigil, Arslan, & Sonmez, 2014; Tsigaropoulos, Mazaris, Chatzidarellis, et al., 2009) have also identified physical

problems such as changes in appetite, weight loss or gain, muscle pain, difficulties in concentration and emotional symptoms such as restlessness, insomnia, decreased self-esteem and social isolation as negative effects emanating from the caregiving role. In contrast, Geere, et al. (2012) in a study aimed at identifying the potential physical health effects of caring for a child with moderate to severe motor impairment in Kenya, observed that caregivers differed in how they perceived the effects of caregiving on their physical health. Detrimental physical effects as a result of caregiving were denied. However, spinal pain of moderate to severe intensity which disrupted activities was reported. The negative physical and emotional health consequences were found to be most evident among mothers who were primary caregivers in most families, youngest, older, and depressed caregivers (Marron, et al., 2012; Murphy et al., 2006). Furthermore, a wide range of emotional consequences such as anger, guilt, and worry that the child would struggle with the condition for a long time, and fear of child death were reported by parents in response to their caregiving experience (Amakali, 2013). In contrast, Hudson, (2004) argued that caring is not necessarily an exclusively negative experience, and that without recognizing the positive elements, there will be a danger of labelling caregiving as completely a burden.

A great deal of evidence shows that caregivers are economically impacted by the illness of their children (Asuquo, Etowa, & Adejumo, 2013; Wilson, et al., 2005). A qualitative study conducted by Emanuel, et al. (2010) on the economic impact of terminal illness on the caregivers involving 11 families in Pallium, India, indicated that caregivers had to change work habits in seven families. All respondents stated that illness had forced them to sell assets, and ten indicated that children had to miss school due to the illness.

Other studies done in India (Nayak, George, Vidyasagar, & Kanath, 2014) and Canada (Sawatzky & Fowler- Kelly, 2003) revealed that many caregivers had to quit work in order to take on full time caregiving responsibilities, and most of them lost their savings.

Transportation costs and special transportation needs for visits to the doctor or treatment were some of the expenses mentioned. In Tanzania, Tarimo's study (2009) reported that caregivers, particularly women, experience severe economic burden from caring, their ability to work in their gardens was reduced thereby affecting their food security.

Financial difficulties due to transportation costs and being discharged from work were also experienced (Sercekus, Besen, Gunusen, & Edeer, 2014). The reviewed literature agrees to the fact that chronic illnesses negatively impact on the economic and quality of life of the caregivers. Strategies need to be formulated to reduce the economic burden that the illness places on patients' caregivers. It can hence be concluded that managing such impact is vital to the quality of life of both the caregiver and the patient.

Despite the negative effects dominating in most of the studies on the caregiving role, positive effects have also been reported. Mawani, et al. (2013) reported caregivers' feelings of gratification to be helping and continuing providing the care. Toljamo, Perala, and Laukkala (2012) in a study on the impact of caregiving found that most caregivers thought that caregiving was worthwhile, had a good relationship with the person they cared for, and coped well as a caregiver. They further noted that caregivers felt that caregiving did not have any negative impact on their emotional well-being as well as physical well-being, and that it did not cause any difficulties with their family. Most of them felt that caregiving had caused no financial difficulties in that they were not trapped in their role as a caregiver. Robinson, Fortinsky, Kleppinger, Shugrue, and Porter (2009)

also argued that caregiving does not lead to symptoms of depression, poor health or social isolation but that many caregivers need support in training and education, physical and mental healthcare. Various other positive aspects of caregiving have been reported that include enhanced relationship with the care receiver, feeling of being rewarded, sense of personal growth, perception of personal satisfaction, duty/obligation, love, and meaningful enjoyment (Li & Loke, 2013; Mackenzie & Greenwood, 2012; Wong & Ussher, 2009; Tarlow, Wisniewski, Belle, Rubert, Ory, & Gallagher-Thompson, 2004; Cohen, Colantonio, & Vernich, 2002). However, most studies reviewed on positive aspects of caregiving were retrospective and concentrated on exploring experiences of bereaved family caregivers. Overall, the studies indicate that caregivers are affected negatively or positively with the demands of caregiving.

Positive aspects of caregiving have been associated with positive coping and adaptation. A study conducted in Sweden by (Henrikson, Carlander, & Arestedt, 2013) on feeling of reward among family caregivers during ongoing palliative care found that the levels of reward in caregiving were high among caregivers. The study further observed that the greatest source of reward involved feelings of being helpful to the patient followed by giving something to the patient that brought them happiness, and being there for them. Thus, measures are needed to help caregivers to cope with the effects of caregiving. Marckezie and Greenwood (2012) agreed that the positive experiences of caregivers are associated with coping strategies whilst Papastaurou, Charalambous, and Tsangari (2009), revealed that 66.4% of caregivers in Cyprus had experienced depression above the cut off point for depression, and the use of coping strategies showed significant differences. In addition, Henrikson (2012) agreed that there

was an increase in the preparedness, competence and rewards in relation to care giving as a result of coping strategies but argued that there were no significant changes in caregivers anxiety, depression, hope and health, hence, the need for health professionals to adequately support caregivers.

The structure of health care services and the nature of support can influence the caregiver experiences (Stajduhar & Davies, 2005). Despite the requirement for healthcare professionals to support children and caregivers when providing palliative care, in reality, the support is inadequate. Caregivers are faced with numerous challenges in accessing palliative care services for their children. Structural challenges originate from the general conditions of the health care systems. These include, organisational obstacles such as long distances, as well as questions of responsibility, referral transport costs to health care facilities for seriously ill patients, follow ups, and the interface between inpatient and outpatient care (Junger, et al., 2010). There are inefficient procurement processes in remote clinics/hospitals, and some palliative care drugs are not held at community health centres in spite of them being on the Essential Drug Lists. Some of the challenges caregivers face relate to healthcare professionals. These include beliefs and attitudes, lack of adequate training and expertise, poor communication between the healthcare professional and patient, caregiver and other healthcare professionals, poor pain and symptom management for the patient, staff shortage and time constraints (Beckstrand & Kirchhoff, 2005; Davies, et al., 2008). These challenges negatively impact on the caregiving role because the care given to children and their caregivers is not comprehensive. However the impact felt by each caregiver may be different due to individual's personal traits, beliefs and values, the support systems that the caregiver has

in place and other factors unique to each caregiver. Therefore, it can be suggested that palliative care providers need to deal with each caregiver as an individual remembering that each caregiver has his/her own caring experience.

Conclusion

Caregivers play a critical role in the care of children with life threatening and limiting conditions receiving palliative care. However, families and friends who mostly assume the care giving role often have minimal preparation for taking the role and face challenges to adjust to this new role. It is important to develop a greater understanding of their experiences, and establish the roles that health services can play to support caregivers. Most of the existing literature is largely drawn from developed countries whose findings may not necessarily apply to a Malawian caregiver because the impact of caregiving on well being may vary according to country and cultural context. Nevertheless, the literature reviewed is still important as it illuminates the study on existing practices elsewhere, and forms the basis for carrying out the present study which will help close the existing knowledge gap on this particular subject.

CHAPTER THREE

METHODOLOGY

Introduction

Methodology are procedures by which researchers go about their work of describing, explaining and predicting phenomena, and are aimed at giving a work plan for research (Rajasekar, Philominathan, & Chimathambi, 2013). This chapter will describe the study design, study place, population and sampling technique. It will also describe the methods that were used in collecting and analysing data including ethical considerations.

Study design

Study design is the blue print for conducting a study, and it provides control that increases the probability that the study results will accurately reflect reality (Burns & Groove, 2007). Thus, this study was descriptive qualitative study. This is an approach that examines human experience through descriptions that are provided by the people involved, and is aimed at describing what people experience in regard to a certain phenomenon, how they interpret the experience or the meaning that the experiences hold for them (Brink, 2006). This design was chosen because it allowed the researcher to get an understanding of the caregivers' experiences of caring for a child who is on palliative care. It was also suitable for time and financial resources available for this research.

The researcher decided to utilize qualitative descriptive approach because she needed to study a population and also the research needed a detailed understanding of the issue which can only be established by talking directly to people. In addition the study area involved identifying what is being experienced by the caregiver which is why the qualitative descriptive approach was appropriate. According to (Hancock, Ocklefold, & Windridge, 2007) in health and social care setting qualitative approach is particularly useful where the research objectives involves real-life context and if the researcher wants to understand the perspectives of participants or explore the meaning of the phenomena. Hence, the approach allowed the researcher to explore the caregivers' experiences.

Study place

The study was conducted at Mzuzu Central Hospital Palliative Care Clinic. This study place was chosen because it is a referral hospital for all districts in the Northern Region, palliative care services were recently introduced, and no study has been done to discover caregivers' experiences of providing care to a child with life-threatening or limiting illnesses at this hospital.

Study population

A subset of the target population from whom the sample is derived is called a study population (Gerrish & Lacey, 2006). The sample was derived from a population of over 211 caregivers whose children have life limiting or threatening conditions, who utilises children palliative care services at Mzuzu Central Hospital, because such caregivers gave a true reflection of the experiences.

Sampling technique and research sample

Non probability, purposive sampling, which is defined as a technique in which people from a specified group are purposely sought out and sampled (Gerrish & Lacey, 2006) was used. Purposive sampling is a common strategy in which the researcher selects the cases to be included in the sample based on his/her knowledge of the population and its elements (Liobondo-Wood & Haber, 2010). The researcher's goal was to understand experiences as they are lived by the participants. Purposive sampling was hence used to pick a sample that had desirable characteristics for the study. According to Creswell (2013) it was essential that all participants had experience of the phenomenon being studied. Therefore, all caregivers who had cared for a child with life threatening or limiting illnesses on palliative care service for over 3 months were included in the study.

The sample size was determined based on informational needs, and the guiding principle in sampling was data saturation, that was sampling to the point at which no new information was obtained and redundancy was achieved. Thirty caregivers participated in the study. The proposed sample size ranged between 18–28, which was expected to increase or decrease depending on data saturation. Hence with 27 participants data saturation had occurred as there was repetition of information and was confirmed with 3 more participants thereby having 30 participants. According to Remsherdt and Flowers (2007), there are no set rules or criteria for sample size in qualitative research because sampling depends on data saturation.

Data collection instruments

A semi-structured interview guide (Appendix F & G) and a tape recorder were used for collecting data. Semi- structured interviews involve a number of open ended

questions based on the topic area that the researcher wants to cover and provides an opportunity for both the interviewer and interviewee to discuss the topic in more detail (Hancock, Ocklefold, & Windridge, 2007). This approach was chosen because it allowed the researcher freedom to probe the interviewee to elaborate on an original response and to ask further questions on the topics discussed. This method was appropriate to the researcher because the researcher wanted to collect data which truly reflected the opinions and feelings of the interviewee concerning the experiences that they go through when caring for children receiving palliative care and also because very little is known on the experiences of caregivers of children who are on palliative care. According to Brikci and Green (2007) semi-structured in-depth interviews are used on topics for which little is known and where it is important to gain an in-depth understanding.

Interview guide questions and prompts were developed by the researcher by formulating them in a way that helped to answer the objectives and other questions were adapted from previous research interview guides. The interview guide consisted of two sections, that is, demographic data and the experiences of caregivers. The interview guide was developed in English and was translated to Chichewa a language that was comprehensible and relevant to the people being interviewed.

Pretesting was done at Mzuzu Central Hospital Palliative Care Clinic in which five participants were selected for the interview, and the interview guide was used while interviewing the caregivers. The instrument was pretested in order to identify problems and rectify them before the beginning of data collection.

Data collection procedure

Semi structured interview guide was used for in-depth interviews with the caregivers of children with life limiting or threatening condition who were on palliative care at the clinic. The researcher with the assistance of the palliative care provider at the clinic identified caregivers whose children had been on palliative care for over 3 months, by asking them and requesting their permission to participate in the study. Caregivers willing to participate in the study were being interviewed. Interviews were used because the researcher was interested in obtaining more personal information from the participants (LoBiondo-Wood & Haber, 2010). According to Petty, Thomson, and Stew (2012), semi-structured interviews involve a few pre-determined areas of interest with possible prompts that help the researcher to guide the conversation. Qualitative data was collected by the researcher using interview guides for a period of approximately four weeks (Appendix A). The researcher and the subjects worked closely together to collect the data. The researcher requested for a quiet, undisturbed and familiar room for conducting the interviews to ensure that the participants were relaxed. Participants were asked questions while looking at the interview guide to ensure that data collected was relevant. Notes were being taken during the interview, and questions and responses were audio-taped.

Data analysis

Data was analysed manually using thematic content analysis (Petty, Thomson, & Stew, 2012). The following process was done;

- The researcher initially read the data and listened to the tape several times to gain familiarity with the text as a whole.
- Codes were then given to sentences, phrases, paragraphs or lines according to similar units.
- Codes were compared across the whole data set to identify variations, similarities, patterns and relationships.
- Data was organised and integrated according to emerging themes and subthemes.

The researcher then wrote reflections and ideas related to sections of data to abstract from the data and deepen analysis (Petty, Thomson, & Stew, 2012).

Trustworthiness of data

Trustworthiness is a way of demonstrating plausibility, credibility and integrity of the qualitative research process (Moule & Goodman, 2009). Four concepts, which are credibility, dependability, confirmability and transferability, were used to describe the aspects of trustworthiness in the study.

Credibility

Credibility enables those reading the study to believe that the data presented is the true representation of the participants' views, experiences or beliefs (Moule & Goodman, 2009). To ensure credibility of the data, the researcher confirmed what the participants meant in whatever they said or did by using probing questions, observation and repeating the responses to them so that they verified their responses. Clarification of the research questions was done during the interview to ensure that caregivers understood the questions before responding. In-depth interviews were conducted by the researcher which

enhanced the development of relationship and trust with the participants, and this in turn enhanced credibility.

Dependability

Dependability is the study's ability to stand the test of time (Moule & Goodman, 2009). It ensures that the research findings are consistent and could be repeated. To ensure dependability, the research processes in the study which included research design and its implementation, data collection and analysis have been reported in detail so that future researchers would be able to repeat the study, and get the same results. Detailed reporting of the processes would also enable the readers of the research report to understand the methods and their effectiveness thoroughly.

Confirmability

According to Brink (2006) confirmability guarantees that the findings, conclusion and recommendations are supported by data and that there is internal agreement between the interpretation and actual evidence. To confirm objectivity of the data, the researcher presented the methods, data presentation and analytical processes to internal and external examiners for review before the end of the study.

Transferability

Transferability refers to the extent to which research findings can be transferred from one context to another by providing a thick description of the data as well as identifying sampling and design details (Moule & Goodman, 2009). Transferability of this study was established through thorough description of the research setting and research processes because this will enable the readers who might include the palliative care

providers, nurses in practice, education, research as well as administration to establish the transferability of the study.

Ethical consideration

Ethics in research involves requirements of daily work, the protection of dignity of subjects and the publication of the information in research (Fouka & Mantzorou, 2011). It provides guidelines for the responsible conduct of biomedical research, educates and monitors scientists conducting research to ensure high ethical standards (University of Minnesota, 2003). To ensure that standards were followed, approval to conduct the study was sought and gained from College of Medicine Research and Ethics Committee (COMREC) (Appendix J), and the management of Mzuzu Central Hospital(Appendix H) and the paediatric ward in- charge (Appendix I) where the study was conducted.

Participants were given adequate information about the study purpose, benefits and risks (Appendix B & C) so that the participants voluntarily, intelligently and clearly gave informed consent which were done in a written form (Appendix D & E). Furthermore, participants were informed that the study did not have any harmful effects, and their participation in the study was voluntary, and that they might withdraw from the study at any time without giving any reasons. They were assured that withdraw or refusal to participate in the study would not affect their access to palliative care services at the hospital. Participants were asked to voluntarily sign the consent form after showing their willingness.

The participants were assured that their responses would be handled in a confidential manner in order to protect their identity. Privacy was maintained throughout

the research process. Names were not used, and their information was not available to anyone except the researcher and her supervisor in order to protect their privacy and confidentiality. The researcher refrained from invading participants' privacy by respecting their views in case of refusal to disclose personal information. Gathered information was stored by the researcher. After data analysis, the data collection materials were destroyed by burning.

CHAPTER FOUR

PRESENTATION OF RESULTS

Introduction

Chapter four presents the findings which emerged during the interview with the caregivers. The study was conducted at Mzuzu Central Hospital, Children Palliative Care Clinic. The aim of the study was to explore the experiences of caregivers of children receiving palliative care. There were thirty caregivers who participated in the study. The study results are presented in five sections which are: Demographic data, the role of caregivers in caring for children receiving palliative care, the supportive systems, care needs of children receiving palliative care, and the challenges caregivers face when caring for children receiving palliative care. The interview results are presented in themes arising from participants responses. Study objectives guided the identification of the themes in the study.

Demographic characteristics

The total number of caregivers who participated in the study was thirty; the variables studied for the caregivers were gender, age of caregivers, religion, marital status, relationship to child, education, age of child at the time of interview, period of caring, tribe, occupation, diagnoses and age at diagnosis.

Majority of the participants 66.7% ($n = 20$) were females while 33.3% ($n = 10$) were males. Participants age-range was 19 to 64 years with a mean age of 38 years, in

which the majority 36.7% ($n = 11$) were aged between 26 to 35 years, followed by 30% ($n = 9$) who were between 30 to 45 years. 20% ($n = 6$) were above 46 years and only 13.3% ($n = 4$) participants were between the ages of 19 to 25 years. All participants 100% ($n = 30$) were Christians who belonged to different denominations, the majority being Roman Catholic 23.3% ($n = 7$) followed by Church Of Central African Presbyterian 20% ($n = 6$).

The children's ages ranged from 1 year 4 months to 16 years with half 50% ($n = 15$) within the age ranges of 5 to 10 years followed by 36.7% ($n = 11$) less than 5 years and 13.3% ($n = 4$) above 10 years. Over half of the participants 56.7% ($n = 17$) had cared for the child for a period of over 3 years followed by 1 to 2 years 23.3% ($n = 7$) and less than 6 months to 1 year 20% ($n = 6$). 56.7% ($n = 17$) of the children were diagnosed between birth to 1 year followed by 26.7% ($n = 8$) between 1 to 5 years, only 16.7% ($n = 5$) were diagnosed above 5 years. Table 1, shows that the top two conditions were sickle cell disease 36.7% ($n = 11$) and congenital heart disease 23.3% ($n = 7$). Four children presented with 2 diagnoses. For instance a child with Down's syndrome presented with Tetralogy of fallot.

Table 1: *Diagnoses of children*

Diagnosis	Number of children (n=30)	%
Sickle cell disease	11	36.7
Rheumatic heart disease	5	16.7
Congenital heart disease	7	23.3
Hydrocephalus	1	3.3
Cerebral palsy	3	10
Laryngomalacia	1	3.3
Down's syndrome	2	6.7
Tetralogy of fallot	1	3.3
Nephrotic syndrome	1	3.3
Wilm's tumour	1	3.3
Skin cancer (xeroderma pigmentosa)	1	3.3

Thematic content analysis

Four themes were identified which included the role of caregivers in caring for children receiving palliative care, supportive systems, care needs of children receiving palliative care and challenges in caring for children receiving palliative care.

The role of caregivers in caring for children receiving palliative care

The sub themes which come out on the role of caregivers in caring for children receiving palliative care were assistance with activities of daily living and health care management.

Assistance with activities of daily living

The caregivers were asked to describe the things that they were doing for their children on a daily basis. Findings revealed that caregivers participated in the care of their children receiving palliative care. The caring roles were dressing, washing clothes, bathing, cooking, feeding and toileting. The caregivers reported that they were bathing, dressing, washing, removing soiled clothes and buying clothes for the children to look beautiful. One female caregiver said: “I have the role of washing for her, bathing and giving her food, buying her clothes so that she should look beautiful” (Participant # 6).

Another male Participant also explained his caring role:

This child does not do anything on his own, we feed him, wash for him, when he is soiled with stools we remove, and we do everything for him. It is close to 8 years now. When he is sick, we ensure that we take him to the hospital to get medication. We also took him to a Chinese hospital in area 25, they saw him and we brought him back. (Participant # 27)

Some caregivers reported on the role of cooking and providing food to their children. Caregivers had to make decisions on the time when they could feed the children as some of them could not speak. They ensured that the children got appropriate foods. Few caregivers reported breastfeeding their children but most of them provided porridge, nsima, Irish potatoes and fruits. A female participant whose child had Down’s syndrome and Tetralogy of Fallot said:

Cooking for him, I need to know that my child now needs food because he does not ask for it. He speaks inappropriately, he just started speaking last year, so you just imagine that now he might need food, even breastfeeding I was just thinking that now I can breast-feed him. He drinks a lot of water. His eating pattern improved after weaning him from breast milk. (Participant # 18)

Caregivers had a role of cleaning and washing for their children. They washed clothes to ensure that children were always clean and free from bad odor, and washed beddings to ensure that they were free from dirt. They said that children could not take care of themselves as they could sit anywhere even on dirty places. Some had persistent secretions dribbling from their mouths, and others were not able to report when they wanted to urinate or pass stools hence soiling themselves. Some caregivers were worried that children might have frequent coughs if the beddings were dusty because of the child's breathing problems, hence the need for them to be clean all the time. One participant aged 45, an aunt to the child said:

I wash her secretion-soiled clothes, and clean her after bowel opening because she cannot clean herself. When she is eating, I put a cloth around her neck so that she should eat well. She cannot remove the cloth on her own. We tell her to clean the mouth because she doesn't know that she is dirty so I do them for her, and try to teach her to do so. (Participant # 29)

Protection from harm

Protection from harm was one of the roles that caregivers played. The findings revealed that caregivers ensured that their children were protected from bad weather and

injury by dressing them in warm clothes, changing clothes according to how the child was feeling, preparing a good place for sleeping and observing them during play.

Participant # 16 said: “She usually feels cold within a few minutes she feels hot so I have the duty of changing the clothes depending on how she is feeling”.

Another participant said:

I do so many things. I encourage her, and stay close to her to ensure that she does not go out often because she ends up being breathless and faints. When she goes to draw water I am always there because she can faint anytime, and if left alone can drown. If I am going out, I ask our relative to keep an eye on her. (Participant # 5)

Children were also being protected from diseases by frequent washing of their beddings and ensuring that they were always clean.

Health care management

All caregivers reported that they were responsible for the health care management of their children. The caregivers reported that they were providing technical as well as supportive care namely medication management, wound dressing, and follow-up care and nutrition support.

Medical management

Caregivers reported that they were committed to giving medication on a daily basis. Medications were being given once or twice a day as advised by the doctors. Caregivers said that they ensured that children had taken medication according to

doctors' instructions. Some caregivers reported giving the medication in the morning before meals while others were giving after meals. Others who administered medication once a day chose to do so in the evening. Some caregivers whose children were older reported on the role of reminding the children to take the drugs. Some caregivers indicated that they were afraid of the consequences of missing the times of administering the medication or indeed failure to administer medication prescribed because they were afraid that the child's body immunity would reduce hence they would face a lot of problems. In addition, caregivers reported on the role of buying medication. They said that they were told to buy medication whenever there were out of stock at the hospital pharmacy. One caregiver reported doing wound-dressing daily. She said that she was dressing the wound soon after bathing the child. The child had an open wound on the right cheek.

One participant described her role of administering medication as follows: "I administer the medication once every day so I choose whether to give him every morning at 6 or every evening until month-end when we come to collect some here" (Participant # 15).

Follow up care

Children receiving palliative care are monitored once every month. They are given dates to go back to the hospital for review. Caregivers were asked on the role they play on hospital follow-up care. Findings revealed that caregivers had the responsibility of ensuring that their children were reviewed on dates of appointment. They had to search for transport for them as well as the child. Most caregivers reported to have problems

with transportation but still found ways to ensure that the child is taken to hospital for review.

Findings also revealed that caregivers were committed to following dates of their appointment. Most of them reported that they took the child to hospital on dates of their appointment, and whenever they faced a problem even before the date of their appointment. Some reported to have missed the dates of their appointment due to lack of money and other commitments but they still went with the child on another day. A male participant who had cared for the child for 3 years said:

We try our best, no matter what, to find transport to ensure that we come to the hospital on the date that we are given. Sometimes we get money by selling maize to find transport to bring her to the hospital. Sometimes we have problems accessing money so do not come on dates of appointment. (Participant # 12)

Nutritional support

Caregivers reported that they were responsible for the children's nutritional support. They were advised on the type of foods to be given to their children to boost their immunity and provide the required nutritional supplements. Caregivers said that they ensured that their children got the required foods as advised by the doctors. Some caregivers reported that they could not provide the meals regularly due to financial problems. The recommended foods included fruits like bananas, eggs, porridge, meat, fish and vegetables, as commented by the following participant: "We make sure that she

drinks tea in the morning. In the afternoon, we prepare fish, vegetables and tomatoes, at times meat. We also give her fruits, for example bananas” (Participant # 17).

The support systems

Family members and community members such as neighbours, friends and church members formed part of the caregivers’ support system.

Family members

Family members were the ones who provided support to caregivers of children receiving palliative care. These included spouses, uncles, sisters and child’s grandmother. Spouses provided most of the support as reported by most of the caregivers. Majority of the caregivers reported that they were assisted by their spouses in the care of their sick children. Spouses supported the families financially and physically. They were buying the necessary food and other things for the child and the home including providing transport for the child to go to the hospital. Spouses were providing money to buy medication at the pharmacy whenever medications were out of stock at the hospital. One female caregiver said: “He is the one who assists with buying the necessary food and providing transport” (Participant # 6).

Participant #11 also said:

When I say that there is no medication at the hospital, he gives me money to buy at the pharmacy, and transport when we are coming to the hospital to get medication. If he gets sick suddenly, we rush her to the hospital thus the issue of transport again arises.

Some caregivers reported that they were going together with their spouses to the hospital whenever their child was sick, and in case of admission, their spouses kept on visiting them. They could also take the child to hospital when sick as well as on dates of appointment, and were also assisting in administering medication. One caregiver reported that her spouse assisted her with washing and looking after the child when she was busy with other household chores.

Caregivers also said that their relatives such as uncles and sisters were supportive in the care of the children as they escorted them to the hospital, visited and gave them food when the child was admitted at the hospital. Some caregivers reported that relatives encouraged them in prayers and provided them with assistance in farming and giving them supplies such as maize. They were also looking after the child when the mother had gone for business. Participant # 5 said: “mostly it is when I am away for business that I ask them to look after the child”.

Grandmothers were reported to be supportive in the provision of care for children receiving palliative care. Some caregivers revealed that the child’s grandmother escorted them to the hospital. They were buying soap for washing when the child was sick. They also assisted with household chores such as cooking, feeding the child, washing soiled clothes, and cleaning the home and assisted the caregivers in cases of problems at home. Grandmothers helped with caring of the child when their mother was busy doing other chores, as one caregiver narrates: “when I am busy or sick she plays a role in that she comes in the morning to cook porridge and feed the child” (Participant # 7).

Community members

Caregivers appreciated the support from community members who included the neighbours, friends, church members and health personnel. Most caregivers reported that their neighbours and friends supported them although some reported no support. The caregivers reported that whenever the child was sick, the neighbours and friends would escort them to the hospital, visit them at home and also in hospital when admitted. They would bring them food and give them money to buy medication. They would also look after the child in case of sudden illness or take the child to the hospital until the caregiver returned. Participant # 5 said: “They come to see the child when she is sick, and when we are at the hospital, they come to see us too. Sometimes when my child falls sick while I am not around, they take her to the hospital”.

Caregivers also reported receiving encouragement from neighbours and friends to keep on taking the drugs and through prayers which helped them to maintain their hope. Participant # 24 said: “I can say that for more support, I have my neighbour who is also her teacher. She is the one who escorted us to the hospital and encouraged us that we should not lose hope, and that everything is possible with the owner, the creator”.

Church members were also supporting them. Few caregivers reported that church members supported them with prayers and household chores. They would bring firewood and draw water for them. One caregiver reported that he was assisted with money to take the child to the hospital and that Christians from various churches visited and prayed for them.

Health personnel

Health personnel formed part of their support system. All caregivers reported that they were being supported by the health personnel. They reported that they were being welcomed and assisted very well by the health personnel. They were able to visit the hospital whenever the children fell sick, and on the dates of their appointment. All caregivers except one reported that they were being given medication every month for their children. Health personnel examined their children to identify problems and admitted them whenever they are very sick for observation. They also provided the caregivers with transport when referred to other hospitals. One participant said:

The health personnel examine the child. When she is very sick, they admit her. They say that they should look after her so that they should see how the body is functioning, and how blood and water is flowing in the body. (Participant # 13)

Majority of the caregivers revealed that health personnel provide education to them. They mentioned that health personnel would call them for seminars and teach them on how to take care of the child, recommended diet, proper hygiene and the challenges that the children face. They also reported that they were being given transport when going home. Few caregivers complained that time had passed by without being called for the seminars. This is what another participant said:

At times they invite us, so they teach us how we can care for the children, how we can love them, and the challenges that the children face especially those that are able to speak. They give us something that we can use for transport when going

home. They encourage us to come with the children so that they should be doing exercises and teach them other things. (Participant # 29)

Four participants reported that they also got support for their children from St John of God and government health centre. St John of God provided the participants with porridge flour. They also assisted them with the teaching of the children and physiotherapy. Some were getting supplementary foods from government health centres because their children were underweight. Participant # 10 said: “I can explain that when the child was found with this problem I was told that I should take her to St John’s where they teach him and do exercises. So I have seen that there is some improvement than it was before. They also encouraged me to look to God saying that one day the child will be fine.

Another participant said: “I receive a lot of support from the hospital in terms of medication. When she was 2 years old, she was failing to walk. I took her to St John of God where they were giving her soya and she started walking. She has stopped getting the soya as of now.” (Participant # 19)

Source of support

Most participants reported doing business, farming, piece works and hospital as their source of support. None of the caregivers belonged to an organization or palliative care support groups but one caregiver reported that she belongs to a village bank group that assists them when the child is sick.

Other children receiving palliative care in the community

Caregivers were asked if they knew or had seen other children with conditions similar to that of their children or those receiving palliative care in their community. Majority of the caregivers reported knowing children who were also receiving palliative care in their community. Most of the caregivers reported that they were not assisting one another because of distance as they stayed far from each other. They reported that they mostly meet at the clinic. Few caregivers reported that they helped one another by encouraging and reminding each other of the dates of appointments and doing exercises with the children as Participant # 16 explains:

The clinicians have told us to be playing and doing exercises with the children. So we form groups depending on the problems that these children have. In those groups we help each other by setting a date and place in someone's house to play with the children so that dates of appointment for physiotherapy come after we have already played with the children. This helps improve her condition other than just staying. Previously, she could not do anything but now she is improving. She was unable to sit but now she can sit. She is now learning to crawl and she feels like standing. So it is the same with my friends, and it is like a family relationship with the friends now.

Some caregivers reported that they knew nobody in their communities but were optimistic that some children were there only that they did not know them, and that the conditions have not been discovered.

Care needs of children receiving palliative care

Caregivers were asked on the things that they need when caring for their children receiving palliative care at home. The sub-themes that emerged include financial needs, information needs, transportation needs, health care needs and other daily needs.

Financial needs

All caregivers reported that they need finances for them to care for their children well. Most participants said that they needed money for transport to the hospital on dates of appointment and when the child is sick. They also needed money for buying necessary things when caring for the children. Majority reported financial difficulties due to the child's illness. Some participants reported that money was scarce due to disturbances in their businesses. Some participants revealed that they were unable to provide the supplementary foods to their children as advised by the doctors due to financial problems. One participant said:

The child needs to be eating foods like meat, chicken, eggs, and bananas frequently. But I do not have a lot of money. That is what I need. If God can bless me with finances, the child's problems will be minimized. He fails to eat chicken. As we were preparing to come here, he did not eat meat or chicken but we managed to give him bananas because of the financial problem. (Participant #22)

Transportation needs

Majority of the participants expressed the pressure that transportation need was exerting on them. Most of the caregivers reported that they had to provide transport for their child to be reviewed every month at the hospital which was difficult as most of them

reported staying far away from the hospital. Some participants reported that they had been told to go to a tertiary hospital whenever the child is sick as the following participants commented:

I can say that we have problems with transport. My wife and I do sacrifice. We carry the child on our back, and my wife feels sorry for me that I should be carrying the child on my back from home to this place. It is like a shameful thing but there is no other way that we can do. (Participant #27)

For instance, at Mapale Health Centre they told me to take the child to Mzuzu Central Hospital each time he falls sick. So it happens that the child is sick but you do not have money for transport yet it is at night. That is why we are saying that the challenge is money. (Participant # 16)

Information needs

Caregivers reported that health workers were providing information on how they should look after their children at home, hygiene and tell them to bring the children to the hospital if they notice anything strange. They supported the idea of calling them for a seminar as they said they learnt some things. Furthermore, they indicated that the money they received from such seminars enabled them to buy some necessities for their child. One of the caregivers reported that he needed enough knowledge in caring for the children and another one expressed the need for feedback on the child's condition.

Health care needs

Most of the caregivers were satisfied with the services provided by the palliative care department. They said that there was improvement in their children's condition due to the care that they received. However, majority of the caregivers pointed out that there was a need to ensure that medication was always available for them. They also raised the need for proper beddings and clothes in order to protect the children from cold. One participant reported the need for wound dressing resources as she dressed the wound at home. She mentioned gauze, cotton wool and plaster as her needs. Some caregivers expressed the need to have their medication available in hospitals that are close to their homes. They reported having problems accessing medication during the rainy season. One participant requested:

We stay very far away. From our home to Mpherembe we pay one thousand kwacha, and from Mpherembe to here we also pay one thousand kwacha. So I wanted to ask if the medication that we are getting here can be given to the hospitals that are close to our homes so that when the date of our appointment comes we can be getting the medication close to us. Now it is better as it is dry season but during the rainy season it becomes difficult to get to this place as the roads are bad.

Daily needs

Most caregivers reported the need for daily resources to care for their children. They reported the need to have enough food such as maize, bananas, cooking oil, sugar, beddings, clothes and soap. Some caregivers reported the need for additional financial support to ensure that they had enough resources to care for the child and family.

Participant # 29 said: “We need food and soap since it is difficult to find them when you do not have anything to do”.

Challenges caregivers face when caring for a child receiving palliative care

Caregivers of children receiving palliative care face a lot of challenges. Majority of the participants reported to have been affected negatively with the caring of their children.

They reported facing financial, social, physical, psychological and health service challenges.

Financial challenges

Majority of the participants reported that they were faced with financial challenges. They reported that they lacked money to buy necessary resources for the child such as food, transport, and that they were using money meant for business to care for the child. Most caregivers revealed that they had difficulties to find finances due to the child’s illness as they could not go very far, failed to go to work, and spend time in hospital. They said that they were affected by the child’s admission as they had to spend money meant for business. They could not search for piece works at far places because they had to be close to the children. Participant # 15 said: “Due to the child problem we face challenges financially. We try to find piece works nearby but we sometimes fail. I cannot go very far because of the child’s illness. I always need to be close to him”.

Most of the caregivers reported that they depended on farming which earned them money that lasted for a short period of time. Others reported that they were not working whilst others relied on piece works hence finding it difficult to meet their care demands.

Participant # 4 said: “As I said we are not working. We depend on farming. Finding money is seasonal so it becomes a problem”.

Some of the caregivers reported that their businesses were affected due to the child’s illness. They said that they would mostly return from their businesses due to the child illness. They reported that their businesses were affected because they spent a lot of time looking after the child at home as well as in hospital. Few caregivers reported being called back from their business places due to the children’s illnesses. The caregivers reported spending over a month looking after the child in hospital or at home. Two of the participants narrated:

It affects my daily life in that I do business. Most of the times it happens that I have gone for my business and I receive a phone call saying that I should go because the child has fainted. So it becomes a problem because I am the one who provides most of the care. Her father is not close to her and rarely provides the care. I can say that since the child became sick, her father has never assisted her. I assist her through the business I do, crying!!! Wiping tears. (Participant # 5)

There is a problem, when she starts coughing; the cough takes a month so for a business person it means you will not order the supplies. You just stay looking after the child meaning that your business has halted and adding another problem at home. Since we rely on business for our food and so if you are not going to do business, it becomes a problem at home. (Participant # 8)

In addition to the above experiences, few participants reported that caring was expensive as they had to buy medication when it was not available at the hospital whilst frequent hospitalizations also put pressure on their financial resources. They had to find money for the child to eat recommended foods and for transport to hospital.

Physical and psychological challenges

Caregivers said that they experience physical and psychological challenges but they said that they are just used to them because they feel that it is their responsibility as they cannot leave the child because of his/her condition. Worries and pain, lack of sleep, disturbance in household chores, living unhappy and unpredictable life and acceptance of the situation were some of the challenges that emerged. One participant said that:

Physically, we have problems but we are just used to them since we cannot give up on the child just because of the problems that she has. It is our responsibility, and we should just get used to it. We are used to it. To whom can we throw her out? (Participant # 2)

Worries and pain

Some participants reported to have worries. They were worried about the child's illness and her needs, the outcome of the illness and the child's future. Some felt that the improvement in the child's condition was minimal. One caregiver asked why God had to give her a child with such a problem. Participant # 25 said: "I have worries; sometimes I think, God, am I the only one with this kind of a child or for what purpose did God give me this child? When is he going to stop coughing? I am not worried about the problem

that he has, but frequent illnesses”. Few reported getting worried about the child’s future since the illness disturbed their growth and education, as Participant # 18 narrates:

I have worries, especially when he is sick I cannot even eat because I think of his future. For instance, his age-mates who are normal may now be starting standard 1 but when I look at him it worries me because of the way he is because he cannot start school. Looking at how he is growing we have just accepted it but we sometimes doubt if this is real.

Few participants reported that they felt pain as a result of carrying the child on their back to the bus depot when going to hospital when the child fails to walk. One caregiver reported doing piece works while feeling pain in order to find assistance for the child. Participant # 20 said:

Physically, it affects me very much because even if it is painful I do not mind until I do my piece works in order for my child to eat and be free to go to school. By the time the pain becomes severe, I have already done my work. If there was someone to assist me I could not have been doing piece works like that but go to the doctor for medication so that I should be fine.

Lack of sleep

Some participants reported that the child’s illness affected their sleep. They said that the illness could start at night while they are sleeping so they woke up to look after the child or take him to the hospital. One participant reported that: “Sometimes the illness

starts at night. She experiences difficulties in breathing. When that happens I fail to sleep and have to wake up early to take child to the hospital” (Participant # 19).

Unhappy and unpredictable life

According to the study findings, some participants revealed that they led unhappy and unpredictable life. They complained that the child’s illness was unpredictable, and are, therefore, supposed to have money all the time as they did not know whether they may go to the hospital or not thus difficult to plan for a day. Few participants also said that they were unhappy and worried of the child’s condition. They reported that when the child was sick, they would also become ill as they were anxious and unhappy as a result of the child’s illness, but felt that with the power of God the child will eventually be fine. Participant # 18 said: “It affects my everyday life because every time I need to have money since his illness is unpredictable. The illness can worsen requiring to go to the hospital so all that require that I have money. It is a very difficult life”. Participant # 13: “I am mostly unhappy and worried but with the power of God I know she will be fine”.

Disturbances in household chores

Some of the caregivers revealed that they had problems in fulfilling their household chores. Caregivers had to balance between caring for the child receiving palliative care and their household chores. They reported failing to perform their chores because caring for the sick child was their priority. They said that they would leave their work at home in order to escort the child to the hospital. Some would stop gardening or cancel their scheduled activities to look after so that the child. Participant # 1 said:

At first it affected me a lot because I had problems in doing my household chores whenever she fell sick. It is better these days because the doctors told me to give the child the drugs daily. If the child does not miss the drugs then I do not face many problems, and my work does not get disturbed. But if the child does not take the medications or I leave her to play a lot, she experiences severe pain in her legs, and she keeps on crying frequently calling and saying come here, come here, so this affects my household chores. But now with consistent medication it is better than before.

Some reported that they had limited time for their chores because they would take time attending to the child, and had to take the child to the hospital. Another participant said:

It affects my daily life especially on the issue of feeding; he does not eat the way other children eat. It takes longer feeding him hence daily programs are disturbed due to inadequate time. A lot of time is spent looking after the child. I just feel like I am retrogressing in my life but since it is my child I stay with him. I just have to plan how I do things. (Participant # 10)

Acceptance of the situation

Study findings revealed that despite the challenges faced, most of the caregivers had accepted their child's condition and look at caring for the child as their responsibility. Most of them showed that they provided the care willingly because they have accepted the situation. They said that they do not get tired because it is their children and that they

are not lazy to care for the children all the time. They said that they had accepted the child as a gift from God. Caregivers reported that caring for the child was not a burden as it was their responsibility to care for the child, as one youthful father narrates:

During the onset of the illness it was like a burden because she was weak but there is no burden that we can say that we are experiencing because we are caring for the life of our child who is our future. So we cannot see it as a burden because it is the responsibility that we have been given. (Participant # 24)

A female participant aged 23 whose child had cerebral palsy also said: “It pains me because I did not expect that I can have a child like this one but since it is God’s plan I accepted it with both hands. I am just used to it since it is mine”. (Participant #25)

Some caregivers said that they had developed ways of accomplishing their daily work demands. They stated that it was difficult to work at home when the child was sick hence they had to work hand in hand. For instance, when the mother had gone to draw water, the father would look after the child. They assisted each other in that way.

Social challenges

Most of the participants reported that they socialised well with their neighbours. However, some caregivers reported to have social challenges such as social isolation, being scorned by people in the community and being pressurised to use traditional medicines.

Social isolation

Study findings revealed that some caregivers failed to gather or socialise with friends. They had limited time for other activities as result socialisation with others was minimal. They reported that chatting or gathering with friends depended on the child's condition. If the child was well they would socialise with others but if she was not well they had to be close to the child hence failing to socialise. Caregivers reported failing to attend to church programs, for instance, women's guild meetings and do business as they mostly thought about the child's condition. The statement is supported by a participant who said:

I do not have time to chat with friends or to do business. Business is done by my husband. I am usually busy caring for the child because there is nobody who can care for him. His grandmother is around but I cannot leave him with one person because I am the one who knows him better so I have to be busy with him myself.
(Participant # 24)

Being scorned by people in the community

Some caregivers lamented the behaviour of some people in their communities. They indicated that they were having problems with some people in their communities who were making discouraging and disappointing remarks due to the children's condition. Some ridiculed them because of their children's condition. In spite of this, most caregivers reported that they were not discouraged with such remarks but few reported being worried. Participant # 15 narrates:

We experienced a lot of things during the onset of the illness because the child was very tinny. People ridiculed us a lot. They were saying that the child was sick because we are infected with HIV. Some went to the extent of saying that we should throw him into the river but we had faith in the doctors and kept coming to this hospital up until the problem was diagnosed. The situation has improved such that the child now goes to school. We did not know that he could be alive.

One of the caregivers reported that her child was being stigmatised and another complained that he was being asked a lot of questions concerning the child's illness. People were asking on the type of illness and the reasons why the child was being taken to the hospital frequently. Participant # 16 said: "At times the child is stigmatised. Some parents tell their children not to play with my child for fear of contracting the disease. That's what happens".

Pressure to use Traditional medicine

Two participants revealed that they were being advised to go to traditional healers by their family members because they did not want them to lose the child. Another one reported that he used both traditional and modern medicine as he was unsure of what would work for the child. Participant # 9 said: We meet as a family and others advise us that we will lose the child if we do not take him to traditional healers. I overcome them because I know that what the hospital personnel tell us is true since they examine the child. I know that leaving the hospital for traditional healers will benefit us nothing. We meet them but we overcome them. On the other hand, I trust in God that everything is possible with him. Our doctors are able to identify the diseases because God is with them.

Health care challenges

Majority of the caregivers reported that the health-care workers were doing a commendable job in supporting children receiving palliative care. Despite the good work, it was seen that some of the caregivers had inadequate information about their child's illness. When given the opportunity to comment, some caregivers asked when the disease will end, and the mode of transmission as follows: participant # 7 asked: "When I am breast feeding him and he bites me, will I not get the sickle cell".

The findings revealed that health worker's focus was on the child's illness than the caregiver. It was clear in statements of some of the participants that their attention was mostly on the child's progress of the condition. Participant # 6 said: "Every time we come to get medication they warmly welcome us, assist the child, give her medication, then we leave for home".

Some caregivers whose children have a heart condition expressed the challenge for timely intervention. They expressed the need for surgery to be done on time so that their children get well and be able to go to school without the caregivers being worried of them. This is reflected in this participant request:

When the child goes to school he meets friends, and when playing like this other day he was pushed by a friend and fainted. So I am worried of what would happen when he goes to primary school. The problem is on the issue of school, so that may be if there was help, since the hospital personnel at times send children for operation. I am requesting for that assistance, if possible, so that when he starts going to school he should be

fine, and I should not have worries but be able to do my household chores well. (Participant # 11)

Caregivers complained that the palliative care clinic was not opening on time, and that there were long queues at the pharmacy that made them spend a long time there before getting medication. Most caregivers reported that they were coming early and from very far for their appointments but would keep on waiting for the clinic to open. One caregiver said:

(Laughing). The problem here is that we come at 6am but we will go home at 2pm but we come from very far, and we just have transport money hence there is no food for the child to eat. Late opening of the clinic is one thing that worries us. (Participant # 15)

Caregivers' Perception of the caring role

The caring role was perceived as challenging as some of the caregivers described it as difficult, a lot of work, a big job and not an easy job as it needed them to be courageous to ensure a good and improved life for the child, as the following caregiver said:

It is a big job. At the beginning sores were erupting from her head even in her face such that when bathing her I could not know where to start from, and I had fear. But later on I became courageous enough to bathe her so that she should be fine. Someone who is not courageous cannot do it but I do dress her and care for her so that she should be happy (Participant #30).

Conclusion

The chapter has presented results of a study conducted at Mzuzu Central Hospital on the caregivers/guardians experiences of caring for children receiving palliative care. The study results are presented in five sections which are, demographic data, the role of caregivers in caring for children receiving palliative care, the support systems, care needs of children receiving palliative care and the challenges caregivers face when caring for children receiving palliative care.

CHAPTER FIVE

DISCUSSION

Introduction

The following chapter presents a discussion of the findings of a study which focused on the experiences of caregivers of children receiving palliative care at Mzuzu Central Hospital, Children Palliative Care Clinic. This study was aimed at understanding what the caregivers go through when caring for children receiving palliative care. In this chapter, the research findings are organised and discussed according to the research objectives of the study. Research strengths, limitations and recommendations are also presented.

Demographic data

In the study, females dominated as caregivers. Female caregivers tend to have the primary responsibility for child care, and are thus affected more by the caring role. This is consistent with previous studies that have reported on female dominance in the caring role (Foreva & Aseenova, 2014; Marron, et al., 2013; Thurman, Jorabi, & Rice, 2012). Despite the majority of caregivers being female, findings show that a substantial proportion of caregivers are men. This indicates that men are involved in the caring role for their children. This agrees with what has been commented by the National Alliance for caregiving and AARP (2009) which stated that the number of men in this known

female role is increasing. This could be due to changes in gender roles and recession. However, the findings revealed that female caregivers provide more care than men caregivers do. They tend to have a primary responsibility in child care which increases their risk for emotional stress and poor quality of life (Caregiving in US, 2014).

The study participants consisted of 30 mothers whose ages ranged from 19 to 64 years of age, the majority being between 26 to 35 years followed by 30 to 45 years. This age-range is the reproductive group which is on the child bearing age group of 15 to 49 years (National Statistical Office (NSO) & ICF Macro, 2011). Thus men and women within this age group are more likely to have a child under the age of 16 than caregivers above 50 years. In addition, caregivers between 26 and 45 years are more likely to be bread-winners than caregivers above 60 years. This may reflect the increased caregiver risk for financial difficulties. Age is significant in caregiving as it has an effect on the quality of life of caregivers providing care. Previous studies have associated the scores of well-being in caregivers with age, in which the increased levels of depression and stress and low ratings of subjective well-being are consistently associated with older caregiver age (McGhan, Loreb, & Penrod, 2013). Older caregivers face double burden because they too often suffer from multiple conditions and decline while on the caring role. This may affect the quality of care being provided to the children receiving palliative care. However, in this study few participants' ages were above 60.

Findings revealed that most participants were Christians who belonged to different denominations. The majority were Roman Catholic, which is one of the major denominations in Malawi. Religion and spirituality play a significant role in the lives of

most caregivers whose children are receiving palliative care (Hexem, Mollen, Carroll, Lanctot, & Feudtner, 2011). Through participation in religious practices, caregivers are able to receive support from both their spiritual communities and from God. It also enables them to define the value of the child and belief about the child's after life. Religion also helps caregivers to deal with tough times hence it is believed that it provides an orientation system through which caregivers cope with consequences of stressful life events and address larger life questions (Pargament, 1997). If caregivers are filled with feelings of hope and spiritual beliefs, they can easily overcome the stresses that come with the caregiving role.

Majority of the participants were married. This shows that they have to balance the demands of their caregiving role, their work and marital relationships. Married caregivers have better options of balancing work and caregiving than single caregivers since they are able to share responsibilities. However, strain and depression have been reported to negatively affect marital relationships (Mc Clorkle & Pasacreta, 2001; Otis green & Juarez, 2012). Similarly, findings from a recent study on caregivers whose child had Down's syndrome revealed that by the time the child was 24 months, 6 couples had divorced, separated or showing signs of poor marital relationship (Byleveldt, 2013). On the contrary this study found that caregiving brought them closer as the majority reported that they were being supported by their spouses in the care of their sick children. This is consistent with the findings of Marcia et al. (2001) who reported that the presence of a child with a disability in a family brings the family together as the family collaborates in caring for the child thereby reducing the chances of divorce.

It was encouraging to find that all participants had ever attended school. Majority went through primary education, few had secondary and very few had tertiary education. It could be suggested, therefore, that any person despite the level of education can assume the caregiving role. Having education is of significance as it allows people to positively contribute and become active members in a society as well as at the hospital. Educated caregivers would easily understand key messages, information that health providers may tell them and situation. Understanding and involvement in patient care plans can influence their care experience. Education level of the caregiver also tends to enable caregivers to have more knowledge to deal with the stressful events. The findings of the education level of the research subjects are of clinical importance because the caregiver educational level influences burden of the caregiver (Rafiyal & Sutharangsee, 2011). Despite all the caregivers attending school, majority had lower education levels which are predictive of higher levels of caregiver depressive symptoms (Schulz & Sherwood, 2009). Lower educational levels appear to increase the risk of financial challenges for the caregivers (Caring for the caregiver, 2004) and has been associated with lower social economic status, thus inadequate resources are available to caregivers despite being faced with the challenges and caregiver related stressors.

Majority of the caregivers were farmers followed by housewives then working and business caregivers. This indicates that unemployed/self-employed caregivers dominated in the interview. Full employment provides secure income and empowerment to the caregivers. Low household incomes and fewer financial resources can result in increased caregiver risk for negative outcomes (Reinhard, Given, Petlick, & Bemis, 2008). Caregivers who are unemployed or with low income may experience more distress

due to inadequate resources to meet children's care demands. This will likely have an impact on the quality of care to be provided to the children receiving palliative care. Families with higher incomes have greater financial resources to buy things that are needed during care hence might not be over-burdened as those with fewer resources.

The children's diagnosis in the study included sickle cell anaemia, rheumatic heart disease, congenital heart disease, hydrocephalus, cerebral palsy, laryngomalacia, Down's syndrome, tetralogy of fallot, nephritic syndrome, wilms tumour and skin cancer. The results of this study were consistent with those of Inglin and Bergstraesser (2011) and Conor and Bermedo (2014) who reported that children requiring palliative care services are those with progressive conditions such as cancer, cardiovascular diseases, neurological disorders, neonatal conditions, metabolic and hematologic conditions. Several studies on paediatric palliative care have concentrated on cancer as the main diagnosis requiring palliative care. Amery (2009) reported that cancer and HIV and AIDS are the major conditions that have increased the need for palliative care. On the contrary, this study found that children with cardiac and haematological conditions were in majority. This may indicate that the need for palliative care for the other conditions is not well known, hence, there is need for awareness on all the conditions that require palliative care services the children.

The role of caregivers in caring for children receiving palliative care

The current study revealed that caregivers mainly assisted with activities of daily living and health care management that is nutrition support, follow up care, and medical management. The findings are consistent with previous studies (Buchanan, et al., 2009;

Zapart, et al., 2007). The significance of caregivers in the caring role may not be overemphasized. A large body of research has reported on the significance of caregivers in caring for children with life-limiting or threatening conditions (Hoffman, et al., 2012; Marrow-Howell & Proctor, 1998; Sipountzi –Krepia, et al., 2008). Most of the physical, emotional, social and psychological support to patients is provided by them. These findings are consistent with the present study. In addition, the findings of this study agrees with studies done by Marrow-Howell and Proctor (1998) and Sipountzi-Krepia, et al. (2008) in that all the caregivers were related to the children and performed various roles. Studies have described the roles that caregivers perform such as provision of nutrition support, medication management, physical care, emotional and spiritual support (Buchanan, et al., 2009; Doris, 2007; Emmanuel, et al., 2008; Plank, et al., 2012; Sawatzky & Fowler – Kelly, 2003). However, Zapart, et al. (2007) in their study noted that depending on the age of the patient, condition and ethnic group and location the roles could be different. Thus in the current study, in addition to the mentioned roles, caregiving roles included making decisions on when to feed the child, protection from harm as in bad weather, infections and injury, nutrition support, follow up care and medical management. These findings are consistent with what previous studies have reported (Gayomali, et al., 2008; Mok, et al, 2012; Plank, et al., 2012). The findings are vital as they may help the health providers on how best to assist the caregivers in the performance of their roles since the caregivers mostly wish to know how to become competent safe caregivers who can better protect their child from harm.

Study findings indicated that family members were the key providers of care. This is similar to what was found in literature (Emmanuel, et al., 2008; Kneipp, Castleman, &

Gailor, 2004). The caregiving role in the current study was provided by the mother, father, grandmother, neighbours and aunt of the children. However, the mother dominated as a key provider of care in the study. There could be a possibility that during the time the interviews were being done, mothers were the ones who escorted the patient to the clinic hence participated in the study. On the other hand, dominating in care provision may not reflect the degree of support provided. It may not be surprising, therefore, if the study agrees with Mawani, et al. (2013) that the mothers were not the only key providers and agrees with Monterosso, et al. (2007) as some children key care providers were aunt, fathers and grandmothers due to either deaths or other life demands. The caregiver relationship with the patient and family members support is paramount in the provision of care because close relationships with patient and support from the family enables caregivers and the patient to feel loved and worthwhile thereby boosting their self esteem and perceptions of their role. Caregiving by members of the family and friends is integral to maintaining the health and wellbeing of children with life limiting illnesses and it allows the children to be in their homes rather than staying in hospital setting.

Most caregivers have accepted to live with their children despite the conditions that they have and look at caring for the child as their responsibility as they cannot live the child because of the illness. They willingly provide the care and do not view it as a burden though it comes unexpectedly. Lack of choice and preparedness in assuming the caregiving role has been reported (Brazil, et al., 2012; Scherbring, 2002; Schulz, et al., 2012). Consistent with the findings in the present study, Gilgis, et al. (2013) and Kusqu, et al. (2009) indicated that majority of the caregivers took on the role because of family

responsibility or as an obligation/duty that they must uphold for their loved ones. On the contrary, Foreva and Assenova (2014) indicated lack of organised services for palliative care as the reason caregivers chose to care. In Malawi, cultural factors play a role in the choice of caregiving as mostly children are cared for by their female relation because women have been placed with the caring responsibility. Lack of choice in caregiving role has been associated with negative impacts such as higher levels of emotional stress and physical strain. These factors are likely to challenge the caregiver's ability to provide quality health care to children. The investigations on caregivers perception of willingness to care is important as it may lead to distress which in turn may result into anger, resentment and poor relationship with the child, hence affecting the provision of care. Caregiver's willingness to care is crucial as it has been reported to improve their ability to cope and look forward (Blindhein, et al., 2012), associated with grief and depressive symptoms (Calvete, et al., 2012). Thus supporting caregivers to accept their situations will enhance their well-being.

The study findings revealed that caregivers perceived the caring role as challenging, a lot of work, and not an easy job. This reflects previous study findings (Blindhein, et al., 2012; Buchanan et al., 2009; Plank, et al., 2012; Navab, et al., 2012). It could be suggested that the caregiver's perception of the caregiving role related to other countries although inadequate resources and support might have influenced their perception (Robinson, et al., 2009).

The care needs of children receiving palliative care at home

Findings in this study revealed that caregivers had unmet financial, information, transportation, health care and other daily needs in meeting the needs of their children which are consistent with previous studies (Docherty, et al., 2012; Hudson, 2004; Zapart, et al., 2007; McILfattrick, 2007); Fonseca, et al., 2012). Caregivers reported the need for money for transportation to hospital as they had to take the child to hospital every month for follow-up care and to buy things required by the child. Majority reported experiencing financial difficulties due to the child's illness hence they were unable to meet their financial demands. Out of pocket expenses have been found to impact heavily on caregivers of children requiring palliative care resulting into the need for additional income and assistance (Herce, et al., 2014; Lindley & Mack, 2010; Zapart, et al., 2007). The study confirms the prevalence of unmet needs among the caregivers of children with life-threatening or limiting conditions receiving palliative care, and is consistent with previous studies (Aoun, et al., 2005; Hudson, et al., 2011; Joad, et al., 2011; Ventura, et al., 2013) that describe numerous unmet needs among these families. Majority of the caregivers in the study were of low to middle income levels hence it may not be surprising that inadequacies were reported since previous research (Lindley & Mack, 2010) has shown that families with low income are at high risk for having inadequate resources and difficulty with access to services that improve the child health outcomes.

An unmet need for information on caring for the child and feedback on the child condition and progress was reported which is consistent with previous studies (Aoun, et al., 2005; Farmer, Marien, Clark, Sherman, & Selva, 2004; Mc ILfattrick. 2007; Selman, 2009). Caregivers need to know more than what palliative care providers would imagine.

They require adequate information because they are always close to the child and are an immediate helper for the child at home. Hence, they need to have adequate information on how to comfort and look after the child at home. Inadequate information leads to negative effects. Ineffective communication and information may lead to poor continuity of care thereby impacting negatively on the care to be received by the patients and caregivers (Ventura, et al., 2013).

Health care needs, that is, availability of medication, affordable ways of transporting children to hospital, wound dressing resources, proper beddings, and clothes, food and educations concerns came out in the study. The finding is familiar to those found in previous studies (Creedy, et al., 2004; Herce, et al., 2014; Greere, 2012; Superveda, 2003). Unmet needs vary depending on the complexity of the child's condition. Caregivers and children with complex conditions reported to have high levels of unmet psychological and emotional needs. In this study, unmet needs in patients and caregivers may have arisen as a result of lack of adequate information about the disease, process and lack of psychosocial support resources. These are mostly attributed to inadequate resources and shortage of staff. With adequate professionals and community support, caregivers may be able to access more resources and function effectively as their needs may be reduced hence, promoting the child's health and quality of life.

Majority of the caregivers were of low socio-economic status, a group that has been reported to require intensive support due to higher levels of unmet needs as a result of high level burden. Unmet needs increase the psychological burden of children and their families thereby decreasing the families' ability to enhance their child's health

(Drotar, et al., 2001, as cited in Farmer, et al., 2004). Psychological and social needs of patients and caregivers have been found to be underestimated (Bajwah, Higginson, Ross, Wells, Riley, & Koffman, 2013), however, these psychosocial needs are important domains in the paediatric palliative care philosophy and quality of life, hence, the need for a comprehensive and well-coordinated paediatric palliative care that will meet the needs of children and caregivers needs to be a priority in Malawi. Previous studies have suggested that promotion of the scope and coordination of care has a positive impact on the child's family and psychological adjustment, satisfaction of care and health care utilization (Drotar, 2001 as cited in Farmer, et al., 2004; Stein, 2001). Such type of strategies can be adopted and used to improve the quality of life of children with life threatening and limiting illnesses. The study findings unveils the significance of thoroughly examining the needs of children and caregivers when providing paediatric palliative care, and palliative care providers are key in ensuring that the caregiver and child needs are met.

Caregiver Support systems

The study findings revealed that family members and community members that is, neighbours, friends, church members and health personnel formed part of the support system. These findings endorses the examples of the support systems that have worked well for caregivers in Canada and Sweden as found by Sawatzy and Fowler- Kelly (2003) and Milberg and Strang (2004). However, the difference is on home care services which are rarely done in this setting. A possible explanation, however, may be shortage of staff and inadequate resources. Despite offering different levels of support together, the

support rendered to caregivers play an important role for the wellbeing of caregivers of children and children in their care.

Caregivers appreciated the support from family and community members which included visiting them when admitted in hospital, escorting them to the hospital when the child becomes ill, looking after the child, provision of food, and money thus, social-emotional support. The National Cancer Institute Dictionary of Cancer Terms and Definitions that defines social support as the network of family, friends, neighbours and community members that are available in times of need to give physical, psychological and financial help (www.cancer.gov). This shows that what transpired in this study was well within acceptable practice. In addition, it relates to the types of support given to caregivers as reported by Casale and Wild 2012. Social support is significant in maintaining good physical and mental health of the caregivers. The caregiver's health has been associated with good parenting and child health (Smith, Fawz, et al. 2010; Stein, Ramchandani, & Murray, 2008). Hence, the effects of social support on caregiver's health can also affect the child's well-being. Social support of high quality promotes resilience to stress, protect caregivers against developing trauma-related disorders, reduces medical morbidity and mortality and improves caregivers' experiences (Ozbay, et al., 2007; Shirai, et al., 2009). Thus, it could be deduced that lack of such support greatly affects the caregiver and the sick child and will deter the efforts of providing quality palliative care services.

Majority of the caregivers reported putting the needs of their child first than theirs and that the health personnel's focus was also directed at the assessment of the sick child.

The findings are similar to what previous studies have reported (Murphy, Christian, Caplin, & Young, 2006; Rodriguez & King, 2009). Caregivers felt that when the child is assisted then they have also been assisted since they come to the hospital due to the child's problems. However, when a child in a family has been diagnosed with a life limiting or threatening illness, the whole family or caregiver becomes sick as well hence requires thorough assessment. Inadequate assessment of caregivers may result in unmet physical, psychological, social and emotional needs which may affect their well-being. Thus, it would be necessary for palliative care providers to conduct a complete assessment of both the child and the caregiver during palliative care follow-up visits.

Family members, especially spouses and grandmothers, community and church members' support were greatly appreciated by the caregivers in the study. Therefore, this study agrees with Benin, et al. (2008), Joad, et al. (2011), Milberg and Strang (2004) and Plank, et al. (2012) that family members and friends play an important role in supporting caregivers during the child's illness. Caregivers reported being supported by community members, health personnel and family members contrary to findings by Gysels, Pell, Straus, and Pool (2011); Amakali and Small, (2013), Inglin, et al., (2011) who reported lack of professional and extended family support. They reported being supported financially, materially, emotionally and psychologically through household chores, prayers and money, and encouragement. This support is vital to caregivers as it enables them to have a break in caring thereby helping them to rest. They are relieved from the caring role demands as they may concentrate on child caring role while others are doing the household chores hence the burden of caring is minimised. Prayers also enable caregivers to improve their faith, perception of life issues thereby enabling them to cope

with the child's illness. It also provides a common theme and potential strength upon which palliative care providers can build strength in their intervention with caregivers (Roff, Burgio, Gutlin, Nicholas, Chaplin, & Hardin, 2004).

Challenges caregivers of children receiving palliative care face

The study also looked at the challenges that caregivers of children receiving palliative care face. Consistent with previous data, the study found caregivers to be greatly impacted by the child's illness, economically, physically, psychologically and socially. Caregiver's failure to meet the child's caregiving demands creates an extensive burden. Financially, caregivers lacked money which was needed to pay for transport, and buy other resources such as food. The respondents found it difficult to find finances as they could not go very far, failed to go to work, spent most of the time in hospital, experienced disruptions in their businesses, and most of them depended on farming. The findings are in agreement with previous studies of caregiver experiences or challenges (Floriani, 2010; Lindley & Mack, 2010; Mc Grath, 2001), all of which demonstrated financial difficulties as a result of caring for a child with life-threatening illnesses. Caregivers lacked money, sold assets and had disruption in their businesses. However Lindley and Mack (2010) in their study found that perception of the financial burden depended on the amount of financial resources the family had at its disposal. Those that did not have sufficient financial resources perceived health care expenses as a burden while those with adequate resources did not perceive it as a burden. In the current study, most caregivers had low education and were farmers living in rural areas which predispose them to limited employment opportunities, lower incomes, limited financial resources and difficulties in getting access to hospital.

Some caregivers were potential earners but disturbances in work and businesses due to caring for children compromised their earning potentials. In order to meet the demands of caregiving, caregivers may use their savings, sell assets and may find other sources of finding finances. Similarly, this study found that caregivers had to use money meant for business and do some piecework to meet the child's health demands. Such effects may lead to stress and depression on the caregivers because they may not have adequate resources and skills to cope with such effects hence it could be suggested that palliative care providers need to evaluate the caregivers of children with life limiting illnesses on palliative care of the risk factors for increased caregiver burden and offering them with assistance that could reduce their perceived challenges of caregiving. On the contrary, no financial challenges were found in Toljamo, et al. (2012) study. Most caregivers felt that caregiving had caused no financial difficulties in their families.

Contrary to Toljamo, et al. (2012) findings on the physical and psychological challenges, the study found that caregivers experienced worries, pain, and lack of sleep, disturbance in household chores, unhappy and unpredictable life and the challenge of accepting the situation. The differences could arise due to differences in setting, cultures or individual perception. However, some studies found similar findings (Floriani, 2010; Houldin, 2007; Mawani, et al., 2013; Marron, et al., 2012; Murphy, et al., 2006). Physical and psychological challenges are of clinical significance as they affect the child's and caregivers' quality of life and level of performance in the care. Despite these, the caregiver's assessment on psychological and social issues has been inadequate in our settings. These findings show the importance of these challenges in the delivery of paediatric palliative care in our setting.

Social isolation, being scorned by people in the community and pressure to use traditional medicines were some of the social challenges found in the study. This is consistent with previous studies (Byleveldt, 2013; Mok, et al, 2003; Monterosso, et al., 2007; Robinson, et al., 2009) but differ in the sense that pressure to use traditional medicines was only reported in this study which could be a result of the traditional beliefs of the participants involved in the study. This finding is vital because such challenges would keep the caregivers away from friends and neighbours and community who are significant in the provision of social and emotional support. Refraining from social interaction may result into neglecting their own needs and may result in feelings of guilt towards themselves and others (Rodriquez & King, 2009). These may also discourage the caregivers from the act of caring or may hide the children thereby affecting the quality of life of the children with life limiting or threatening illnesses.

Contrary to findings on communication with health professional by Beckstrand and Kirchhoff (2005) and Davies, et al. (2008) there was good relationship and communication among patients, caregivers and palliative care providers. They portrayed positive attitudes despite staff shortage and time constraints. The health personnel's relationship and good communication may influence caregivers' positive outcome experiences which may impact on the caregiver's role resulting into adequate provision of care to the children. Despite the challenges, caregivers felt that it was their responsibility to look after their children. Positive experiences such as feeling of satisfaction to assist the child, being close to the child and acceptance of the child as a gift from God were reported. This confirms what other studies have highlighted (Mawani, et al., 2013; Toljamo, et al., 2012; Li & Loke, 2013 Wong & Ussher, 2009) that caring

for a child with life limiting illnesses has both positive and negative experiences. Positive experiences are significant because they have been related to caregivers' ability to cope with the challenges of caring. Thus, positive aspects of caregiving have been associated with positive coping and adaptation (Henrikson, et al., 2013; Mackenzie & Greenwood, 2012).

Constraints and limitations

The study was conducted at one site due to inadequate time for data gathering and financial constraints as the study was a requirement for the fulfilment of a Master's Degree in Child Health Nursing of which the researcher had to follow the school calendar. However, conducting the study at multiple sites could have enriched its findings. The study was conducted in one setting and region which might limit its generalization, and also because the results are based on individual experiences of caregivers of children receiving palliative care at Mzuzu Central Hospital. In addition, some eligible participants could not be interviewed because they complained that they did not have enough time for the interview and some interviews were terminated due to constant interruptions by the children as the caregivers could not concentrate on the interview.

Dissemination of the findings

Dissemination of the results will be done to health professionals and research interest groups locally at departmental and national level meetings, and at caregivers meetings, seminars and conferences. Findings of the study will possibly be published as a journal article where it may be accessed by palliative care providers and other health

professionals in practice and education. Copies of the report will be submitted to COMREC, Mzuzu Central Hospital and Kamuzu College of Nursing library.

Recommendations

- Palliative care providers need to look at the caregivers of children receiving palliative care as care recipients as well hence they should be able to assess the psychological, social, emotional, financial, and spiritual challenges that they encounter in their caring role which requires their comprehensive support.
- Palliative care providers should lobby for the availability of resources for the children on palliative care so that their quality of life should be enhanced.
- Palliative care providers need to find out about the organisations working in their surrounding communities so that they should be able to lobby for support, and advise the caregivers accordingly.
- Palliative care providers should initiate the creation of support groups for families with children receiving palliative care so that they could be able to meet and share information, experiences and support each other.
- Health education and sensitization of the communities on palliative care conditions and the significance of supporting families that have children with life limiting and threatening illnesses on palliative care needs to be done
- Palliative care providers should plan for interventions that will enhance caregivers coping and adaptation and most importantly ensure that caregivers are assisted physically, psychologically, socially and with available resources to enable them care for the child at home.

- Health care providers need to provide adequate information to the caregivers on the condition and how to care for the child at home, and the palliative care secretariat need to develop guidelines on the important information that caregivers should be given.
- There is need for Ministry of Health to come up with policies that will consider the caregivers quality of life
- Research need to be conducted on the interventions that could help the caregivers to cope with the challenges and provide care effectively.
- Management of Mzuzu Central Hospital should ensure that adequate and staff trained in palliative care is being deployed to the palliative care clinic to improve care and reduce caregivers waiting time for the providers.
- Nursing and medical programs should ensure that students gain knowledge and skills on assessment and management of caregivers of children who are on palliative care by including it in their curriculum so that caregiver care should be improve

Conclusion

Caregivers of children receiving palliative care are paramount in promoting the health and quality of life of the children receiving palliative care. Caregivers perform various roles in their caregiving role. They assist with activities of daily living and health care management in addition to their family roles. Children with life-limiting or threatening illnesses receiving palliative care require enhancement of their quality of life, hence they need transportation to hospital,

finances for daily expenses, education, adequate information, physical and emotional support, and health care support. Family members, community members such as neighbours, friends, church members and health care personnel formed part of their support system.

Caregivers' experiences in caring included, social, financial physical, psychological and health care challenges and satisfaction to care. These findings provide evidence of the significant unmet needs and challenges that caregivers go through when providing care to children who are receiving palliative care. Hence Palliative care providers should plan for interventions that will enhance caregivers coping and adaptation should be developed and most importantly ensure that caregivers are assisted physically, psychologically, socially and with appropriate resources to enable them care for the child at home and the Ministry of Health planning team should come up with policies and pilot interventions that have been used in other countries that have helped caregivers to cope with the challenges and provide the care effectively. there is need to conduct other studies that will investigate the challenges of caregivers of children depending on the conditions since the study revealed that challenges may depend on the child condition and complexity.

Reference

- Abernethy, A., Burns, C., Wheeler, J. & Currow, D. (2009). Defining distinct caregiver subpopulations by intensity of end-of- life care provided. *Palliative Medicine*, 23, 66–77.
- Africa Palliative Care Association. (2010). *APCA standards for providing quality care across Africa*. Kampala, APCA
- Amakali, K., & Small, L. F. (2014). A support program for caregivers of children with heart disease in rural Namibia. *Open Journal of Social Sciences*, 2, 97-104.
- Amakali, K., & Small, L. F. (2013). The plight of parents/caregivers of children with heart disease in the rural areas of Namibia : a problem of coping. *Global Journal of Health Sciences*, 5 (2), 62- 73.
- Amery J. (2009). *Children palliative care in Africa*. London, Oxford University Press.
- Aoun, S. M., Kristjanson, L. J., Currow, D. C. & Hudson, P.L. (2005). Caregivers for the terminally ill: at what cost. *Palliative Medicine*, 19, 551- 555.
- Archbold, P.G., Stewart, B. J., Greenlick, M. R., & Harvath, T. (2007). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing and Health*, 13 (6), 375–384. DOI: 10.1002/nur.4770130605

- Asuquo, E. F., Etowa, J.B., & Adejumo, P. (2013). Assessing the relationship between caregiver burden and availability of support for family caregivers of HIV patients in Calabar, South East Nigeria. *World Journal of AIDS*, 3, 335 -344.
- Baidoobonso S. (2014). *Effect of supportive interventions on informal caregivers of people at the end of life: a rapid review*. Toronto: Health Quality Ontario.
- Beckstrand, R. L., & Kirchhoff, K. T. (2005). Providing end-of-life care to patients: critical care nurses' perceived obstacles and supportive behaviors. *American Journal of Critical Care*, 14(5), 395 -403.
- Benini, F., Spizzichino, M., Trapanotto, M., & Ferrante, A. (2008). Paediatric palliative care. *Italian Journal of Paediatrics*, 34, 4. doi: 10.1186/1824-7288-34-4
- Blindheim, K., Thorsnes, S. L., Brataas, H.V., & Dahl, B. M. (2012).The role of next of kin of patients with cancer learning to navigate unpredictable caregiving situations. *Journal of Clinical Nursing*, 22, 681- 689.
- Bond, J., Greyson, B. A., Bamford, C., Buck, D., Mc Namee, P., & Wright, K. (1999). Informal caregiving for frail older people at home and in long term care institutions: who are key supporters? *Health and Social Care in Community*, 7(6), 434 – 444.
- Boucher, S., Downing, J., & Shemilt, R. (2014).The role of play in children palliative care. *Children*, 1, 302 – 317.

- Buchanan, R., Radin, D., Chakravorty, B., & Tyry, T. (2009). Informal care giving to more disabled people with Multiple Sclerosis. *Disability and Rehabilitation*, 31(15), 1244 – 1256.
- Brazil, K., Thabane, L., Foster, G., & Bédard, M. (2009). Gender differences among Canadian spousal caregivers at the end of life. *Health and Social Care in the Community*, 17(2), 159–166.
- Brikci, N. & Green, J. (2007). *A guide to using qualitative research methodology*. London, Medicines sans Frontieres.
- Brink, H. (2006). *Fundamentals of Research Methodology for Healthcare Professionals* (2nded.). Cape Town, Juta & Co (pvt) Ltd.
- Burns, N. & Groove, S.K. (2007). *Understanding Nursing Research: Building Evidence-Based Practice* (4thed.). St Louis, Saunders: Elsevier.
- Byleveldt, T. A. (2013). *Exploring the well-being of caregivers of a family member with Down's syndrome in Namibia*. Unpublished master's thesis, University of Namibia.
- Cadell, S., Kennedy, K., & Hemsworth, D. (2012). Informing social work practice through research with parent caregivers of a child with a life-limiting illness. *Journal of Social Work in End-of-life and Palliative Care*, 8(4), 356-381.

- Calvete, E., & Lo'pez de arroyabe, E. (2012). Depression and grief in Spanish family caregivers of people with traumatic brain injury: The roles of social support and coping. *Brain Injury*, 26 (6), 834–843.
- Candy, B., Jones, L., Drake, R., Leurent, B., & King, M. (2011). Interventions for supporting informal caregivers of patients in the terminal phase of a disease. *Cochrane Database of Systematic Reviews*, 6 CD007617. DOI: 10.1002/14651858.CD007617.pub2.
- Casale, M. & Wild, L. (2012).The relationship between social support and the health of HIV positive Caregivers of children. A review of empirical literature. *Vulnerable Children and Youth Studies*, 7 (3), 260 -282.
- Cohen, C. A., Colantonio., & A. Vernich, L. (2002). Positive aspects of caregiving: rounding out the caregiver experience. *International Journal of Geriatric Psychiatry*, 17, 184- 188.
- Connor, S.R. & Bermedo, M. C. S. (eds). (2014). *Global atlas of palliative care at the end of life*. London, Worldwide Palliative Care Alliance.
- Creedy, D., Collis, D., Ludlow, T., Cosgrove, S., Houston, K., Irvine, D., Fraser, J. & Maloney, S. (2004).Development and evaluation of an intensive intervention program for children with a chronic health condition: a pilot study. *Contemporary Nurse*, 18(1/2).

- Creswell, J.W. (2013). *Qualitative inquiry and research design: choosing among five approaches* (3rded.). New Delhi, SAGE publications.
- Davies, B., Sehring, S.A., Partridge, J.C., Cooper, B.A., Hughes, A., Philp, J.C., Amidi-Nouri, A. & Kramer, R.F. (2008). Barriers to palliative care for children: perceptions of paediatric health care providers. *Paediatrics*, 121, 282- 289.
- Docherty S. L. Thaxton C. Allison C. Barfield R. C. & Tamburro, R.F. (2012). The nursing dimension of providing palliative care to children and adolescent with cancer. *clinical medicine insights: Paediatrics*, 6, 75 – 88.
- Doris, T. (2007, April – August). Care for the family in palliative care, palliative medicine Doctors – *HKSPM Newsletter*, 1& 2, 26.
- Emmanuel, N., Simon, M.A., Burt, M., Joseph, A., Sreekumar, N., kundu, T., ...
Emmanuel, L. (2010). Economic impact of terminal illness and the willingness to change it. *Journal of Palliative Care*, 13(8), 941-944.
- Emmanuel, R.H., Emmanuel, G.A., Reitschuler, E.B., Lee, A.J., Kikule, E., Merriman, A., & Emmanuel, L. L., (2008). Challenges faced by informal caregivers of hospice patients in Uganda. *Journal of Palliative Medicine*, 11(5), 746 – 753.
- Farmer, J.E., Marien, W.E., Clark, M, J., Sherman, A., & Selva, T. J. (2004). Primary care support for children with chronic health conditions: Identifying and predicting unmet family needs. *Journal of Paediatrics Psychology*, 29 (5), 355 – 367.

- Floriani, C.A. (2010). Home-based palliative care: challenges in the care of technology-dependent children. *Journal de Pediatria (Rio J)*, 86(1), 15-20.
- Fonseca, C., Rebelo, T., Andracke, C., Lopez, P., Franco, T., Rodrique, D., & Antunes, A. (2012). Needs of the end of life of patient's caregivers in terms of nursing care: systematic review of the literature. *Journal of Palliative Care Medicine*, 2 (5):1-5.
- Foreva, G. & Assenova, R. (2014). Hidden patients: the relatives of patients in need of palliative care. *Journal of Palliative Medicine*, 17(1), 56 – 61.
- Foster, T. L. (2008). *A Mixed Method of Study of continuing bonds: maintaining connections after the death of a child*. Doctoral dissertation. Graduate school of Vanderbilt University, Nashville, Tennessee.
- Fouka, G. & Mantzorou, M. (2011). What are the major ethical issues in conducting research? Is there conflict between the research ethics and nature of nursing? *Health Science Journal*, 5(1), 3 – 14.
- Francis, L.E., Worthington, J., Kypriotakis, G., & Rose, J.H. (2010). Relationship, quality and burden among caregivers of late-stage cancer patients. *Support Care Cancer*, 18(11), 1429 – 36.
- Gayomali, C., Sutherland, S. & Finkelstein, F. (2008). The challenge for the caregiver of the patient with chronic kidney disease, *Nephrol Dial Transplant*, 23, 3749 – 3751.

Geere, J. L., Gona, J., Omondi, F. O., Kifalu, M.K., Newton, C.R., & Hartley, S. (2012).

Caring for children with physical disability in Kenya: potential links between caregiving and carers' physical health. *Child: Care Health and Development*, 39(3), 381 – 392.

Gerrish, K. & Lacey, A. (2006). *The research process in nursing* (5thed.). Oxford, Blackwell publishing.

Girgis, A., Lamberts, S., Johnson, C., Waller, A., & Currow, D. (2013). Physical, psychosocial, relationships, and economic burden of caring for people with cancer : a review. *Journal of Oncology Practice*, 9(4), 197 – 202.

Gilgis, A., Lambert, S.D., Mc Elduff, P., Bonevski, B., Lecathelinias, C., Boyes, A., & Stacey, F. (2013). Somethings change somethings stay the same: a longitudinal analysis of cancer caregivers' unmet supportive care needs. *Psycho- Oncology*, 22, 1557 – 1564.

Glajchen, M. (2004). The emerging role and needs of family caregivers in cancer care. *The Journal of Supportive Oncology*, 2 (2), 145 – 155.

Grant, L., Brown, J., Leng, M. Bettega, N. & Murray, S.A. (2011). Palliative Care making a difference in rural Uganda, Kenya and Malawi: three rapid evaluation field studies. *Biomed Central Palliative Care*, 10 (8). doi:10.1186/1472-684X-10-8

Grant, M., Sun, V., Fujinami, R., Sidhu, R., Otis-Green, S. Juarez, G. Klein, L., & Betty, F. (2013). Family caregiver burden, skills preparedness, and quality of life

in non-small-cell lung cancer. *Oncology Nursing Forum*. 40(4), 337–346.

doi:10.1188/13.ONF.337-346.

Gysels, M., Pell, C., Straus, L., & Pool, R. (2011). End of life care in Sub-Saharan Africa: a systematic review of qualitative literature. *Biomed Central of Palliative Care*, 10 (6), 1-10

Hancock, B., Ockleford, E., & Windridge, K. (2007). *An introduction to qualitative research*. Nottingham: The National Institute for Health Research (NIHR), Research design service for East Midlands.

Harding, R., Sheer, L., Albertyn, R. (2010). *The status of paediatric palliative care in sub-Saharan Africa: an appraisal*. London: The Diana princess of Wales Memorial fund, Kings College.

Hebert, R.S., & Schulz, R. (2006). Caregiving at the end of life. *Journal of Palliative Medicine*, 9 (5), 1174- 1187.

Henrikson, A., Årestedt, K., Benzein, E., Ternstedt, B., & Andershed, B. (2012). Effects of a support group programme for patients with life-threatening illness during ongoing palliative care. *Medicine*, 27(3), 257 –264.

Henriksson, A., Carlander, I., & Årestedt, K. (2013). Feelings of rewards among family caregivers during ongoing palliative care. *Palliative and Supportive Care*, 1-9.
doi: 10.1017/S1478951513000540.

- Henrikson, A., Ternestedt, B., & Andershed, B. (2011). Meeting the needs of family members of persons with life-threatening illness: A support group program during ongoing palliative care. *Palliative and Supportive Care*, 9, 263- 271.
- Herce, M. E., Elmore, S.N., Kalanga, N., Keck, J.W., Wroe, E.B., Phiri, A., Mayfield, A. (2014). "Assessing and responding to palliative care needs in rural Sub-Saharan Africa: results from a model intervention and situation analysis in Malawi." *PLoS ONE*, 9 (10), e110457.doi:10.1371/journal.pone.0110457.<http://dx.doi.org/10.1371/journal.pone.0110457>.
- Hexem, K.R., Miller, C.J., Carroll, K., Lanctot, D.A., & Feudter, C.(2011). How parents of children receiving paediatric Palliative care use religion, spirituality or life philosophy in tough times. *Journal of Palliative Medicine*, 14 (1), 39- 44.
- Hoffman, M., Mofolo, I., Salima C., Hoffman, I., Zadrozny, S., Martinson, F., & Vander Horst, C. (2012). Utilization of family members to provide hospital care in Malawi: the role of hospital guardians. *Malawi Medical Journal*, 24(4), 56 – 60.
- Hodgson, N. A., Black, B. S., Johnston, D., Lyketsos, C., & Samus, Q.M. (2014). Comparison of unmet care needs across the dementia trajectory: findings from the maximizing independence at home study. *Journal of Geriatrics Palliative Care*, 2(2), 5.

- Houldin, A.D. (2007). A qualitative Study of caregivers' experiences with newly diagnosed advanced with Colorectal Cancer. *Oncology Nursing Forum*, 34(2) 324-340.
- Hudson, P. (2004). Positive Aspects and Challenges associated with Caring for a dying relative. *International Journal of Palliative Nursing*, 10, 58 -65.
- Hudson, P., & Aranda, S. (2014). The Melbourne family support program: evidence-based strategies that prepare family caregivers for supporting palliative care patients. *Supportive & Palliative Care*, 4, 231 – 237.
- Hudson, P.L., .Aranda, S., & Kristjanson, L.J. (2004). Meeting the supportive needs of family caregivers in palliative care: challenges for Health Professionals. *Journal of Palliative Medicine*, 7(1), 19 – 25.
- Hudson, P., & Payne, S. (2011). Family Caregivers and Palliative Care: Current Status and Agenda for the Future. *Journal of Palliative Medicine*, 14(7), 864 – 869.
- Inglin, S., Hornung, R., & Bergstraesser, E. (2011).Palliative care for children and adolescents in Switzerland: a need analysis across three diagnostic groups. *European Journal of Paediatrics*. 170, 1031 -1038.
- Israels, T., Ribeiro, R. C., & Molyneux, E. M. (2010). Strategies to improve care for children with Cancer in Sub Saharan Africa. *European Journal of Cancer*, 46 (1), 1960- 6.

- Jermal, A., Bray, F., Ferlay, J., Ward, E., & Forman, D. (2011). Global cancer statistics. *Ca Cancer Journal for Clinicians*, 61(2), 69 – 90.
- Joad, A. S.K., Mayamol, T.C., & Chaturvedi, M. (2011). What does the informal caregiver of a terminally ill cancer patient need? A study from Cancer Centre. *Indian Journal of Palliative Care*, 17 (3) 191 – 196.
- Junger, S., Vedder, A.E., Milde, S., Fischbach, T., Zernikow, B., & Radbruch, L. (2010). Paediatric palliative home care by general paediatricians: a multimethod study on perceived barriers and incentives. *Biomed Central, Palliative Care*, 9, 11.
- Knapp, C. A., Madden, V. C., Curtis C., M. Sloyer, P., & Shenkman E.A. (2010). Family support in paediatrics palliative care: How are families impacted by their children's illnesses ? *Journal of Palliative Medicine*, 13 (4), 421 – 426.
- Kneipp, S.M., Castleman, J.B., & Gailor, N. (2004). Informal caregiving burden: An overlooked aspect of the lives and health of women transitioning from welfare to employment. *Public Health Nursing*, 21(1), 24 – 31.
- Kusgu, M. K., Dural, U., Yasa, Y., Kiziltoprak, S., & Onen, P. (2009). Decision pathways and individual motives in informal caregiving during cancer treatment in Turkey. *European Journal of Cancer Care*, 18, 569 – 576.
- Li, Q. & Loke, A. Y. (2013). Positive aspects of caregiving for cancer patients: a critical review of the literature and directions for future research. *Psycho – Oncology*, 22, 2399 – 2407.

- Liben, S., Papadatou, D., & Wolfe, J. (2008). Paediatric palliative care: challenges and emerging ideas. *Lancet*, 8,371(9615), 852-64.
- Lindley, L.C. & Mark, B.A. (2010). Children with Special health needs: impact of health care expenditures on family financial burden. *Journal of Child Family Studies*, 19(1), 79 -89.
- Lindsey, E., Hirschfeld, M., Tlou, S., & Nuebe, E. (2003). Home- based care in Botswana: experiences of older women and young girls. *Health Care for Women International*, 24, 486 – 501.
- Liobondo –wood, G., & Haber, J. (2010). *Nursing research: method and critical appraisal for evidence based practice* (7thed.). Mosby, Mosby Inc.
- Lund, L., Ross, L., Petersen, M.A., & Groenvold, M. (2014). Cancer caregiving tasks and consequences and their associations with caregiver status and the caregiver's relationships to the patient: a survey. *Biomed Central Cancer*, 14, 541.
- Mackriel, J. (2011). *Assessing the quality of palliative care in Malawi: a review of methods*. Unpublished Master's thesis, University of Malawi, Blantyre.
- Mackriel, J., Hunt, J. (2008). Palliative Care; what do you really mean? *Malawi Medical Journal*, 20(4), 109 – 111.
- Malcom, C., Forbat, L., Knighting, K., & Kearney, N. (2008). Exploring the experiences and perspectives of families using a children's hospice and professionals

providing hospice care to identify future research priorities for children's hospice care. *Palliative Medicine*, 22, 921–928.

Major, D. A. (2003). Utilizing role theory to help employed parents cope with children's chronic illness. *Health Education Research*, 18(1), 45–57.

Marcias, M.M., Clifford, S. C., Saylor, C.F., & Kreh, S.M. (2001). Predictors of parenting stress in families of children with spinal bifida. *Children's Health Care*, 30 (1), 57 -65.

Marckenzie, A. & Greenwood, N. (2012). Positive experiences of caregiving in stroke: a systematic review. *Disability and Rehabilitation*, 34(17), 1413 -1422.

Marron, E.M., Redolar- Ripoll, D., Boixado, J.M., Nieto, R., Guillamon, N., Hernandez, E., & Gomez, B. (2013). *Universitas Psychologica*, 12(3), 767 -777.

Martinez, Y.J., & Ercikan, K. (2009). Chronic illnesses in Canadian children: what is the effect of illness on academic achievement, and anxiety and emotional disorders? *Child: Care, Health and Development*, 35 (3), 391–401.

Mawani, N., Amine, B., Rostom, S., Badri, D. E., Ezzahri, M., Moussa, F., Et al., (2013). Moroccan prents caring for children with juvenile idiopathic arthritis: positive and negative aspects of their experiences. *Paediatric Rheumatology*, 11 (39), 1- 6.

Mc Corkle, R. & Pasacreta, J. (2001). Enhancing caregiver outcomes in palliative care. *Cancer Control*, 8(1), 36 -45.

- Mc Ghan, G., Loeb, S., & Penrod, J. (2013). End of life caregiving: challenges faced by older adult women. *Journal of Gerontological Nursing*, 39 (6), 45 – 54.
- Mc Grath, P. (2001). Finding on the impact of treatment for childhood Acute Lymphoblastic Leukaemia on family relationships. *Child and Family Social Work*, 6, 229 – 237.
- Mc Ilfatrick, S. (2007). Assessing palliative care needs: views of patients, informal carers, and health care professionals. *Journal of Advancing Nursing*, 57 (1), 77 - 86.
- Ministry of Health. (2011). *Introduction to Palliative Care: Health Care Workers Providers' Manual*. Lilongwe, Ministry of Health.
- Ministry of Health. (2011). *National Palliative Care Guidelines*. Lilongwe, Ministry of Health.
- Mok, E., Chan, F., Chan, V., & Yeung, E. (2003). Family experiences caring for terminally ill patients with Cancer in Hong Kong. *Cancer Nursing*, 26 (4), 267 – 75.
- Monterosso, L., Kristjanson, L. J., Aoun, S., Marianne B., & Phillips, M. B. (2007). Supportive and palliative care needs of families of children with life-threatening illnesses in Western Australia: evidence to guide the development of a palliative care service. *Palliative Medicine*, 21, 689–696.

- Morgan, D. (2009). Caring for dying children: Assessing the needs of the paediatric palliative care Nurse. *Paediatrics*, 35(2), 86 – 91.
- Morrow- Howell, N. L., & Proctor, E.K. (1998). Informal caregiving to older adults hospitalized for depression. *Aging and Mental Health*, 2(3): 222- 231.
- Moule, P., & Goodman, M. (2009). *Nursing Research: An introduction* (2nd ed.). London, SAGE Publications Inc.
- Murphy, N. A., Christian B., Caplin. D. A., & Young, P.C. (2007). The health of caregivers for children with disabilities: Caregivers perspectives. *Child: Care Health and Development*, 33(2), 180 – 187.
- Msyamboza, K.P., Dzamalala, C., Mdokwe, C., Kamiza, S., Lemerani, M., Dzowela, T. & Kathyola, D. (2012). Burden of cancer in Malawi, common types, incidence and trends: National population based Cancer Registry. *Biomed Central Research Notes*, 5, (149) doi:10.1186/1756-0500-5-149.
- National Alliance for Caregiving., & AARP. (2014). *Caregiving in the US, Executive Summary*. Retrieved February 2, 2015, from: <http://www.caregiving.org>
- National Alliance for Caregiving., & AARP. (2004). *Caregiving in the US*. National Alliance for Caregiving., & AARP. Retrieved from: <http://www.caregiving.org>
- National Alliance for Caregiving., & AARP. (2009). *Caregiving in the U.S*. Retrieved February 2, 2015. Retrieved from: http://www.caregiving.org/data/Caregiving_in_theUS_2009_full_report.pdf.

- National Statistical Office (NSO) and ICF Macro. (2011). *Malawi Demographic and Health Survey 2010*. Zomba, Malawi, and Calverton, Maryland, USA: NSO and ICF Macro.
- Navab, E., Negarandeh, R., & Peyrovi, H. (2012). The lived experiences of Iranian family member caregivers of person's with Alzheimer's disease: caring as captured in the whirlpool of time. *Journal of Clinical Nursing*, 21, 1078 – 1086.
- Nayak, M.G., George, A., Vidyasagar, M.S., & Kamath, A. (2014). Quality of life of family caregivers of patients with advanced cancer. *Journal of Nursing and Health Science*, 3 (2 Ver. I), 70-75.
- Nicholl, H. M., & Begley C. M. (2012). Mothers experiences of caring for a child with complex needs. *Journal of Paediatric Nursing*, 27, 642 – 651.
- Northouse, L.L., Katapodi, M.C., Song, L., Zhang, L., & Mood, D.W. (2010). Intervention with family caregivers of cancer patients: meta- analysis of randomized trials. *CA Cancer Journal of Clinicians*, 60(5), 317 -339.
- Ockerby, C., Livingston, P., O' Connell, B., & Gaskin, C.J. (2013). The role of informal caregivers during cancer patients' recovery from chemotherapy. *Scandinavian Journal of Caring*, 27: 147 – 155.
- Ogce, F., Ozkan, S., Okcin, F., Yaren, A., & Demiray G. (2013). Evaluation of quality of life of breast cancer patient next- of-kin in Turkey. *Asian Pac J Cancer Prev*, 14, 2771-6.

- Otis-Green, S., & Juarez, G. (2012). Enhancing the social well-being of family caregivers. *Oncology Nursing*, 28(4), 246–255.
- Ozbay, F., Douglas C., Johnson, D. C., Dimoulas, E., Morgan III, C. A., Charney, D., & Southwick, S. (2007). Social support and resilience to stress: from neurobiology to clinical practice. *Psychiatry*, 35 -40.
- Palliative Care Association of Malawi. (2012). *Factsheet on palliative care for children in Malawi*. Lilongwe, Palliative Care Association of Malawi.
- Papastavrou, E., Charalambous, A., & Tsangari, H. (2009). Exploring the other side of cancer care: the informal caregiver. *European Journal of Oncology Nursing*, 13, 128 – 136.
- Pargament, K.I. (1997). *The psychology of religion and coping: theory and practice*. New York: Gullfold Press.
- Penrod, J., Baney, B., Loeb, S. J., McGhan, G., & Shipley, P. Z. (2012). The influence of the culture of care on informal caregivers' experiences. *ANS. Advances in Nursing Science*, 35(1), 64–76. doi:10.1097/ANS.0b013e318244555a.
- Petty, N, J., Thomson, O. P., & Stew, G. (2012). Ready for a paradigm shift? Part 2: introducing qualitative research methodologies and methods. *Manual Therapy*, 17(5), 378 -84. doi: 10.1016/j.math.2012.033004.

- Plank, A., Mazzon, V., & Cavada, L. (2012). Becoming a caregiver: new family carer's experiences during transition from hospital to home. *Journal of Clinical Nursing*, 21, 2072 – 2082.
- Polit, D.F., Beck, C.T. (2004). *Nursing research: principles and methods* (7thed.). Philadelphia, Lippincott Williams & Wilkins.
- Rafiyah, I. &Sutharangsee, W. (2011). Review: burden on family caregivers caring for patients with Schizophrenia and its related factors. *Nurse Media Journal of Nursing*, 1(1), 29 – 41.
- Rajasekar, S., Philominathan, P., & Chinnathambi, V. (2013). *Research Methodology*, Manuscript. Retrieved January 22, 2014 from <http://arxiv.org/pdf/physics/0601009v3.pdf>
- Reinhard, S. C., Given, B., Petlick, N.H., & Bemis, A. (2008). Supporting family caregivers in providing care. In R.G.Hughes. (Ed.), *Patient safety and quality: an evidence- based handbook for nurses* (Chapter 14). Rockville, MD: agency for healthcare research and Quality (US),
- Remsherdt, M.A., & Flowers, D.L. (2007) Understanding qualitative research. *American Nurse Today*, 2(9), 20 – 22.
- Robison, J., Fortinsky, R., Kleppinger, A., Shugrue, N., & Porter, M. (2009). A broader view of family caregiving: effects of caregiving and caregiver conditions on depressive symptoms, health, work and social isolation. *Journal of Gerontology Series B, Psychological Sciences and Social Sciences*, 64(6), 788 -98.

- Rodriguez, A., & King, N. (2009). The lived experiences of parenting a child with a life limiting condition: a focus on mental health realm. *Palliative and Supportive Care*, 7, 7 – 12.
- Roff, L.L., Burgio, L.D., Gitlin, L., Nichols, L., Chaplin, W., & Hardin, J.M. (2004). Positive aspects of Alzheimer's caregiving: The role of race. *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences*, 59, 185–190.
- Sapountzi – Krepia, D., Lavdaniti, M., Chogios M., Arsenos, P., Paralikas T., Triantafylidou P., & Georgiadou, C. (2008). Nursing staff shortage and in-hospital informal care in an Oncology hospital in Greece: the nursing staff's perceptions. *International Journal of Nursing Practice*, 14, 256 – 263.
- Sawatzky, J.E., & Fowler – Kelly, S. (2003). Impact of caregiving: listening to the voice of informal caregivers. *Journal of Psychiatric and Mental Health Nursing*, 10, 277 – 286.
- Sercekus, P., Besen, D.B., Gunusen, N. P., & Edeer, A.D. (2014). Experiences of family caregivers of children of cancer patients receiving chemotherapy, *Asian Pacific Journal of Cancer Prevention*, 15(12), 5063 – 5069.
- Scherbring, M. (2002). Effect of caregiver perception of preparedness on burden in an oncology population. *Oncology Nursing Forum*, 29 (6), E70 – 6.
- Schubart, J.R., Kinzie, M. B., & Farace, E. (2008). Caring for the brain tumour patient: family caregiver burden, and unmet needs. *Neuro Oncology*, 10, 61 – 72.

- Schulz, R., & Sherwood, P. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing*, 108(9), 23 – 27.
- Selman, L., Higginson, I. J., Agupio, G., Dina, N., Downing, J., Gwyther, L., ... Harding, R. (2009). Meeting information needs of patients with incurable progressive disease and their families in South Africa and Uganda: Multicentre qualitative study. *Biomedical Journal*, 338, b1326.
- Sepulveda, C., Habiyambere, V., Amandua, J., Borok, M., Kikule E., Mudarya, B., Ngoma T., & Solomon, B. (2003). Education and debate. *Biomedical Journal*, 327, 209- 13.
- Sepulveda, C., Marlin, A., Yoshida, T., Ullrich, A., (2002). Palliative Care; The World Health Organisation's global perspective. *Journal of Pain and Symptoms Management*, 24(2), 91- 96.
- Sitairesmi, M.N., Mostert, S., Schook, R. M., Sutaryo., & Veerman, A.J. (2010). Treatment refusal and abandonment in childhood acute lymphoblastic leukaemia in Indonesia: an analysis of causes and consequences. *Psycho-Oncology*, 19, 361–367.
- Shirai, Y., Koerner, S.S., & Kenyon, D. B. (2009). Reaping caregiver feelings of gain: the roles of socio-emotional support and mastery. *Aging & Mental Health*, 13(1), 106–117.

Skilbeck, J.K., Payne, S.A., Ingleton, M.C., Nolan, M., Carey, I., & Hanson, A., (2005).

An exploration of family carers' experience of respite services in one specialist palliative care unit. *Palliative Medicine*, 19, 610- 618.

Smith, F. M., Eustache, E., Oswald, C., Surkan, P., Louis, E., Scanlan, F., ...Mukherjee, J.

(2010). psychosocial functioning among HIV-affected youth and their caregivers in Haiti: Implications for family-focused service provision in high HIV burden settings. *AIDS Patient Care STDS*, 24(3), 147–158.

Social support [Def. 1]. (n.d). *National Cancer Institute Dictionary of Cancer Terms and*

Definitions. Retrieved April 10, 2015, from <http://www.cancer.gov>

Stajduhar, K. I. & Davies, B. (2005). Variations in and factors influencing family

members' decisions for palliative home care, *Palliative Medicine*, 19, 21-32.

Statistics Canada. 2012. "Portrait of Caregivers". Retrieved April 2, 2015, from

http://www5.statcan.gc.ca/access_acces/alternative_alternatif.action?l=eng&teng=Portrait%20of%20caregivers,%202012&tfra=Portrait%20des%20aidants%20familiaux,%202012&loc=/pub/89-652-x/89-652-x2013001-eng.pdf

Stein, A., Ramchandani, P., & Murray, L. (2008). Impact of parental psychiatric disorder

and physical illness. In M. Rutter, D. Bishop, D. Pine, S. Scott, J. Stevenson, E.

Taylor, & A. Thapar (Eds.), *Child and Adolescent Psychiatry* (5th ed., pp. 409–422). Oxford: Oxford Blackwell Publishing.

- Tarimo, E. A., Kohi., T.W., Outwater, A., Blystad, A. (2009). Gender roles and informal care for patients with AIDS: A qualitative study from an urban area in Tanzania. *Journal of Transcultural Nursing*, 1, 61–68. doi: 10.1177/1043659608325843.
- Tarlow, B.J., Wisniewski, S.R., Belle, S.H., Rubert, M., & Ory, M.G. Gallagher-Thompson, D. (2004). Positive aspects of caregiving contributions of the REACH Project to the development of new measures for Alzheimer’s caregiving. *Research on Aging*, 26 (4), 429-453.
- Thurman, T.R., Jarabi, B., & Rice, J. (2012). Caring for the caregiver: Evaluation of support groups for guardians of orphans and vulnerable children in Kenya. *AIDS Care*, 24(7), 811-819.
- Toljamo, M., Perala, M., & Laukkala, H. (2012). Impact of caregiving on finishing family caregivers, *Scandinavian Journal of Caring sciences*, 26(2), 211- 218.
- Tsigaropoulos, T., Mazaris, E., Chatzidarellis, E., Skolarikos, A., Varkarakis, I., & Deliveliotis C. (2009). Problems faced by relatives caring for cancer patients at home. *International Journal of Nursing Practices*, 15, 1-6.
- Ugur, O., Elcigil, A., Arslan, D., & Sonmez, A. (2014). Responsibilities and difficulties of caregivers of cancer patients in home care. *Asian Pacific Journal of Cancer Prevention*, 15, 725- 9.
- UNAIDS. (2012). *Global Report: UNAIDS report on the global AIDS epidemic*.
UNAIDS.

University of Minnesota, centre for Bioethics. (2003). *A Guide to research ethics*.

Retrieved January 14, 2014, from:

http://www.ahc.umn.edu/img/assets/26104/Research_Ethics.pdf

Ventura, A. D., Burney, S., Brooker, J., Fletcher, J., & Ricciardelli, L. (2013). Home - based palliative care: A systematic literature review of the self reported unmet needs of patients and carers. *Palliative Medicine*, 0(0): 1 – 12.

Whittier, S., Coon, D., & Aarker, J. (2003). *Caregiver support interventions*. Research Brief, 10. Washington: National Association of States unit on Aging.

Wilson, L. S., Moskowitz, J.T., Acree, M. Heyman, M, V., Harmatz, P., Ferrando, S.J., & Folkman, S. (2005). The economic burden of home care for children with HIV and Other Chronic Illnesses. *American Journal of Public Health*, 95(8), 1445-1452.

Wong, W.K.T., & Ussher, J. (2009). Bereaved informal cancer carers, making sense of their palliative care experiences at home. *Health and Social Care in Community*, 17(3), 274- 283.

Zapart, S., Kenny, P., Hall, J., Servis, B., & Wiley, S. (2007). Home based palliative care in Sydney Australia: the carer's perspective on the provision of informal care. *Health and Social Care in Community*, 15(2), 97 -107

Outline of Appendices

Appendix A. Time frame

Activity	December	January	February	May	June	June	July
Topic identification and literature search							
Proposal writing							
Proposal submission to supervisor							
Proposal submission to COMREC							
Pre-testing of data collection tools							

Appendix B: Caregivers' Information Letter

CAREGIVERS' INFORMATION ON EXPERIENCES OF CAREGIVERS OF CHILDREN RECEIVING PALLIATIVE CARE AT MZUZU CENTRAL HOSPITAL

Dear Participants,

I am Bertha Chaputula, a Masters in Child Health Nursing Student at Kamuzu College of Nursing. In partial fulfilment of my Masters Programme, I am conducting a research study on caregivers/guardians experiences of caring for a child receiving palliative care at Mzuzu Central Hospital. I would like to invite you to participate in the research study on the above mentioned subject.

Purpose of the study

The study will provide information that will enlighten health care providers on the caregivers' needs and challenges and assist in devising ways of assisting caregivers of children receiving palliative care. Your participation in the study will be helpful because you will provide an insight on what caregivers' experiences and how best to assist them.

Reason for choosing you to take part in the study

You have been chosen to participate in the study because your child has a life threatening or limiting illness and you are utilizing children palliative care services.

Willingness to participate in the study

Your participation in the study is voluntary. You are free to withdraw from being a participant at any time, and there is no punishment. Withdraw will not affect care of your child in any way.

Risks in participating in the study

The procedures followed in the study do not have any foreseen harmful effects to you, your child and family. 1

The study and its procedures have been approved by the appropriate boards, research committee at College of Medicine, Kamuzu College of Nursing and Mzuzu Central Hospital.

Study procedure

The study procedure involves answering in an in-depth interview. The interview will be conducted in a quiet environment to avoid disturbances, and will take approximately 30 – 40 minutes. Numbers will be used for identification to ensure confidentiality. Collected information will be kept by the researcher, and will only be accessed by people directly involved in the research. The collected information will be destroyed by burning after data analysis.

Contact details

If you have any questions about the study or being a participant you may contact:

The Chairperson, COMREC Secretariat, Private Bag, 360,
Blantyre, 3. Tel: 01871911

Professor E. Chirwa, Kamuzu College of Nursing, P.O Box 415, Blantyre.

Bertha Chaputula

Kamuzu College of Nursing

P. O Box 415, Blantyre. Tel. 0888377466

Appendix C: Kalata Yofotokoza Za Kafukufuku

KALATA YOFOTOKOZA ZA KAFUKUFUKU PA ZOMWE OSAMALIRA ANA OMWE ALI NDI MATENDA OWOPSYEZA MOYO KAPENA KUCHEPESA MOYO OMWE AMALANDIRA THANDIZO KU CHIPATALA AYENERA KU DZIWA

Wokondedwa

Ine ndine Bertha Chaputula, mmodzi mwa ophunzira za unamwino pa sukulu yaukachenjede ya Kamuzu koleji komwe ndikupanga maphunziro a zosamalira ana. Pakalipano, ndikupanga kafukufuku wofuna kudziwa zomwe oyang'anira ana omwe ali ndi matenda owopsyeza kapena kuchepesa moyo omwe amathandizidwa kuchipatala amakumananazo. Ndikukupemphani kuti mutengenawo mbali mu kafukufukuyu.

Cholinga cha kafukufuku

Cholinga cha kafukufuku ndi kuti tidziwe zomwe oyang'anira ana omwe ali ndi matenda owopsyeza kapena kuchepesa moyo omwe amathandizidwa kuchipatala amakumana nazo posamalira anawa. Tikufuna tifufuze zomwe oyanganira anawa amachita pothandiza anawa, zofunazawo, momwe amapezera mathandizo komanso zovuta zomwe amakumananazo. Kafukufukuyu athandiza kupeza njira yomwe a chipatala angathandizire oyang'anira anawa kuti azilandira chisamaliro chokwanira.

Kutenganawo mbali mu kafukufuku

Mwasankhidwa kutengana wombali mu kafukufuku chifukwa mumasamalira mwana yemwe ali ndi matenda owopsyeza kapena kuchepesa moyo omwe amathandizidwa

kuchipatala. Simuli okakamizidwa kutenga mbali mu kafukufukuyu. Ndinu ovomerezedwa kusiya kutengapo mbali nthawi iliyonse popanda kupereka zifukwa ndipo palibe chilango chili chonse komanso sizingasokoneze chithandizo chomwe mwana wanu akulandira.

Palibe kuopsya kwina kuli konse mukatengapo mbali mukafukufuku. Kafukufukuyu anavomerezedwa ndi akadaulo owunika a kafukufuku a College of medicine ndi Mzuzu Central Hospital. Mukavomereza kutenganawo mbali mukafukufukuyu mudzafunsidwa mafunso kwamphindi 30 kufikira 45. Muli kupephedwa kuyankha mafunso mmene mukudziwira komanso moona mtima. Mmzajambulidwa mawu pamene mukuyankha mafunso koma opangitsa kafukufukuyu adzizalemba zina mwazomwe muzizakambirana.

Ngati pangakhale nkhwana kapena mafunso ena ali onse okhuza kafukufukuyu muli omasuka kufunsa ma funso anukwa:

Wapampano College of Medicine Research Council, Private Bag, 360, Chichiri, Blantyre. nambala, 01989766 or Bertha Chaputula, Kamuzu College of Nursing, P.O. Box 415, Blantyre. Mukhoza kuimba pa nambala iyi : 0888377466

Appendix D: Participant's Consent Form

**PLEASE READ AND SIGN THE FORM IF YOU ARE INTERESTED IN
TAKING PART IN THE STUDY**

The study has been described to me in a language that I understand and I freely and voluntarily agree to participate. I have been given an opportunity to ask questions about the study and its process and my questions on the study have been answered. I understand that my identity and information will not be disclosed at any point and that I am free to withdraw from the study without giving reasons. I also understand that the study will not in any way affect me negatively.

Participant's signature / fingerprint

Date.....

Researcher's signature

Date.....

For further inquiries, you may contact: The Chairperson, COMREC Secretariat, P/Bag, 360, Chichiri, Blantyre 3. or Call 01989766.

Appendix E: Kalata Yovomereza

Werengani ndikutsindikiza dzina lanu pa malo omwe aperekedwawo ngati muli osangalatsidwa kutenganawo mbali mu kafukufukuyu

Nda fotokozeredwa mchiyankhulo chomveka bwino zakafukufukuyu ndipo mosakakamizidwa ndikuvomereza kutenganawo mbali mu kafukufukuyu. Ndapatsidwa mwayi ofunsa mafunso ndikuyankhidwa mwatsatanetsatane ndipo ndamvetsetsa kuti zizindikiro zanga komanso uthenga omwe nditayankhule zizasungidwa mwachinsinsi. Ndamvetsanso kuti sindizapeza vuto lina lililonse pa chifukwa chotenganawo mbali mu kafukufukuyu.

Otengambali Tsiku

wakafukufuku Tsiku

Ngati muli ndifunso mukhoza kulembera kwa: The Chairperson, COMREC Secretariat, P/Bag, 360, Chichiri, Blantyre 3 kapena imbani pa nambala iyi 01989766.

**CAREGIVERS EXPERIENCES OF CARING FOR CHILDREN RECEIVING
PALLIATIVE CARE AT MZUZU CENTRAL HOSPITAL**

PART A. DEMOGRAPHIC DATA

NUMBER OF PARTICIPANT.....

DATE.....

In this section you will be asked your personal information,

A1. GENDER

a. Female1

b. Male2

A2. AGE OF CAREGIVER IN YEARS

How old are you?

a. Below 19 years1

b. 20 -25 years2

c. 26 -35 years3

d. 35 – 45years4

e. Above 46 years 5

A3. RELIGION

Which religion do you belong to?

a. Christianity1

- b. Islam2
- c. Other3

A4. MARITAL STATUS

What is your current marital status?

- a. Single1
- b. Married2
- c. Divorced3
- d. Widow/widower4
- e. Separation5
- f. Other...6

A5. RELATIONSHIP TO THE CHILD

What is your relationship to the child?

- a. Son1
- b. Daughter2
- c. Grandchild3
- d. Other.4

A6. EDUCATION LEVEL

What is the highest level of education that you have attained?

- a. Primary level 1
- b. Secondary level2

A7. AGE OF THE CHILD AT INTERVIEW

How old is your child?

- a. Less than 5 years1
- b. Years to 10 years2
- c. Above 10 years3

A8. PERIOD OF CARING

For how long have you been caring for the child receiving palliative care?

- a. Less than 6 months1
- b. 6 months to 1 year2
- c. 1 year to 2 years3
- d. Above 3 years4

A9. What tribe do you belong to?

- a. Chewa1
- b. Tumbuka2
- c. Yao3
- d. Ngoni 4
- e. Tonga 5
- d. Other6
- c. Tertiary level3
- d. None4

A10. What is your occupation?

A11. DIAGNOSIS OF THE CHILD

A12. Age at diagnosis

PART B: EXPERIENCES OF CARING FOR YOUR CHILD

B1. What are your roles in the care of your child?

What are the things that you do for your child?

Probes

What role do you play in,

Follow up care?

Medication?

Personal care?

Can you explain a typical day in the care of your child?

How does your participation in care influence your daily life?

B2. You have been caring for the child for some time, how could you describe your experience?

Probes

Can you explain further?

Anything else you would like to add?

B3. What support services do you have?

Probes

Who assists you in the care?

Family

Friends

Community

Hospital

Can you explain further?

Where do you get the things you need for your child?

B4. You are the one who spent most of the time with the child, Can you explain the challenges that you face when providing palliative care to the child

Probes

Social

Financial

Physical

In your community are there other children who are also receiving palliative care?

B5. As a caregiver, what are your care needs when caring for your child at home?

We have now covered the main points; do you have any comments, observations or conclusion about palliative care services or care giving that you would like to say?

Further probes

Can you explain further?

Can you tell me more?

Anything else you would like to add

Appendix G: Mulozowa Zokambirana

ZOMWE OSAMALIRA ANA OMWE ALI NDI MATENDA OWOPSYEZA

KAPENA KUCHEPESA MOYO AMAKUMANA NAZO POSAMALIRA ANAWO

Nambala

Tsiku

Chigawo choyamba ndikufunsani zokhuza moyo wanu

A1. Osamalira mwana ngati ndi a amuna kapena a akazi

a. mwamuna1

b. mkazi2

A2. Zaka za osamalira mwana odwala

Kodi muli ndizaka zingati?

a. zochepera 191

b. 20 -25 years2

c. 26 -35 years3

d. 35 – 45years4

e. 46 kupita mtsogolo 5

A3. Kodi ndinu a chipembezo chanji?

a. Chikhristu1

b. Chisilamu2

c. Zipembezo zina3

A4. Kodi muli pa banja?

- a. Sindili pa banja1
- b. Ndili pa banja2
- c. Banja linatha3
- d. Nanfedwa4
- e. Tinanyanyalitsana5
- f. Zina6

A5. Kodi pali ubale wanji ndi mwanayu?

- a. Mwana wanga1
- b. Mdzukulu2
- c. Zina3

A6. Za maphunziro

Kodi munaphunzira kufika pati?

- a. Pulayimale1
- b. Sekondale2
- c. Sukulu yaukachenjede3

A7. Mwana wanu ali ndizaka zingati?

- a. Sochepera 51
- b. 6 - 102

b. Zopitilira 103

A8. Kodi mwakhala mu kusamalira mwanayu kwa nthawi yaitali bwanji?

a. Kochepera miyezi 61

b. Miyezi 6 kufikira chaka2

c. Chaka chimodzi kufika ziwiri3

d. Kupitilira zaka zitatu4

A9. Kodi ndinu a mtundu wanji?

a. Chewa1

b. Tumbuka2

c. Yao3

d. Ngoni 4

e. Tonga 5

f. Mitundu ina6

A10. Kodi mumagwira ntchito yanji?

A11. Kodi mwana wanu ali ndi matenda anji?

A12. Zaka zomwe matenda anayamba

Gawolachiwiri: kudziwa za zomwe osamalira ana omwe alindi matenda owopsyeza

moyo kapena kuchepesa moyo amakumananazo posamalira anawo

B1. Ndi ntchito zANJI zomwe mumachita posamalira mwana wanu?

Mafunso otsatira

Pa nkhani yokaonedwa kuchipatala?

Pa mankhwala?

Tandiuze momwe mumasamalira kapena zomwe mumamuchitira mwana wanu kukacham'mawa pakana madzulo?

Kodi kusamaliramwana wavuto limeneli kumakhudza bwanji umoyo wanu watsiku ndi tsiku?

B2. Mwakhala mukusamalira mwanayu kwakanthawindithu, mungandifotokozereko zina mwa zomwe mumakumananazo posamalira mwanayu?

Mungathekuonjezerapo?

B3. Ndimathandizo otani omwe mumapezeka nawo?

Mafunso otsatira

Mumathandizidwa ndi ndani posamalira mwana wanuyi?

A chibale

Azinanu

anthu a kudela kwanu

Achipatala

Zinthu zofunika posamalira mwanayu mumazipeza kuti?

B4. Mumatenga nthawi yambiri kusamalira mwana wanu, mungandifotokozereko zovuta zomwe mumakumanazo posamailra mwanayu?

Mukakhalidwe ndi anthu ena

Ku mbaliya chuma

Kuthupi

Ku dela komwe mumakhala aliko ana ena omwe amalandira thandizo ngati lanuli?

B5. Ndizinthu ziti zomwe mumafuna panthawi yomwe mukusamalira mwana wanu kunyumba?

Tsopano tafika pa mapeto pa zokambirana zathu, muli ndizowonjezera pa zokambirana zathu?

Zikomo potenganawo mbali pakafukufuku

Appendix H: Letter of permission from Mzuzu Central Hospital

Telephone: 01 320 916 / 911/620
Fax: 01320217/320225/270



In reply please quote No.....

The Hospital Director,
Mzuzu Central Hospital,
Private Bag 209,
Luwinga,
Mzuzu 2.

2nd May, 2014.

Bertha Chaputula
Kamuzu College of Nursing
P.O. Box 415
Blantyre

Dear Mrs Chaputula,

**RE: PERMISSION TO TEST RESEARCH TOOLS AND COLLECT DATA FOR
RESEARCH AT MZUZU CENTRAL HOSPITAL CHILDREN PALLIATIVE
CARE CLINIC**

Reference is made to your letter dated 2nd May, 2014, in which you requested to conduct research including testing of tools for your research titled "Experiences of caregivers/guardians of children receiving, palliative care at Mzuzu Central Hospital."

I wish to inform you that permission has been granted that you test research tools and collect data at our palliative care clinic. I look forward to dissemination of findings of the study and the report will be shared with Mzuzu Central Hospital Library.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'R. Nyirenda'.

Mrs R. Nyirenda
Hospital Director

Appendix I: Permission from head of paediatric department Mzuzu C. Hospital

Telephone: 01 320 916 / 911/620

Fax: 01320217/320225/270



In reply please quote No.....

The Hospital Director,
Mzuzu Central Hospital,
Private Bag 209,
Luwingu,
Mzuzu 2.

22nd May, 2014.

Bertha Chaputula
Kamuzu College of Nursing
P. O Box 415,
Blantyre.

Dear Mrs Chaputula

RE: PERMISSION TO TEST RESEARCH TOOLS AND COLLECT DATA FOR RESEARCH

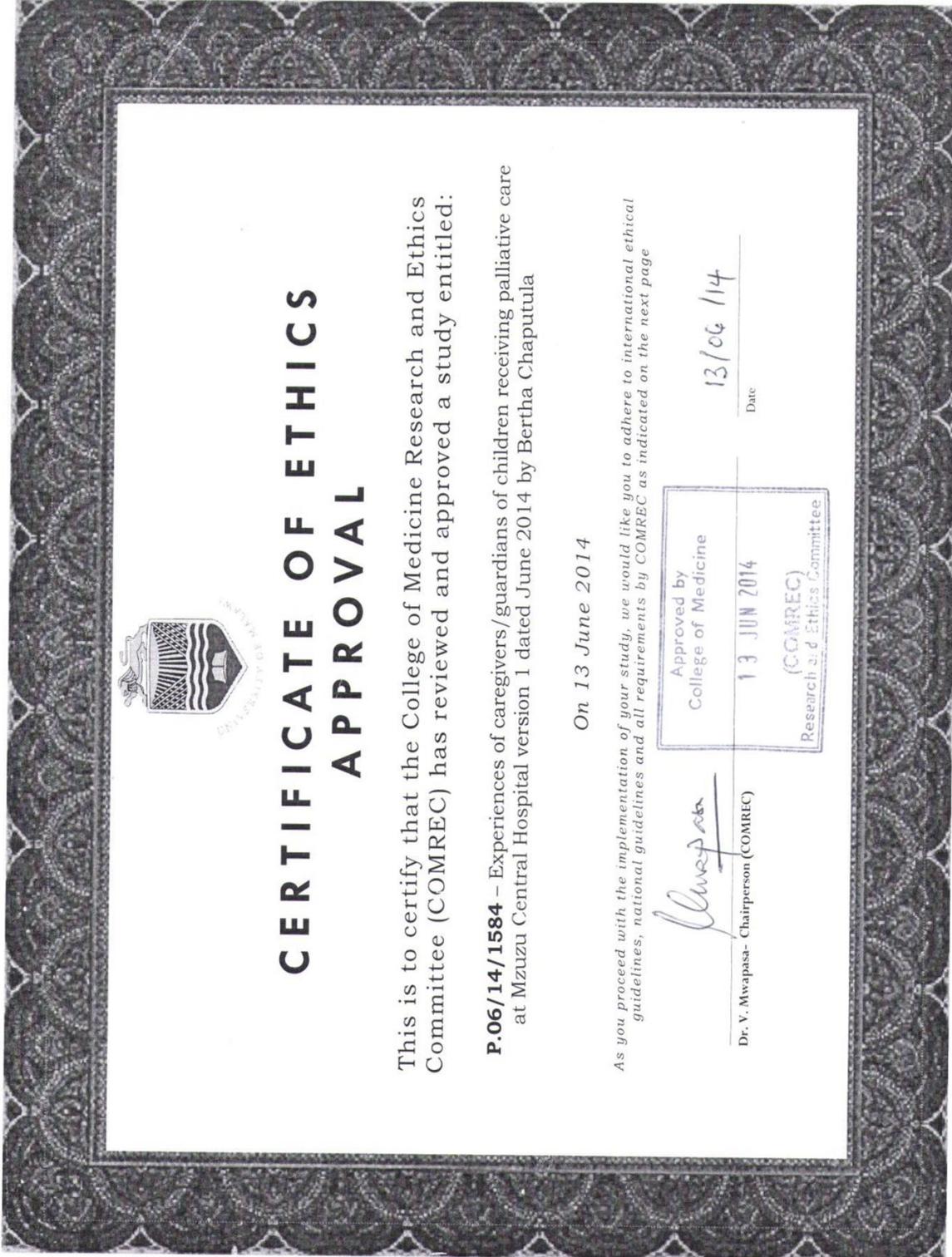
Reference is made to your letter dated 2nd May, 2014, in which you want to test research tools and collect data for research titled "Experiences of caregivers /guardians of children receiving palliative care at Mzuzu Central Hospital".

I wish to inform you that permission has been granted that you test research tools and collect data at our palliative care clinic. I look forward to dissemination of findings of the study and that the report will be shared to this institution

Yours sincerely,


Dr. Eleazar Onglatco Jr.
Paediatrician

Appendix J: Certificate of Ethical Approval from COMREC



**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.06/14/1584 – Experiences of caregivers/guardians of children receiving palliative care at Mzuzu Central Hospital version 1 dated June 2014 by Bertha Chaputula

On 13 June 2014

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

Approved by
College of Medicine
13 JUN 2014
(COMREC)
Research and Ethics Committee

[Signature]
Dr. V. Mwapasa- Chairperson (COMREC)

13/06/14
Date