



Kamuzu College of Nursing

**PARENTS' PERCEPTIONS OF AVAILABLE SUPPORT FOLLOWING DIAGNOSIS
OF CHILDHOOD CANCER AT KAMUZU CENTRAL HOSPITAL, LILONGWE,
MALAWI**

Master of Science (Child Health Nursing) Thesis

By

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Nursing

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DECLARATION

I, Beatrice Gundo hereby declare that this thesis is my original work and that I have not submitted it or any part of it for any degree at any other University within or outside Malawi. Work of other people used in this thesis has been acknowledged appropriately.

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CERTIFICATE OF APPROVAL

The undersigned certify that this thesis represents the student's own work and effort and has been submitted with our approval.

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DEDICATION

I dedicate this work to my husband, Rodwell and daughter, Maziko. This is truly a product of your great perseverance, support and encouragement.

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ABSTRACT

The purpose of this study was to explore parents' perception of available support following diagnosis of childhood cancer at Kamuzu Central Hospital, Lilongwe, Malawi. The study utilized descriptive design of quantitative research to achieve research objectives. Sixty participants participated in the study. Data were collected using a questionnaire developed by the researcher based on literature review. Statistical Package for the Social Science (SPSS) version 20 was used to analyze the data.

Majority of the parents reported that there are nurses and doctors who care for their sick children. They also reported availability of information regarding children's condition, treatment, food, spiritual support and accommodation if needed. The parents rated highly the availability of treatment (excellent, 68.4%, n=41). Majority of the parents reported that provision of accommodation was good (good, 85%, n=51) and that they are treated as an individual rather than a typical parent of cancer child (good, 100%, n=60). Parents also reported that children are not cared for holistically (e.g. mental, emotional and social needs) instead only their physical needs are met (81.7%, n=49) and all parents reported that there is poor provision of advice on how to get information or to contact other parents, organizations.

In relation to treatment, parents reported poor explanation on treatment (70%, n=42), and on the types of cancer services available (80%, n=48). Majority of the parents reported that provision of spiritual support is good (76.7%, n=46) and there is adequate treatment at the facility (83.3%, n=50), however they are not provided with an opportunity to make decisions about treatment (71.7%, n=43).

The study highlights areas of concern for practice, management, education and research relevant to paediatric oncology. Health professionals need to update themselves on paediatric oncology through conducting research and attending research conferences on pediatric oncology. They also need to facilitate parents' access to information and should be able to give timely, appropriate information.

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LIST OF ABBREVIATIONS

COMREC: College of Medicine Research Committee

CAM: Cancer Association of Malawi

KCH: Kamuzu Central Hospital

KCN: Kamuzu College of Nursing

MOH: Ministry of Health

NSO: National Statistics Office

NMCM: Nurses and Midwives Council of Malawi

SPSS: Statistical Package for the Social Sciences

RPC: Research and Publications Committee

WHO: World Health Organization

DEFINITION OF TERMS

Cancer: abnormal activation of cellular genes that control cell growth and cell mitosis (Guyton & Hall, 2006).

Childhood cancer: a child is any person below the age of 16 (Child Care, Protection and Justice Act, 2010). In this study childhood cancer will refer to all children below the age of 18 with a diagnosis of cancer.

Chronic illness: A chronic illness is defined as any disorder that persists over a period of 3 months or more and affects physical, emotional, intellectual, vocational, social, or spiritual functioning (Medical Dictionary Definitions, 2009). In this study cancer is the chronic illness.

Family: Family is a unit where one or two more individuals depend on one another for emotional, physical and/or financial support. The members are related either by blood, marriage or adoption (Stanhope & Lancaster, 2004).

Health professional: A health care provider is defined as people whose job it is to protect and improve the health of their communities. In this study it will refer to a nurse, clinician or medical doctor who manages children with cancer

Parent: to be a father or a mother. In this study parent refers to a caretaker of a child, it may be a grandmother, grandfather, aunt or uncle.

Support: giving assistance to someone. In this study support will refer to health related which involves giving information, medication, and nursing support.

CHAPTER 1

INTRODUCTION

1.0 Introduction

The presence of childhood cancer brings crisis for families. Childhood cancer places the well being of the entire family at risk of major psychological and social disturbances (Jackson et al., 2007). The emotional impact of cancer on parents of children diagnosed with cancer is extreme and long lasting, even when a confident prognosis can be reasonably given (Hashemi, Razavi, Sharif, & Shahriari, 2007). Parents experience feelings of self blame, they also blame others especially medical professionals for not acting or diagnosing their child's illness early (Clarke, Mitchell & Sloper, 2004). There is need to provide physical, emotional, social, psychological as well as spiritual support to parents for them to cope with the situation.

Successful parental involvement in the child's cancer treatment relies on their understanding of the diagnosis, treatment and the available support (Yeh, 2003). Among other resources and individual resilience factors, the availability of support seems to be essential to the maintenance of the psychological and physical well being among parents of children with cancer (Norberg & Boman, 2007). Parents, who have a child afflicted with cancer, would face distress and emotional problems, if they do not receive enough social and spiritual support (Hashemi et al., 2007; Ruland, Hamilton & Schejodt-Osmo, 2009).

According to World Health Organization (2009), there are 160,000 new cases of childhood cancer per year and 90, 000 deaths worldwide. There are 180, 000 new cases of childhood cancer every year in the Sub- Saharan region and cancer death rate is at 144 per 1000 live births of child (You, 2010).

Driven by early exposure of viruses, high incidence of malaria, protein energy malnutrition and high incidence of Human Immunodeficiency virus (HIV), Sub Saharan Africa has an increase in child hood cancers (You, 2010). In Malawi, a total of 1, 365 children were diagnosed with cancer from 2007 to 2010 (Msyamboza et al., 2012).

1.1 Background

When a child has cancer, parents experience a wide range of emotions and experiences (Clarke et al., 2004; Houtzager, Grootenhuys & Last, 2005). These emotions include feelings of fear and helplessness and tough patterns of coping (Jackson et al., 2007). The parents face distress, anxiety regarding multiple hospitalizations and chemotherapy side effects. Parents worry whether their child's cancer will get cured (Taleghani, Fathizadeh & Naseri, 2012). The diagnosis of chronic disease in childhood causes mental shock, stress, sentiments of anger, sorrow, and increased intensity in their interpersonal relationships for both the child and the family (Norberg, Lindblad & Boman, 2005).

The diagnosis of chronic condition in childhood and adolescence brings about many changes in the lives of young patients and their families. Patients and parents are suddenly placed in the position of coping with a wide array of new situations, such as painful and frightening symptoms, uncertainty of prognosis, and changes in social relationships (Norberg et al., 2005). Families are presented with additional tasks, responsibilities, and concerns over additional care of the child, uncertainty about the future, and emotional grieving (Clarke et al., 2004).

The situation is very distressing particularly if the diagnosis of the disease is for a child who was previously healthy (Houtzager et al., 2005). When children are diagnosed with and treated for cancer, they and their family members encounter major challenges and stressors related to the short and long term side effects of treatment and possible disease relapse. Moreover, throughout treatment, families must manage repeated hospitalizations, hospital visits, financial difficulties, uncertainty about the child's prognosis, and fear of his/her possible death (Houtzager et al., 2005).

These challenges and stressors can disrupt the daily lives of all family members and alter the balance within family system (Kazak, 2005). Immediately after the diagnosis of cancer, parents feel an overwhelming sense of stress, urgency, disbelief and numbness (Hashem et al., 2007). Parents and families struggle to adjust to the many demands and threats that arise from cancer diagnosis and subsequent treatment (Murphy, Flowers, McNamara & Young-Saleme, 2008). Caring for a child with cancer is psychologically and behaviorally complex process for parents, involving various aspects of family life.

The psychological and existential challenge of parenting a child who has cancer influences the lives of parents for years, even after the end of treatment (Yeh, 2003). The effectiveness of medical treatment depends not only on the treatment itself but also on parental cooperation; care during and after treatment as well as parental support (Yeh, 2003). Among the resources and individual resilience factors, the availability of support seems to be essential to the maintenance of psychological and physical wellbeing among parents of children with cancer (Norberg & Boman, 2007).

Support in cancer is defined as a network resources or the set of relationships through which an individual receives help in dealing with demands and achieving goals, supportive behaviours or the specific acts intending to help someone and subjective appraisal of these network resources and behaviours (Norberg & Boman 2007; Woodgate, 2006). In this study support will refer to network of resources available for parents of children with cancer, supportive behaviours by health professionals, information giving, and availability of resources such as treatment, food, accommodation, spiritual support and staff.

1.2 Problem statement

Cancer as a chronic illness brings stress and disruption to the family. While it is important to engage in medical management of cancer, health professionals must reconcile with family support. This means that parents need a lot of support so that they cope with the illness of their child and prevent stress.

Despite an increase in survival rate in childhood cancer and regardless of prognosis or outcome, each diagnosis has an impact on the child, parents, the family and the entire community. Parents go through emotional stress hence need for support. According to a study done by Jones (2012), on the challenges of quality care for family caregivers in pediatric cancer care, parents indicated that the most helpful forms of support when their child is diagnosed with cancer are timely education about their child's health status from health care providers and emotional as well as psychological support from family members. However the support is not adequately offered. There is little in the literature regarding the needs for care and assistance parents experience as they manage their child's disease and treatments (Essen, Enskar & Scolin, 2001).

While major advances have been made in the treatment of childhood cancer, with survival rates exceeding 70%, health professionals' support on psychological adjustment by parents of children with cancer is still behind. Many parents feel that they are not told about the disease condition, treatment as well as the prognosis of their child's condition (Griffiths, 2009). Currently, there is no information regarding parents' perception of support when a child is diagnosed with cancer in Malawi. The unit gets resources including staff from Baylor Children's Hospital, however this focuses on medical management and does not address support needs of parents of children with cancer. Therefore the study aims at exploring the support services as well as perception of parents of children with cancer on the available support.

1.3 Significance of the study

The findings will guide health care planners on strategies that can be used to support parents of children with cancer. The findings will also guide health workers on health education strategies to parents and guardians regarding childhood cancer. The strategies covering information, economic support, coping support for parents, as well as support groups will be considered after the study findings. The study will assist health workers in planning for family centered care during the diagnosis, treatment of childhood cancer and follow up of care. The findings will also identify possible areas for further research.

1.4 Study objectives

1.4.1 Broad objective

To assess how parents of children diagnosed with cancer perceive support rendered by health professionals at Kamuzu Central Hospital.

1.4.2 Specific objectives

1. To assess the type of support available following diagnosis of cancer in children
2. To elicit parents' perception of support rendered by health professionals following diagnosis of childhood cancer.

1.5 Summary

Family members go through a traumatic experience when a child is diagnosed with cancer. Nurses have a great responsibility to help families meet their needs during critical illness. Moreover, throughout treatment, families must manage repeated hospitalizations, hospital visits, financial difficulties, uncertainty about the child's prognosis, and fear of his/her possible death (Houtzager et al., 2005).

These challenges and stressors can disrupt the daily lives of all family members and alter the balance within family system (Kazak, 2005). Immediately after the diagnosis of cancer, parents feel an overwhelming sense of stress, urgency, disbelief and numbness (Hashem et al., 2007). Parents and families struggle to adjust to the many demands and threats that arise from cancer diagnosis and subsequent treatment (Murphy et al., 2008). Caring for a child with cancer is psychologically and behaviorally complex process for parents, involving various aspects of family life.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

The literature review relates to parents' perception on available health related support following a diagnosis of childhood cancer. Literature review is a critical summary of research on a topic of interest and often prepared to put a research problem in context (Polit & Beck, 2010). It aims at generating an understanding of what is known on a particular situation (Burns & Grove, 2009). The review puts together findings of research on childhood cancer from both developed and developing countries.

A computer assisted literature search was done through various academic databases such as Cumulative Index of Nursing and Allied Health Literature (CINAHL), PubMed, Open Access, HINARI, ScienceDirect.com and Google scholar in order to review what is known about parents' perceptions of available support following diagnosis of childhood cancer. Manual search from what peers and other researchers did was done from Kamuzu College of Nursing library. In addition, textbooks and unpublished documents were also accessed and reviewed. The search for articles was limited to publications from 2000 to 2014, except few articles which were published earlier than 2000. The researcher selected articles which were published in English. Some articles were identified from the bibliography of the retrieved articles.

An integrative literature review was conducted to find studies and articles relevant to parents' perceptions of available support following diagnosis of childhood cancer. Integrative literature review identifies, analyses, and synthesizes research findings from independent studies

to determine the current knowledge (what is known and not known) in the particular area (Burns & Grove, 2011). The terms used during the search were as follows: cancer AND children; childhood cancer AND parents; childhood cancer AND available support, childhood cancer AND treatment; childhood cancer AND challenges OR problems; childhood cancer AND parents' perception of support; childhood cancer AND impact on parents OR effects on parents; childhood cancer AND parents' coping strategies; childhood chronic illness AND parents' coping strategies; childhood cancer AND family centered care.

This chapter presents the literature that was reviewed to come up with what is known on the topic of the study. The literature review was guided by the objectives of the study and focused on previous studies relating to parents' perceptions of available support following diagnosis of childhood cancer. The literature has been divided into the following areas: impact of childhood cancer on parents, coping strategies used by parents of children with cancer, cancer support services and their challenges, parents' or guardians' perception of support services when a child has cancer and family centred care in the childhood cancer.

2.2 Impact of childhood cancer on parents

Chronic illness such as cancer in children places the well being of the entire family at risk of major psychological disturbances. In a study by Hashemi et al. (2007) on coping strategies used by parents of children with cancer in Shiraz, Southern Iran, showed that the emotional impact of cancer on parents of children diagnosed with cancer is extreme and long lasting, even when a confident prognosis can be reasonably given. When a child has cancer, parents experience a wide range of psychological emotions and experiences (Clarke et al., 2004; Houtzager et al., 2005). As reported by Jackson et al. (2007), these emotions include feelings of

fear, helplessness and tough patterns of coping. The threatening nature of childhood cancer and the aggressiveness of prescribed cancer treatments place huge anxiety and depression on the family of children suffering from cancer (Young, Woods, Findlay, & Heney, 2002; Fedele, Mullins, Worfe-Christense & Carpentier, 2011).

In another study done at UK regional cancer centre by Fotiadou, Barlow, Powell & Langton (2008) which examined the relationship between optimism, anxiety, depression, life satisfaction, coping and subjective perception in 100 parents of children with cancer and 117 parents of healthy children, showed that parents of children with cancer had higher levels of anxiety, depression, than the comparison group. On the other hand, when a diagnosis of cancer has been confirmed, parents blame themselves. They perceive themselves as failures as they have failed to advocate and protect their children (Young et al., 2002).

In addition to seeing themselves as failures, they look back on the pre diagnosis period and feel they had not been sufficiently vigilant in detecting the early symptoms of their children's illness. Some parents blame themselves for having failed to protect their child from hazards during pregnancy and childhood and that they had failed as advocates and protectors for their children (Young et al., 2002). Likewise, parents experience feelings of self blame, they blame others especially medical professionals for not acting or diagnosing their child's illness fast (Clarke et al., 2004).

In addition to psychological burdens on parents, changes in their children's appearance resulting from therapies and the illness add to their suffering (Taleghani, Fathizadeh, & Naseri, 2012). Parents fear that their child's experiences during the illness would have a long lasting impact and permanently alter the course of their development. According to William, Chung, Ho, Chiu & Lopez (2012) parents of childhood cancer survivors fear the long term outcomes of

cancer as they develop chronic health problems in early adulthood. Similarly, other studies have revealed that when children are diagnosed with and treated for cancer, they and their family members encounter major challenges and stressors related to the short and long term side effects of treatment including disability, infertility and possible disease relapse (Houtzager et al., 2005; Alfano & Rowland, 2006; Young et al., 2002). Some studies have shown that parents face distress, regarding multiple hospitalizations and chemotherapy side effects. Parents worry whether their child's cancer will get cured (Taleghani et al., 2012; Houtzager et al., 2005; Taleghani, Yekat & Abadi, 2008).

A study by Fedele et al. (2011) on cultural beliefs and coping strategies related to childhood cancer: The perceptions of South Asian immigrants parents in Canada revealed that cancer is associated with death, and for most people cancer cannot be associated with children hence experience increased levels of depression and anxiety. Furthermore parents are also bothered with the changing of appearance which includes being skinny, hair loss and paleness of the sick child (Woodgate, 2006).

Clarke et al. (2004), emphasizes that families are presented with additional tasks, responsibilities and concerns over additional care of the child. Consistent with this are the findings of a study conducted by Young et al. (2002) that reported that the diagnosis of childhood cancer brings with it a set of new physical responsibilities and role expectations to parents. According to Norberg et al. (2005), families have a commitment of being close to their child at all times to provide comfort and to keep watching the sick child. Parents are suddenly placed in the position of coping with a wide range of new situations and changes in social relationships. It has also been acknowledged that childhood cancer leads to disruptive families because of long time and frequent hospitalization (Young et al., 2002; Woodgate, 2006).

Financial changes that families face during childhood tragedy have also been frequently noted. Throughout childhood cancer treatment, families must manage repeated hospitalizations, hospital visits and all these lead to financial difficulties for the families (Houtzager et al., 2005). Similarly in a review of literature by Kazak (2005) on evidence based interventions for survivors of childhood cancer and their families reported that the challenges and stressors that come in the family can disrupt the daily lives of all family members and alter the balance within family system. Likewise, repeated hospitalizations and the need felt by parents to be at their child's bedside not only affect the way they fulfilled their family responsibilities, but also impacted negatively on their jobs which in the end they lose (Taleghani et al., 2012).

2.3 Coping strategies used by parents of children with cancer

Coping is a process involving cognitive and behavioral attempts to meet the demands of and to control the emotions generated by a situation (William et al., 2012). Parents use different strategies to cope with childhood cancer. In a review of literature by Alfano & Rowland (2006), on recovery issues in cancer survivorship: A new challenge for supportive care stresses that successful coping interventions yield humble effects including less depression, lower mood disturbance, greater marital satisfaction, less emotional discomfort and more positive growth to families of children with chronic conditions.

Coping by parents of children with cancer is a dynamic process whose crucial goal is to help them come to terms with the disease and the problems it causes. There are five components of the coping process in childhood cancer as reported by Yeh (2003). These include: confronting treatment, maintaining family integrity, establishing support, maintaining emotional well being, and searching for spiritual meaning. However, nurses conclude that these stages have a

sequential pattern when the medical condition of the child is relatively steady. In contrast, these components are less obvious when complications and relapses frequently occur in an unpredictable manner (Yeh, 2003).

Findings of a study conducted in Hong Kong by Wong and Chan (2006) on experiences of Chinese parents with children having cancer showed that parents tolerate their children's disease and try to actively fight it by positive thinking and keeping a positive eye to the future. This manner of thinking motivates parents to get involved in their child's care, determine the priorities in life and acquire necessary information. In Taiwan, Huang, Mu & Chiou (2008) conducted a qualitative study on Parental experience of family resources in single parent families having a child with cancer. In this study five major themes that assist parents with coping were identified. These include: facing the disease with courage, hope kindled by professionals, constructing parental role ability, assisting the children to live with the illness and family flexibility. The results also demonstrated that families with a child suffering from cancer employ family resources to assist in coping and to maintain family role as well as stability.

Other studies have found that majority of ill patients and guardians use religious beliefs when coping with illness and in this regard, a key factor is the cultural context of the country in which the patient lives (Hassankhani et al., 2009; Yeh, 2003; Bussing & Koenig, 2010). Religious beliefs and cultural background are critical to an individual's ability to cope with a disease like cancer (Taleghani et al., 2008). Information seeking is reported as another strategy of coping with childhood cancer (Zwaanswijk, et al. 2011). Information seeking by parents of children with cancer assist them to restore their emotional balance (Hashemi et al., 2007).

2.4 Cancer support services and their challenges

Support in cancer is defined as a network of resources or a set of relationships through which an individual receives and use in dealing with demands and achieving goals (Norberg & Boman, 2007; Woodgate, 2006). Support includes supportive behaviours which have been found to be helpful to both children with cancer and parents in coping and adjusting with cancer (Ritchie, 2001; Woodgate, 2006). Findings of a study by Haluska (2002) on sources of social support: Adolescents with cancer stressed the importance of having strong support system in helping children and parents cope with cancer. However, Taleghani et al. (2012) noted that there is no integrated organized support existing for parents of children with cancer. The literature reviews support in form of medical care and treatment of cancer, information on cancer, social and emotional support as well as spiritual support.

2.4.1 Medical care and Treatment of cancer

Advancements in modern science and technology have contributed to the progress of cancer treatment (Pedro, Galvao, Rocha & Nascimento, 2008). Literature indicates that there has been notable progress in the treatment and prognosis of childhood cancer for the past decades (Ruland et al., 2009; Narsavage & Romeo, 2003; Norberg & Boman, 2007; Wu, Chin, Haase & Chen, 2009), such that today most children with cancer survive the illness (Taleghani et al., 2012). However, a review of literature by Rodriguez-Galindoa, Friedricha, Morrissey & Frazier (2013) on global challenges on paediatric oncology revealed that despite available treatment parents do not believe in the effectiveness of the chemotherapy offered to their children. As such there is an increase in refusal and abandonment of therapy in countries with limited resources and this contributes to therapeutic failure.

2.4.2 Provision of information on cancer

Provision of information in managing childhood cancers is very important. Clear and broad information about the disease and treatment helps parents to make sense of their situation and make appropriate plans (Sloper, 2000). In addition to parents making sense out of their situation, Zwaanswijk et al. (2011) states that current guidelines in pediatric oncology care encourage health care providers to share relevant information with patients and parents to enable their active participation in decision making. Parents wish to be fully and truthfully informed and prefer to participate in treatment decision making.

The seeking of information on the part of parents can be understood as a reasonable attempt to learn as much as possible about childhood cancer in order to identify their new situation and negotiate new arrangements. It is a great approach for them because they find it encouraging to learn and practice new skills and to practice possible alternatives (Patistea, 2005). A study in Greece by Patistea & Babatsikou (2003) on parents' perceptions of the information provided to them about their child's leukemia revealed that during the course of the disease families go through a number of critical and overlapping phases. In each phase, parents naturally have many questions that need to be answered if they are to deal effectively with the comprehensive stressors associated with the disease so that they become knowledgeable carers of their child.

Unless they are health care professionals, mothers and fathers have very limited and inaccurate information about the child's medical condition. On the other hand, members of the health care team, particularly physicians, represent the most significant source of information, especially during the initial phase of the disease (Patistea & Babatsikou, 2003). Adequate and

accurate medical information is important for parents to obtain a sensible view of the situation and to help them move in a positive direction.

However, much basic information is not presented to parents or is presented in a highly technical fashion that further increases their confusion. Despite the emotional distress of all family members of children with cancer, additional information regarding implications of the disease is rarely incorporated even in the most standard intervention designs (Young et al., 2002).

2.4.3 Social and emotional support

Social support is referred to as an interaction process between people, who through systematic contacts establish bonds of friendship and share information. It contributes to mutual well being and constructing positive factors in prevention and health maintenance (Pedro et al., 2008). Among the resources and individual resilience factors, the availability of social support seems to be essential to the maintenance of psychological and physical well being among parents of children with cancer. Generally, in the face of severe stress, it is a fact that social support is supposed to work beneficially in several ways such as affecting the use of various coping strategies, improving self efficacy and influencing the evaluation of the stressor (Norberg & Boman, 2007).

Another factor that makes life easier for parents of children with cancer is to share their experiences with parents in similar conditions. This relates to sharing of information while believing that having a common pain helps parents to understand and console each other. Informal exchanges between parents of children with cancer serve as an important source of support. Parents do not talk about their children's disease with friends but tend to discuss with parents with similar problems about their problems (Wong & Chan, 2006).

Furthermore, a study conducted by Han (2003) on Korean mothers' psychosocial adjustment to their children's cancer showed that the more social support parents get, the better they adapt to their child's disease.

Counseling is another aspect of emotional support that needs to be appreciated in childhood cancer. However, in Sweden a study by Norberg & Boman (2007) on parents' perceptions of support when a child has cancer reported poor provision of counseling services. The results indicated that parents of children with cancer at all ages and stages of the illness highlighted counseling services for parents as an unmet need.

Diagnosis or relapse of the disease tends to be the most difficult phase for the parents and therefore need more emotional support. During treatment, parents look for informational support. After being told the diagnosis and treatment has been resumed, families start to seek and receive the different types of social support, which favor their adjustment in this trajectory. On the other hand, a study by Pedro (2008) on social support and families of children with cancer: An integrative review found that the support offered tends to decrease over time due to the duration of treatment.

2.4.4 Spiritual support

Faith and religious beliefs bring comfort to parents. Parents of children with cancer seek religious counseling to help ease their feeling of guilt and cope with their child's illness. Performing religious traditions, praying and other acts of religious devotion offer inner emotional soothing (Taleghani et al., 2012). Equally, Gall (2004), states that having a special relationship with God helps individuals to endure difficult situation and strengthens the individual in dealing with uncontrollable events, such as the diseases.

Taleghani et al. (2008), added that feeling God's presence in parents' lives gives them hope that therapies would succeed and that their child would recover from cancer. The belief in God gives them peace of mind and strength to fight the problem. Having a special relationship with God helps individuals to endure difficult and unavoidable events. In a study by Yah (2002) on life experiences of Taiwanese adolescents with cancer, searching for spiritual meaning was an aspect many participants raised. However, Gall (2004) indicated that patients and parents face a huge amount of anxiety if they imagine that the disease is God's way of punishing them.

2.5 Parents' perception of support when a child has cancer

Support is important in maintaining psychological wellbeing. However, severe stress may influence a person's perception of the availability and value of support from others (Norberg & Boman, 2007). Parents seem to value availability of parents of children with cancer as they provide opportunities to talk to them and understand their situation (Ritchie, 2001; Woodgate, 2006). Therefore, helping parents of children with cancer maintain a relationship with others is the important element of support in childhood cancer.

A study by Mitchell, Clarke & Sloper (2006) on care and support needs of children and young people with cancer and their parents in the United Kingdom (UK) treatment centers, revealed that parents, irrespective of their child's age, were satisfied with the medical information they received from doctors and nurses at diagnosis (80%) and during treatment (81%). Similarly, children and young people of all ages were satisfied with the information they received about their illness at the time of diagnosis (75%). In contrast, the study revealed unmet need with regard to accessing different types of information and for whom information was

targeted. Parents felt that there was no video information about cancer and its treatment and there were no cancer books as well as brochures for them to read.

Norberg and Boman (2007) indicated that perceived support often diminishes over time in parents of children with cancer. As parents cope with severe emotional distress, they view interventions aiming at providing social support as not sufficient. This complex association between perceived support and distress indicates that maintaining positive perceived support should be a central goal of nursing and psychosocial care of parents of children with cancer.

2.6 Family centered care in childhood cancer

A family is a basic unit of care for children (Richter, 2010). Furthermore, Kazak, Rourke, & Crump (2003) emphasize that the family system is important for children with a chronic illness. Chronic illness requires all family members to adapt to medical appointments, new responsibilities, financial strain and physical absences of multiple family members. When examining the adjustment of children affected by cancer, it is important to consider the adjustment of the entire family; hence family centered approach becomes important.

Family centred care describes a philosophy or approach to providing services for children and their families. In the broadest sense, family centered care means welcoming the family as partners in the care of the child. It promotes the development of an equal partnership between parents and health care professionals that is beneficial to the child (Van Schie, Siebes, Ketelaar & Vermeer, 2004). The concept is based on respect for all families, recognition of each family's strengths and willingness to build on such strengths. It promotes that information is shared with families in an honest and unbiased manner. Families are empowered to make choices and health

professionals are expected to support the choices and ensure that services meet the needs of all the families by respecting their racial, ethnic, cultural and social economic diversity (Dyke, Buttigieg, Blackmore & Ghose, 2005).

Having a child diagnosed with cancer is one of the most difficult and painful life experiences for a family. From very early on, the families have to be involved in complex treatment procedures and deal with their own feelings and uncertainty at the same time (Svavarsdottir & Sigurdardittir, 2006). Models of healthcare delivery, such as family centered care have become standard in providing high quality health care for children undergoing cancer treatment.

Such models emphasize providing information and fostering and supporting the active inclusion of parents in their children's treatment and management (Holm, Patterson & Gurney, 2003). To receive standard care, families of children with cancer need family centered interventions that are effective and appropriate to the healthcare services offered (Whittemore & Grey, 2002).

The opinions of both the patient and the parent are important in pediatrics (Poder, Ljungman & Essen, 2010). Although there is growing recognition that the family is central to the patient's recovery, information is limited on how to help families as they manage the demands associated with family care giving (Northouse, 2005).

2.7 Summary

Even when the confident prognosis can be reasonably given in most child cancer cases, the emotional impact of the diagnosis of cancer is extreme and long lasting (Hashemi et al., 2007). Parents and families struggle to adjust to the many demands and threats that arise from

cancer diagnosis and subsequent treatment (Murphy et al., 2008). Caring for a child with cancer is psychologically and behaviorally complex process for parents, involving various aspects of family life. The psychological, social and physical challenge of parenting a child who has cancer influences the lives of parents for years, even after the end of treatment (Yeh, 2003).

There are many forms of support available for parents of children with cancer. These include availability of treatment, provision of emotional and social support, as well as information in relation to diagnosis, treatment and progress of cancer. There is need to assess the stage at which the child is so that appropriate support should be rendered.

CHAPTER 3

METHODOLOGY

3.0 Introduction

Research methodology refers to the strategy the researcher uses to collect, manipulate or interpret data from the study (Leedy & Ormrod, 2010). Research methods are techniques researchers use to structure a study, to gather and to analyze information relevant to the research question (Polit & Beck, 2010). This chapter presents the research design, study setting, sample size and sampling method, instrument that was used, data collection and analysis. An explanation of how ethical issues were addressed during the study is also presented.

3.1 Research design

The study utilized descriptive design of quantitative research. Descriptive design provides an accurate account of characteristics of a particular individual, situation or group (Burns & Grove, 2005). Descriptive design is used to get a picture of a situation as it naturally happens (Burns & Grove, 2011) and was considered appropriate for this study because it aimed at describing how parents perceive the support rendered to them when a diagnosis of cancer has been confirmed in their children. Burns & Grove (2005) also state that a descriptive study is designed to gain more information about characteristics within a particular field of study and its purpose is to provide a picture of a situation as it naturally happens. Descriptive designs are also used to identify problems with current practice and to make judgments (Burns & Grove, 2005).

Quantitative research is the study of the phenomena that lend themselves to precise measurements and quantification (Polit & Beck, 2004). This is a formal, objective, systematic process to describe and test relationships and to examine cause and effect interactions among variables (Burns & Grove, 2005). Numeric information results from formal information are analyzed with statistical procedures (Polit & Beck, 2004).

3.2 Study setting

The study was conducted at Kamuzu Central Hospital in Lilongwe, which is a referral hospital in Malawi. The hospital caters for the country's central region which has a population of 5,510, 195 (National Statistics Office of Malawi, 2013). The hospital has a bed capacity of 933. The paediatric ward has 280 beds representing 30% of the hospital's total bed capacity. Kamuzu Central Hospital was selected because it is the only facility that manages childhood cancers in the country's central and northern regions. There is a section within the paediatric ward where children with cancer are admitted. These patients are referred from district hospitals.

The cancer unit is funded by the Baylor College of Medicine-Abbott Fund Children's Clinical Centre of Excellence and is headed by a Pediatrician. The hospital was opened in 2006 as a response to an increase in number of HIV positive children or those exposed to HIV. The hospital gets funding from The Abbott Fund, a global health care company that is based in Illinois, United States. There are two physicians and two nurses who work in the unit. The physicians and the nurses underwent on-the- job training on management of childhood cancer. Parents or guardians of the sick children stay at the hospital throughout hospitalization of the children.

3.3 Study Population

The study population for this study was parents or guardians of children who brought their children as outpatient, for cancer treatment or review at the hospital.

3.4 Sampling method and sample size

Selection of parents of children with cancer was based on a consecutive sampling method whereby all children who met the inclusion criteria were recruited until sufficient sample size was obtained. This was relevant for the study to achieve a good representation of the overall population (parents of children) within a reasonable period of time. Sampling is a process of selecting subjects who are representative of the population being studied (Burns & Grove, 2011). Consecutive sampling involves recruiting all of the people from an accessible population who meet the eligibility criteria (Polit & Beck, 2010). Every eligible subject is selected and this means that a complete accessible population is studied. Salant & Dilliman (2006) also stated that consecutive sampling is the best choice of non-probability sampling technique since studying everybody available there is a good representation of the overall population in a reasonable period of time.

A preliminary audit showed that the facility admitted 21,933 children in 2013, with an average of 20 childhood cancer admissions per month (KCH, 2013). Children with cancer are admitted for only two weeks during which they receive chemotherapy and then they are discharged to be treated as outpatients. In this study the researcher recruited 60 participants.

3.5 Inclusion criteria and exclusion criteria

Parents or guardians of children diagnosed with cancer and admitted to the hospital or those who brought their children for review were included in the study. Parents or guardians with very sick children diagnosed with cancer and admitted in other units like intensive care unit or high dependency unit were excluded from the study because of the high level of stress that these parents experience. In addition, parents of children with cancer who refused to take part in the study were also excluded.

3.6 Data collection period

Data collection was conducted over a period of 2 months from 1st September, 2014 to 31st October, 2014.

3.7 Data collection procedure

Parents or guardians who met the inclusion criteria were requested to participate in the study. Parents or guardians of admitted children were approached and face to face interviews using the developed questionnaire were conducted at a convenient time for them without disturbing hospital activities. For parents or guardians who brought their children to clinics for review, face to face interviews using the developed questionnaire were conducted at the end of the review. For both groups, a library that was not operational during data collection period within the hospital was used for the interviews. The library was locked during the period of interviews.

3.8 Data collection instrument

A questionnaire developed by the researcher based on review of literature was used (Appendix A). The questionnaire was translated to Chichewa version (Appendix B). The researcher utilized a Likert scale approach because the study aimed at identifying perception of parents on available cancer support services. Likert scales are useful when measuring characteristics of people such as attitudes or perceptions, feelings or opinion (Morse, 2010; Burns & Grove, 2011). Likert scales are useful question type when the researcher wants to get an opinion, or experience or perceptions of participants on a subject (Vanek, 2010; Waddington, 2000).

The questionnaire consisted of 3 parts as follows: demographic information, available support and perception of parents on support. The first part of the questionnaire required parents to provide the following demographic data: age, home language, level of education, relationship to the sick child, occupation and religion. Demographic data was important because it was considered that some of the components such as level of education, religion would influence the perception of support rendered to children with cancer. The second part of the questionnaire required parents to rate the availability of support services, based on their understanding and personal experiences. There were 8 statements related to available support services to be rated on the following scale: excellent, very good, good, fair and poor. This part had 5 points because it was measuring quality of available support.

The third part of the questionnaire had questions related to parents' perception on available childhood cancer support services. The parents were required to rate the extent to which available support happens to them. There were 20 statements related to parents'

perception on available. The options for the responses were to a great extent, to a moderate extent, to a small extent and not at all. This part had 4 points because it was measuring the degree how available services were being done to parents. Completion of the each questionnaire took less than 45 minutes.

The Likert scale utilized closed ended questions because of the quantitative nature of the study. Polit & Beck (2010) stated that quantitative researchers collect primarily quantitative data. The Likert scale utilized in the study did not have a neutral point. It was noted during pilot study that the questionnaire did not have questions that warranted neutral responses. Aldeson & McCoach (2010) concludes that with a neutral point category, participants will be less discriminating and declare themselves as neutral more often and omitting the neutral point makes participants to be more thoughtful, resulting in more precise ratings. Garland (1991) concluded that eliminating the neutral point category from Likert scales provides some evidence that social desirability bias, arising from respondents' desires to please the interviewer or appear helpful or not be seen to give what they perceive to be a socially unacceptable answer, can be minimized. A scale without neutral responses is preferable because respondents are obliged to make definite choice.

3.9 Pre-testing of the instrument

Pre-testing of the tool was done in August, 2014. Pre-testing of the tool was conducted at Kamuzu Central Hospital, paediatric ward cancer unit. Pre-testing of data collection tool was done on 10 participants who met the inclusion criteria as in the main study (Parents or guardians of children diagnosed with cancer and admitted to the hospital or those who came as outpatients for review or treatment). Pilot study was done to check if the questions were clear as well as to determine how long it was going to take for the parents to finish responding to the questions. The

pilot study was also done to identify areas that needed corrections before commencing data collection. Results of pre-test were not included in the final analysis. There were no major issues identified therefore no changes were made to the questionnaire. It took 40 minutes for the parents to finish responding to the questions.

3.10 Reliability and validity of the data collection instrument

Reliability was ensured by accurate and careful phrasing of questions to ensure consistency (Gerish & Lacey, 2010). Pre-test was also conducted to enhance reliability of the tool (Van Teijlingen & Hundley, 2001). Reliability is the consistency with which an instrument measures the attribute (Polit & Beck, 2010). To ensure validity the development of the questionnaire was based on literature review. Research supervisor and experts working in the pediatric cancer unit reviewed the tool. Validity is the degree to which an instrument measures what it is supposed to measure (Polit & Beck, 2010).

3.11 Data management

Questionnaires were assigned a code number and locked in the researcher's office drawer to which only the researcher had access. Consent forms were kept separate from the questionnaires. The questionnaires were checked for completeness by the researcher before data were entered into the computer programme for analysis. The records will be kept until the research is complete and afterwards the records will be destroyed. Data are being stored on a password protected computer.

3.12 Ethical considerations

The following ethical considerations were applied:

- The research proposal was submitted to Kamuzu College of Nursing (KCN) Research and Publication Committee (RPC) and College of Medicine Research Ethics Committee (COMREC) for approval (Appendix C).
- Permission to conduct the study was sought from the Director of Kamuzu Central Hospital.
- An information letter explaining the purpose of the study was attached to each data collection questionnaire.
- A written consent was sought from the participants to show their willingness to participate in the study (Appendix G).
- Participants were given an opportunity to ask questions in relation to the study.
- Code numbers instead of personal names were used during data collection and reporting of the findings to protect participants' confidentiality and anonymity.
- Participants were allowed to withdraw at any time without any penalty. Their decision not to participate in the study did not in any way affect the care for their sick children.
- Only the researcher had access to the data until final submission of the research report.

3.13 Data analysis

Data was cleaned manually after collection. Data was entered into the computer by the researcher. Statistical Package for the Social Science (SPSS) version 20 was used to analyze the data. Data were analyzed using descriptive statistics such as means, median and standard

deviation. Frequencies and percentages were used to summarize the data. The results were then presented in tables.

3.14 Dissemination of findings

Findings of the research will be disseminated through seminars, national and international conferences. At national level, the findings will be shared with health workers at Kamuzu Central Hospital and Baylor Children's Hospital in form of a presentation during morning meetings. Copies of the findings will be presented to stakeholders such as Ministry of Health (Kamuzu Central Hospital), Kamuzu College of Nursing Library and College of Medicine Research Centre secretariat. Internationally, a research article will be developed and published in any of paediatric journals. The research findings will also be presented at international conferences.

3.15 Summary

This chapter has presented research methodology. This included research design, setting, population, sample and sampling, data collection, instrument used including its validity and reliability as well as ethical issues.

CHAPTER 4

RESULTS

4.1 Introduction

This chapter presents results of the study. The results will be presented as follows: demographic data, available support and participants' perception of available support. Descriptive statistics such as frequencies, percentages, mean, standard deviation have been used to present the results in tables.

4.2 Demographic data

Demographic data included sex, age, tribe, education, Relationship of parent/guardian to the sick child and religion. The total sample for the study was 60, with the majority being females (78.3%, n=47).

Sex

Majority of the participants (78.3%; n=47) were females and 21.7% (n=13) were males.

Age

The age range for 57 participants (95%) was 20 to 70 years with a mean of 38.5 and Standard Deviation of 10.6. Majority (33.3%; n=20) were in the age group of 31 to 40 years, followed by 25% (n=15) in the age group of 41-50, then 23% (n=14) were between 20-30 years and 13.3% (n=8) were above 51 years. 5.0% (n=3) did not know their age (Table 1).

Tribe

Majority 78.3% (n=47) were Chewa, 18.3% (n=11) were Tumbukas, and there was one Yao and one Lomwe.

Education

Majority (66.7%; n=40), had primary education, followed by 23.3% (n=14) who had no education, and only 10% (n=6) had secondary education.

Relationship of parent/guardian to the sick child

76.7% (n=46) were mothers, 15% (n=9) were fathers, 6.75 (4) were grandparents and one was a sister.

Religion

Majority of the participants were Christians, 93.3% (n=56) and 6.7% (n=4) were Moslems.

Table 1: Demographic characteristics of participants

CHARACTERISTIC	FREQUENCY(n=60)	PERCENTAGE (%)
<i>Sex</i>		
Female	47	78.3
Male	13	21.7
<i>Age</i>		
20-30 years	14	23
31-40 years	20	33.3
- 41-50 years	15	25
- >50 years	8	13.3
- Don't know	3	5
<i>Religion</i>		
- Christian	56	93.3
- Moslem	4	6.7
<i>Tribe</i>		
- Chewa	47	73.8
- Tumbuka	11	18.3
- Lomwe	1	1.7
- Yao	1	1.7
<i>Relationship of participant to the sick child</i>		
- Mother	46	76.7
- Father	9	15
- Grandparent	4	6.75
- Sister	1	1.7

4.3 Available cancer support services

The following available support services were rated by majority of the participants as either excellent, very good or good: nurses who care for their sick children, doctors who care for their children, information regarding children's condition, time offered to discuss child's condition, treatment, food, spiritual support and accommodation if needed. The participants rated highly the availability of treatment (excellent, 68.4%, n=41; very good, 18.3%, n=11 and good 13.3%, n=8). On the other hand 25% and 21.6% indicated that availability of nurses and doctors respectively, is either fair or poor. Twenty percent of the participants rated information as being poor and 25% reported that accommodation that is provided by the hospital is either fair or poor (Table 2).

Table 2: Available cancer support services

AVAILABLE SUPPORT	PARTICIPANTS' RESPONSES				
	Excellent n (%)	Very good n (%)	Good n (%)	Fair n (%)	Poor n (%)
Nurses who care for your child	4 (6.7)	18 (30)	23 (38.3)	13 (21.7)	2 (3.3)
Doctors who care for your child	5 (8.3)	26 (43.3)	16 (26.7)	11 (18.3)	2 (3.3)
Information regarding your child's condition	6 (10)	19 (31.7)	23 (38.3)	8 (13.3)	4 (6.7)
Time offered to discuss your child's condition	6 (10)	23 (38.3)	23 (38.3)	6 (10)	2 (3.3)
Treatment	41(68.4)	11(18.3)	8 (13.3)	0	0
Food if needed	8 (13.3)	35 (58.3)	12 (20)	4 (6.7)	1(1.7)
Spiritual support	3 (5)	31(51.7)	17 (28)	6 (10)	3 (5)
Accommodation if needed	4 (6.7)	25 (41.7)	16 (26.7)	12 (20)	3 (5)

4.4 Perception of support

Part three of the questionnaire sought to elicit participants' perception of support. The statements on perception of support were related to social and emotional support, informational support, medical care and spiritual support. Participants were requested to indicate the extent to which health workers provide the support services.

4.4.1 Social and emotional support

Majority of the parents (86.7%, n=52) indicated that they are treated to a great extent as an individual rather than a typical parent of cancer child. In addition, 76% (n=46) of the parents reported that they are helped to a great extent to be competent as parents and rated highly that they are helped to be competent as parents and 51.7% (n=46) also indicated that a caring atmosphere is provided to a great extent. Furthermore, 50% (n=30) indicated that accommodation is provided to a great extent. A significant proportion of the parents, (48.3%, n=29) and (46.7%, n=28) reported that staff at the facility show willingness to help and are approachable to a great extent respectively.

On the other hand, 96.7% (n=58) of the parents reported that they are not provided with advice on how to get information or to contact other parents, organizations. Apart from that, a considerable proportion of the parents, (43.3%, n=26) and (38.3%, n=23) seem not to be satisfied with the provision of holistic care of children (e.g. mental, emotional and social needs) as they reported that holistic care is either not done or it is done to a small extent respectively.

4.4.2 Informational support

Participants were asked to indicate the extent to which doctors and nurses provide informational support. Majority of parents (95%, n=57) considered consistency in giving information about the child's condition being met to a great extent (56.7%, n=34) or to a moderate extent (38.3%, n=23). Similarly, 81.7% (n=49) of the parents, believed that they are told about the results of their sick children after assessment is done to their children. On the other hand, all parents (100%, n=60) reported that provision of information in various forms such as leaflets, video is not met. Apart from that, majority of parents (71.7%, n=43) reported that they are not allowed to choose when to receive information and the type of information they want. Furthermore, a significant percentage of parents (58.3%, n=35) believed that explanation of the types of cancer services available is done but to a small extent at the facility. The results also reveal that majority of parents (55%, n=33) thought that the need for provision of information about the child's condition such as causes of cancer, how it progresses, future outlook is met to a small extent. In relation to treatment, a considerable percentage of parents (48.3%, n=29) indicated that explanation on treatment is done but to a small extent.

4.4.3 Medical care and spiritual support

Participants were asked to indicate the extent to which medical and spiritual support is provided. Majority of the parents (83.3 %, n=50) indicated that treatment at the facility was available to a great extent. Furthermore, parents (76.7%, n=46) rated provision of spiritual support as being met to moderate extent (41.7%, n=25) and to a great extent (35%, n=21). Apart from that, an important percentage of parents (41.7%, n=25) and (30%, n=18) rated provision of opportunity to make decisions about treatment as being done to a small extent and not at all respectively.

Table 3: Perception of support by parents

Qn	To what extent do people who work with your child	Participants' responses			
		To a great extent n(%)	To a moderate extent n(%)	To a small extent n(%)	Not at all n(%)
1	Help you feel competent as a parent?	46 (76.7)	14 (23.3)	0	0
2	Provide you with a caring atmosphere rather than just give you information?	31(51.7)	21(35)	8(13.7)	0
3	Show that they are approachable?	28(46.7)	21(35)	11(18.3)	0
4	Show willingness to help?	29(48.3)	28(46.7)	3(5)	0
5	Let you choose when to receive information and the type of information you want?	1(1.7)	1(1.7)	15(25)	43(71.7)
6	Provide you with information about your child's condition?	9(15)	13(21)	33(55)	5(8.3)
7	Have information available about your child's cancer e.g. Its causes, how it progresses, future outlook?	2(3.3)	1(1.7)	13(21.7)	44(73.3)
8	Give you information about your child that is consistent from person to person?	34(56.7)	23(38.3)	2(3.3)	1(1.7)
9	Have information to you available in various forms such as leaflets, video	0(0)	0	0	60(100)
10	Fully explain treatment choices?	3(5)	15(25)	29(48.3)	13(21.7)
11	Fully explain the types of cancer services available?	2(3.3)	10(16.7)	35(58.3)	13(21.7)
12	Tell you about results from assessment?	49(81.7)	7(11.7)	3(5)	1(1.7)
13	Provide an opportunity for you to make decisions?	2(3.3)	15(25)	25(41.7)	18(30)
14	Provide adequate treatment?	0	50(83.3)	5(8.3)	5(8.3)
15	Provide accommodation?	30(50)	21(35)	7(11.7)	2(3.3)
16	Treat you as an individual rather than a typical parent of cancer?	52(86.7)	8(13.3)	0	0
17	Provide spiritual support?	21(35)	25(41.7)	9(15)	5(8.3)
18	Provide enough time to talk to so you don't feel rushed?	16(26.7)	20(33.3)	21(35)	3(5)
19	Provide advice on how to get information or to contact other parents, organizations?	0	0	2(3.3)	58(96.7)
20	Look at the needs of your whole child e.g. mental, emotional and social needs instead of just physical needs?	2(3.3)	9(15)	23(38.3)	26(43.3)

4.5 Summary

This chapter presented results of the study. Most of the participants were females. All the statements on available support services were rated as excellent, very good and good by the participants. However there were inconsistencies on the extent to which different support services are provided. Participants rated some support services as being provided to a great extent, while others as moderate extent, small extent and not all.

CHAPTER 5

DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

This chapter presents discussion of results, conclusion and recommendations. The discussion will be based on the study objectives. Specifically the study assessed the type of support available following diagnosis of cancer in children and elicited parents' perception of support rendered by health professionals following diagnosis of childhood cancer. In this study, data were collected at Kamuzu Central Hospital. The discussion will focus on the following areas: available cancer services and parents' perception of the available support. This is followed by limitations of the study and recommendations for nursing management, nursing education, clinical practice, areas for further research and conclusion.

5.2 Available cancer support services

Results of this study showed that participants generally indicated that support services are available at the facility. However, participants highly rated availability of the following services; treatment, food if needed, time offered to discuss child's condition, spiritual support and information regarding children's condition. These results are similar to findings of previous studies (Bhatia, 2012; Aldridge & Roesch, 2007; Yeh, 2003) which showed that there is improvement in therapeutic and supportive care in pediatric cancer. These findings could be attributed to a number of reasons. The hospital gets support from the Baylor College of Medicine-Abbott Fund Children's Clinical Centre of Excellence which was established by Baylor International Paediatric AIDS Initiative (BIPAI). This is stand-alone clinic in Malawi dedicated

to the care and treatment of HIV-infected children, and training of different cadres of health professionals in the management of paediatric HIV/AIDS. This support includes medication and staff. These nurses and doctors who work at the cancer unit follow a prescribed policy that encourages them to provide information to children and their guardians. In addition, the hospital, where this study was carried out, provides meals to patients and their guardians. As for spiritual support, the hospital has a Chaplain who offers spiritual support to patients and their guardians. In addition, the hospital allows other religious leaders to visit patients and their guardians for spiritual support. These results suggest that childhood cancer services such as treatment, spiritual support and information are available to patients and their guardians at the facility.

5.3 Perception of support

Studies have shown that support services help parents as well as patients with cancer cope with the situation (Alfano & Rowland, 2006; Mitchell, Clarke & Sloper, 2006; Woodgate, 2006; Haluska, 2002). Parents of children with cancer value the support they receive from health care team members (Hedstrom, Skolin & von Essen, 2004). Results of this study showed that different types of support are perceived differently.

5.3.1 Social and emotional support

Majority of participants indicated that events or situations related to social and emotional support are provided to a great extent. All participants reported that they are helped to be competent in caring for their sick children. These results are supported by available literature which shows that parents of children with cancer feel enabled in their parental role as they care for their sick children (Arnadottir & Egilson, 2012). Results show that parents are provided with a caring atmosphere rather than just information. The results also show that staff is willing to help the

parents. The results are consistent with findings of Arnadottir & Egilson (2012) who reported that childhood cancer health professionals are supportive.

Participants rated to a great extent on provision of accommodation. Kamuzu Central Hospital as a referral hospital provides accommodation for both sick children and their parents. This is good because parents' availability is necessary during hospitalization of their sick children. This fosters good relationship between parents and health workers. It also enhances the provision of information to parents so that they are involved in the care of their sick children. A study by Woodgate (2006) also reported that children perceive availability of parents as more supportive.

The study revealed that advice on how to get information or to contact other parents in similar situations or, organizations was not met. The results are consistent with the results of a study by Bellin, Osteen, Heffernan, Levy, & Snyder- Vogel (2011) which stated that 50% of participating parents reported difficulties in receiving information about how to connect with other parents or and 54% of health care professionals admitted inconsistency in promoting family to family connections for social, informational, or shared experiences. Other studies have indicated that parents prefer communicating with other parents who are in similar circumstances in caring for a family member with a chronic illness such as cancer (Neufeld et al., 2002; Randhawa & Owens, 2004; Wong & Chan, 2006).

The results of the study show that there is poor provision of advice on how to get information or to contact other parents, organizations. The results are in contrast with the results of Clarke, Mitchell & Sloper (2004) that reported availability of support groups in various facilities. Possible reasons for the results of the present study include the fact that parents come from far areas and may be difficult to have them at the facility after discharge and form support

groups. Most of the parents cannot afford transport money to come at the facility to meet with their fellow parents since most of the parents are not working. The other reason could be due to lack of organizations that deal with childhood cancer in Malawi. So far it is only Baylor College of Medicine-Abbott Fund Children's Clinical Centre of Excellence which is close to the facility, which offer support but cannot meet all the needs of the parents including provision of transport. There is evidence that education and support group programmes can increase knowledge about cancer and provide support networks for cancer patients and families (Narsavage & Romeo, 2003). The results imply that a caring atmosphere is provided and this includes provision of accommodation. However, there is lack of advice on how to seek extra support from other parents in similar situations, or organizations.

5.3.2 Informational support

Participants generally reported that information is available at the facility. However, majority of participants reported that they do not choose when to receive information and the type of information they want. Information giving is one of the important aspects in paediatric cancer. Parents go through tremendous stress when their children have cancer because of long duration, painfulness and severe side effects of treatment and the uncertainty of disease progression. Provision of quality of information is an important role in supporting parents of children with cancer as they pass through stress as well as fulfilling their parental and caring obligations (Young et al., 2002). Information from health professionals is needed to overcome stresses that parents have when their children have cancer (Yeh, 2003).

The results of this study show that the majority of the participants are not provided with information about their child's condition. The study also shows that the majority of the participants reported that there is no information available about the child's cancer such as its causes, how it progresses as well as its future outlook. These results are similar to those reported in other studies (Mack, 2006; Whitton & Williams, 2008) which revealed that parents of children with cancer are not well educated in many areas such as the management of the conditions as well as of the practical problems of everyday life. The results are also consistent with those that were reported by Dyke, Buttigieg, Blackmore & Ghose (2006) that provision of general information to families on a range of issues such as condition of the child, treatment outcome and side effects need improvement.

Inadequacy of information given to parents concerning their child's cancer may be attributed to the following reasons; the fact that physicians are unavailable to answer questions, the uncertain nature of the disease in terms of its course and its prognosis, the confusing medical language used by health care staff to explain aspects of illness, the large number of health related subspecialists involved in the care of the child and the poor organization of the local health services (Mack, 2006; Zwaanswijk, 2011). Physicians sometimes worry that information about prognosis may take away hope. The majority of parents found prognostic information important to maintaining hope, even when it was upsetting, and even when the child's prognosis was poor (Mack, 2006). In addition, there is evidence to support that parents are unable to internalize detailed information regarding the disease and its clinical course during the first few days after diagnosis. It usually takes a great deal of time before the family understands the severe changes resulting from the diagnosis and can more easily assimilate the information given (Patistea & Babatsikou, 2003).

Poor provision of information as reported in this study could be due to the fact that health workers do not have adequate information on cancer as most of them are not trained in oncology, negative attitude towards information giving to parents and poor planning of their work such that they do not prioritize information giving. However, Foster, Lafond, Reggio & Hinds (2010) stated that information giving in childhood cancer is important as it diminishes the likelihood of confusion about the illness and its treatment.

The other possible reason is the delay in confirmation of the diagnosis of cancer. In this study, it was noted that as participants were waiting for the results of the tests done to confirm the diagnosis of cancer, parents were not told anything about cancer. Ideally, the information provided to parents is pertinent to the diagnosis, the pathophysiological changes of the bodily functions, the side effects of therapy, the treatment plans and options and the long term biological consequences (Patistea & Babatsikou, 2003).

All participants responded that there is no information available in various forms such as leaflets or videos. Similar findings have been reported in other studies (Arnadottir & Egilson, 2012; Dyke et al., 2006; Raghavendra et al., 2007) indicating that professionals need to emphasize providing oral and written information so that parents can make informed decisions. They also have to ensure that the information given is important, timely, and situation specific. Possible reasons for not providing other forms of information could be lack of funding for the production of leaflets and inadequate health professionals who are trained in childhood oncology. It was found that the health facility does not have trained personnel in oncology rather they are trained on the job.

Similarly, a study by Couson & Greenwood (2011) revealed that much basic information is either not presented to parents or is presented in a highly technical fashion that further increases their confusion. Parents frequently express their concerns regarding the way that medical personnel announce the diagnosis and inform them about the disease. Sometimes physicians are too abrupt whereas, in other instances, they overwhelm parents with medical information and statistical data far in excess of what parents can understand. Traditionally, when informing parents, health care professionals focus on complex medical issues, whereas, parents only want to deal with their intense feelings resulting from the diagnosis (Patistea & Babatsikou, 2003). Results of the study demonstrate that information that is provided to parents of children with cancer is not sufficient. Specifically, parents are not provided with information about their child's condition. In addition the facility does not provide other sources of information on cancer, such as leaflets or videos.

5.3.3 Medical care and spiritual support

Majority of participants rated that treatment is generally available at the facility. Contrary to these results are the findings reported by Hadley, Rouma, & Saad-Eldin (2012) which stated that there are inconsistency cancer drug supplies. Additionally, studies have also reported that less than 20% of children in sub-Saharan Africa have access to curative cancer treatment (Hadley, et al. 2012; Chirdan, Bode-Thomas & Chirdan, 2009). The results of the current study are not strange in view of the support that the hospital gets from Baylor College of Medicine-Abbott Fund Children's Clinical Centre of Excellence. However, the results of the study also demonstrated that explanation on treatment was poor. In contrast, a study by Mitchell, Clarke & Sloper (2006), found that participants were satisfied with information about treatment.

Poor information giving in this study could be due to negative attitude of staff in giving out information. Living with pediatric cancer uncertainty, parents are often desperately in need of reassurance and concrete information about treatment. Constant reassurance of when the treatment would end and its ultimate outcome is necessary for parents to commit to completing treatment (Yeh, 2003). Provision of such information empowers families to make decisions about their children and alleviates the stress that arises from ignorance and uncertainty.

The results showed that participants are not given the opportunity to make decisions about treatment. This could be due to negative attitude of health professionals in giving information to parents. The results of the current study have also indicated that parents are not given adequate information about their children's illness, and then these parents may not be in a position to make decisions about treatment because they do not have adequate information. Health professionals feel that parents cannot contribute efficiently to the care of their children hence leaving them out. Based on their research with families experiencing childhood cancer, Sanders, Thompson, & Wilkinson, (2007) concluded that those parents who are successfully involved in the long term care of their children have adequate and detailed information about the disease and this assist them in coping successfully

There is provision of spiritual support at the facility. Parents of children with cancer believe that it is only God who knows the cause of cancer and that he has the capacity to heal (Taleghani, Fathizadeh & Naseri, 2012; Yeh, 2003). Most of the participants were religious and provision of spiritual support is good as most of them need spiritual support. Studies on coping strategies in the event of chronic illness reported that majority of ill patients and guardians use religious beliefs when coping with illness (Hassankhani et al., 2009; Taleghani et al., 2008).

A study by Taleghani (2008) revealed that religious beliefs and cultural background are critical to an individual's ability to cope with a disease like cancer. Faith and religious beliefs bring comfort to some parents. While expressing frustration with science, parents do not cease to hope that a divine miracle might cure their child. Although medical care and spiritual support are made available to parents, the results suggest that the parents are not given an opportunity to make decisions about treatment.

5.4 Summary

The purpose of this study was to assess how parents of children diagnosed with cancer perceive support rendered by health professionals at Kamuzu Central Hospital. The results showed that information, treatment, spiritual support services are available at Kamuzu central hospital. However, participants highly rated availability of treatment, food if needed and spiritual support. The study revealed that children with cancer are not cared for holistically at the facility. Despite being reported as important to parents of childhood cancer, there are no support groups for parents at the facility. Information giving regarding childhood cancer is also a challenge at the facility. Participants reported that they are not given information on their children's condition.

5.5 Limitations of the study

The study was conducted at one facility and used a small sample size which was identified using non probability convenience sampling method. This would limit generalization of the findings.

During data collection, it was noted participants had other issues that were not captured because the study utilized quantitative design and data collection focused on the questionnaire that was used. The issues that were identified were as follows: participants reported that trained staff was not available at the oncology unit during weekends which make parents seek assistance from staff that are not trained in oncology. They also reported of few staff who does not respect them as parents.

In addition, time was another limiting factor since the study is for academic purpose and had to be completed within the stipulated time to meet the due dates.

5.6 Recommendations of the study

Based on the results of the study, recommendations have been made to help improve childhood oncology care and management. The recommendations have implications for practice, management, education and future research.

5.6.1 Clinical nursing practice

- There is a need to establish support group programs that connect parents with other parents with similar problems of child's cancer diagnosis so that they speak with someone who has gone through the same process to share ideas and experiences.
- Health professionals should be sensitive to the religious needs of parents in hospital settings by ensuring that they are aware of the facilities (e.g., chapel) on site. Parents should be encouraged and feel comfortable to pray in the ward with their child, and health care professionals should respect their privacy.
- It is essential that health professionals tailor initial discussions to the level of understanding of family members and assess their comprehension of the explanations offered.
- When working with families of children with cancer in hospital or community settings, health professionals need to facilitate parents' access to information and offer them written instructions and other published materials.
- There is need for in service training of health professionals working in the Oncology unit as most of them focus on medical management instead of other support needs.

5.6.2 Nursing management

- Launch childhood cancer awareness campaigns that disseminate information about the prognosis and treatment of childhood cancer in the communities to promote pediatric cancer awareness.

5.6.3 Nursing education

- Increased emphasis should be placed on training health related professionals in using a multidisciplinary approach to provide coordinated and comprehensive care for families experiencing childhood chronic illness, including cancer.

5.6.4 Nursing research

- Most progress in pediatric cancer treatment has been stimulated by research involving children in Western countries. Since the susceptibility to and pathogenesis of cancer are heavily influenced by genetic background, environmental exposure, and lifestyle, there is need to broaden research to include cases in developing countries like Malawi.
- A qualitative study on the same area should be conducted as it was noted that participants in this study had lots of issues to share.
- There is a need to plan for research for the whole hospitals that treat childhood cancers so as to know the situation for Malawi as a nation.
- Future research should try to understand what parents of children with cancer need most during the cancer trajectory, either the family as a whole or each member of the family.

5.7 Conclusion

These results suggest that paediatric cancer services such as treatment, spiritual support and information are available to patients and their guardians at the facility. The findings imply that a caring atmosphere is provided and this includes provision of accommodation. However, there is lack of advice on how to seek extra support from other parents in similar situations. Findings of the study demonstrate that information that is provided to parents of children with cancer is not sufficient. Specifically, parents are not provided with information about their child's condition. In addition the facility does not provide other sources of information on cancer, such as leaflets or videos. Although medical care and spiritual support are made available to parents, the findings suggest that the parents are not given an opportunity to make decisions about treatment.

The study demonstrated that there were variations on how parents perceived support services namely treatment, food, accommodation, information and spiritual support. They recognize that other support services such as treatment, food and accommodation are readily available however they feel they are not provided with adequate information about their sick children's condition. They also perceive that they are not given the opportunity to make their own contributions about treatment. To ensure adequate information in childhood cancer, there is a need to provide childhood cancer trainings to health professionals so that they are updated with cancer issues.

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APPENDICES

APPENDIX A: DATA COLLECTION QUESTIONNAIRE

STUDY TITLE: PARENTS' PERCEPTION OF AVAILABLE SUPPORT FOLLOWING A DIAGNOSIS OF CHILDHOOD CANCER AT KAMUZU CENTRAL HOSPITAL

CODE NUMBER

PART 1: DEMOGRAPHIC DATA

Instruction: *Please indicate your response inside the box*

1.0	Age	<input type="text"/>
2.0	Gender	<input type="text"/>
3.0	Home language	<input type="text"/>
4.0	Tribe	<input type="text"/>
5.0	Level of education	<input type="text"/>
6.0	Relationship to patient	<input type="text"/>
7.0	What is your occupation?	<input type="text"/>
8.0	Religion	<input type="text"/>
9.0	When was the child diagnosed with cancer?	<input type="text"/>

PART 2: AVAILABLE SUPPORT

Instruction: *The following statements indicate possible available support. Please indicate to what extent are the services available.*

HOW WOULD YOU RATE THE AVAILABILITY OF THE FOLLOWING SERVICES	excellent	very good	good	fair	poor
1. Nurses who care for your child	5	4	3	2	1
2. Doctors who care for your child	5	4	3	2	1
3. Information regarding your child's condition	5	4	3	2	1
4. Time offered to you to discuss your child's condition	5	4	3	2	1
5. Treatment	5	4	3	2	1
6. Food if needed	5	4	3	2	1
7. Spiritual support	5	4	3	2	1
8. Accommodation if needed	5	4	3	2	1

PART 3: PERCEPTION OF SUPPORT

Instruction: *Please indicate how much the following events or situation happens to you.*

TO WHAT EXTENT DO THE PEOPLE (DOCTORS, NURSES) WHO WORK WITH YOUR CHILD.....	To a great extent	To a moderate extent	To a small extent	Not at all
1. Help you to feel competent as a parent	4	3	2	1
2. Provide you with a caring atmosphere rather than just give you information	4	3	2	1
3. Show that they are approachable	4	3	2	1
4. Show willingness to help	4	3	2	1
5. Let you choose when to receive information and the type of information you want?	4	3	2	1

6. Provide you with information about your child's condition	4	3	2	1
7. Have information available about your child's cancer e.g. its causes, how it progress, future outlook	4	3	2	1
8. Give you information about your child that is consistent from person to person	4	3	2	1
9. Have information available to you in various forms, such as leaflet, video.	4	3	2	1
10. Fully explain treatment choices	4	3	2	1
11. Fully explain the type of cancer services available at the facility	4	3	2	1
12. Tell you about results from assessment	4	3	2	1
13. Provide an opportunity for you to make decisions about treatment	4	3	2	1
14. Provide adequate treatment	4	3	2	1
15. Provide accommodation	4	3	2	1
16. Treat you as an individual rather than a typical parent of a child with cancer	4	3	2	1
17. Provide spiritual support	4	3	2	1
18. Provide enough time to talk so you don't feel rushed.	4	3	2	1
19. Provide advice on how to get information or to contact other parents, organizations.	4	3	2	1
20. Look at the needs of your "whole" child (e.g. at mental, emotional and social needs) instead of just at physical needs?	4	3	2	1

APPENDIX B: MAFUNSO A KAFUKUFUKU

**MUTU: “MMENE MAKOLO AMAWONELA CHITHANDIZO CHACHIPATALA
PAMENE MWANA WAPEZEKA NDI MATENDA A KHANSA PACHIPATALA
CHACHIKULU CHA KAMUZU”**

NAMBALA YANU

GAWO LOYAMBA: MBIRI YANU

Lamulo: *Lembani mkati mwa bokosi*

1.0 Zaka

2.0 Ndinu akazi kapena amuna

3.0 Chilankhulo chanu

4.0 Mtundu wanu

5.0 Sukulu munafika nayo pati

6.0 Ubale wanu ndi wodwala

7.0 Mumagwila ntchito yanji?

8.0 Chipembedzo

9.0 Mwana anapezeka liti ndi khansa

GAWO LACHIWIRI: CHITHANDIZO CHOMWE CHIMAPEZEKA

Lamulo: lembani yankho lanu mubokosi molingana ndi momwe zinthu izi zimapezekela pano

KODI ANTHU/ ZINTHU IZI ZIMAPEZEKA BWANJI PACHIPINDA CHA KHANSA CHINO	mowi likiza	kwambi ri	zimape zeka	zimapezeka pang'ono	sizipe zeka
1. Anamwino omwe amathandiza mwana wanu	5	4	3	2	1
2. Adotolo omwe amathandiza mwana wanu	5	4	3	2	1
3. Mauthenga okhudza matenda a mwana wanu	5	4	3	2	1
4. Nthawi yomwe mumapatsidwa kulongosola za mwana	5	4	3	2	1
5. Mankhwala	5	4	3	2	1
6. Chakudya ngati chifunika	5	4	3	2	1
7. Chilimbikitso chazimu	5	4	3	2	1
8. Malo ogona akafunika	5	4	3	2	1

PART 3: MMENE MUMACHIWONELA CHITHANDIZOCHI

Lamulo: lembani yankho lanu mu bokosi molingana ndi momwe inu mukuwonela kuti zinthu izi zimakuchitikilani.

KODI ANTHU OMWE AMATHANDIZA MWANA WANU (MADOKOTALA, ANAMWINO).....	amapanga kwambiri	amapanga ko	amapanga pang'ono	sapanga
1. Amakuthandizani kuti inuso mudziwe zinthu ngati kholo	4	3	2	1
2. Amapanga malo achipatala kukhala malo a msangala osati kumangopeleka mauthenga	4	3	2	1
3. Ndianthu oyankhulika.	4	3	2	1
4. Ali ndi mtima wofuna kuthandiza	4	3	2	1
5. Amakupatsani mwayi woti musankhe nthawi yoti mukambilane komaso zoti mukambilane.	4	3	2	1

6. Amakupatsani mauthenga okhudzana ndi matenda a mwana wanu	4	3	2	1
7. Ali ndimauthenga okudzana ndi momwe matenda akhansa amayambila, ndimmene imafalikila mnthupi, komanso zatsogolo la odwala	4	3	2	1
8. Amakupatsani mauthenga ofananafanana ngati anthu achipatala	4	3	2	1
9. Ali nawo mauthenga a khansa opezekelatu mtima pepala or mmavideo	4	3	2	1
10. Amafotokoza ndondomeko za makhwala omwe amapezeka	4	3	2	1
11. Amakuuzani chithandizo chokhudza khansa chomwe chimapezeka pachipatalapa	4	3	2	1
12. Amakuuzani zotsatila akamuyeza mwana wanu	4	3	2	1
13. Amakupatsani mwayi wopeleka maganizo anu pamakhwala omwe akuyenela kulandila mwana wanu	4	3	2	1
14. Amapeleka mankhwala okwanila	4	3	2	1
15. Amakupatsani malo ogona akafunika	4	3	2	1
16. Amakwanilitsa zofuna zanu zina ngati munthu	4	3	2	1
17. Amakupatsani chithandizo chauzimu	4	3	2	1
18. mumakhala ndi nthawi yokwanila kuti mukambilane za mwana wanu	4	3	2	1
19. Amakulangizani za komwe mungapeze mauthenga ena owonjezela monga kukumana ndi amnzanu omwe ndi vuto ngati la mwana wanu kapena kumabungwe ena	4	3	2	1
20. Amamuona mwana wanu kumbali zonse monga maganizo ake, zokuna zake zina ndi zina osati amangoona za khansa zokhazo	4	3	2	1

**APPENDIX C: APPROVAL CERTIFICATE FROM COLLEGE OF MEDICINE
RESEARCH COMMITTEE (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.05/14/1568 – Parents’ perception of available support following diagnosis
of childhood cancer at Kamuzu Central Hospital by Beatrice Gundo**

On 31 July 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*

 Dr. V. Mwapasa- Chairperson (COMREC)	<div style="border: 1px solid black; padding: 5px; text-align: center;">Approved by College of Medicine 05 AUG 2014 (COMREC) Research & Ethics Committee</div>	<div style="border: 1px solid black; padding: 5px; text-align: center;">05/08/2014 Date</div>
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APPENDIX D: AUTHORIZATION LETTER FROM KAMUZU CENTRAL HOSPITAL

University of Malawi KAMUZU COLLEGE OF NURSING

PRINCIPAL
DR. A. MALATA, DipNur, MRM
B.Sc. MN, Ph.D.



P/BAG 1, LILONGWE, MALAWI
TELEPHONE: 265 (0) 1751 622/200
TELEGRAMS: NURSING
FAX: (0) 756 424
EMAIL: Principal@kcn.unima.mw
Website: www.kcn.unima.mw

Our Ref.: KCN/AR (ASW)

29th January 2014

Hospital Director
Kamuzu Central Hospital
P.O Box 149
Lilongwe

Dear Sir,

RE: PERMISSION TO CONDUCT RESEARCH AT KAMUZU CENTRAL HOSPITAL

I write to request for your authorization to let Mrs Beatrice Mnunkha Gundu to collect data at your institution. Mrs Gundu is a student at Kamuzu College of Nursing pursuing Master of Science degree in Child Health Nursing and her registration number is KCN/MScCHN/12/03.

Mrs Gundu would like to collect data for her dissertation titled "Parents Perception of Available Support Following Diagnosis of Childhood Cancer at Kamuzu Central Hospital". The dissertation is a requirement in partial fulfilment for the degree she is expected to obtain.

May you please assist her accordingly?

Yours faithfully


Yamikani Chilinde
FOR: REGISTRAR

CC: Student File



*approved
meulavah*

APPENDIX E: PARTICIPANTS' INFORMATION SHEET

PARENTS' PERCEPTION OF AVAILABLE SUPPORT FOLLOWING A DIAGNOSIS OF CHILDHOOD CANCER AT KAMUZU CENTRAL HOSPITAL

Please read the information below and sign the form next page if you are taking part in this study

My name is Beatrice Gundo, currently I am a student at Kamuzu College of Nursing (University of Malawi), pursuing a Master Degree course in Child Nursing. As part of the requirements, I am conducting a study **on parents' perception of available related support following a diagnosis of childhood cancer at Kamuzu central hospital, Lilongwe, Malawi**. The study will be conducted at Kamuzu central hospital paediatric ward. You are therefore being invited to take part in a research study. The study has been approved by the Research and Ethics Committees of Kamuzu College of Nursing and College of Medicine. Before you decide to participate in the study, it is important to understand why the research is being conducted and what will involve. Please ask if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The purpose of the study is to assess how parents of children diagnosed with cancer perceive support rendered to them by health professionals at Kamuzu Central Hospital. The study findings will guide health planners on additional strategies to support parents of children with cancer. The strategies covering information, economic support, maintaining the child's education, coping support for parents and siblings, as well as support groups will be considered after the study findings. The results will assist health workers on how to involve parents in caring for cancer children so that the care provided is family centred.

Do I have to take part?

Participation in this study is voluntary. You are free to take part or not or to withdraw at any time you feel like without giving reasons. Your refusal to take part in the study will not affect the quality of health care you are going to receive in any way. If you agree to take part you will be asked to sign a consent form. Information about you will be confidential and no one will identify who answered the questions. No names will be written on the questionnaires. Instead, code numbers will be used. The questionnaires will be destroyed at the end of the study.

What do I expect as a participant?

You will be asked to indicate your responses on the questionnaire which you will be given. The questionnaire has 25 questions with eight possible responses. You need to indicate one answer against each question. You will be required to answer the questions truthfully and it will take 45 minutes.

What are the possible risks for taking part?

There are no known risks associated with this study.

What are the possible benefits?

Findings of the study will assist in planning of support rendered to families and their children who are diagnosed with cancer. The study findings will be communicated to all involved in the care of childhood cancer through a written report.

If something goes wrong what will happen?

Complaints concerning how you have been treated during the course of the study can be forwarded to Kamuzu College of Nursing number on 0111873623.

Contacts for further information

If you need further information or you are worried about any aspect of the study, please contact Beatrice Gundo, Cell number 0888 303 787 and Dr. Kabuluzi on 0995 984 612

OR

The Secretariat, College of Medicine Research Ethics Committee

Private Bag 360, Blantyre, Malawi.

Telephone number 0111 871911

APPENDIX F: KALATA YOLONGOSOLA ZA KAFUKUFUKU

Chonde werengani kalatayi ndi kusayinira pa tsamba lakuseli ngati mukulowa nawo mukafukufuku ameneyu.

Mfundo zofunika kwa olova nawo mukafukufuku

Dzina langa ndi Beatrice Gundo, ndikupanga maphunziro a ukachenjede kusukulu yanamwino ya Kamuzu College of Nursing (University of Malawi). Mbali ina ya maphunzirowa ndikupanga kafukufuku pa mutu woti **mmene makolo amawonela chithandizo chachipatala pamene mwana wapezeka ndi matenda a khansa pachipatala chachikulu cha kamuzu.** Kafukuyu adzachitikila ku chipinda cha ana odwala makamaka mbali ya ana odwala khansa. Muli kupephedwa kutenga nawo mbali mu kafufukuyu. Kafukufukuyu wavomelezedwa ndi akomiti yoonza za research ya Kamuzu College of Nursing komanso College ya madotolo. Mukuyenera kumvetsetsa cholinga cha kafukufukuyu musanapange chisankho cholowa nawo. Kutenga nawo mbali pa kafukufuku ameneyu ndi kosaumiriza ayi. Ngati chilipo china chomwe simunamvetse chokhudzana ndi kafukufuku ameneyu, mutha kufunsa.

Kodi cholinga cha kafukufukuyu nchiani?

Cholinga chakafukufukuyu ndikufuna kudziwa mmene makolo amawonela chithandizo chachipatala pamene mwana wapezeka ndi matenda a khansa pachipatala chachikulu cha Kamuzu. Izi zidzathandiza akulu a zaumoyo kupeza njira zothandizila makolo omwe ali ndi ana amene apezeka ndi matenda a khansa, mu mauthenga, komaso poyambitsa magulu omwe angamakambilane za matenda a ana awo omwe ali ndi khansa. Zotsatirazi zidzathandizaso kupeza njira zoti chisamaliro chisamakhale cha ana okha komaso makolo.

Kodi ndingatenge nawo mbali pakafukufuku uyu?

Ndikufuna kwanu kusankha kutenga nawo mbali mukafukufukuyu kapena ayi. Muli ndi ufulu kufuna kusiya nthawi imene mukufuna ndipo izi sizizaletsa ine kulandira thandizo lomwe mwabwelera.

Mayankho anu azasungidwa mwachimsinsi ndipo dzina lanu silizalembedwa penapaliponse chifukwa tizagwiritsa ntchito ma nambala. Ma pepala onse azaotchedwa pomaliza pakafukufuku ameneyu.

Kodi chidzachitike ndi chiyani ngati nditenge nawo mbali?

Mudzapatsidwa chikalata cha mafunso chomwe udzayankhepo. Chikalatachi chili ndi mafunso 25 ndipo pali mayankho angapo pa funso lili lonse. Inu mudzafunsidwa kupeleka yankho limodzi pa mayankhopo. Mudzafunsidwa kuyankha mafunso mwachilingamo ndipo izi zidzatenga mphindi 45 kuti mumalize mafunso onse.

Patapezeka zovuta zokhuzana ndi kafukufukuyu chingachitike ndi chiyani?

Ngati pangapezeke zovuta kapena nkhawa ina ili yonse yokhuzana ndi kafukufukuyu, khalani omasuka popereka madandaulo ku Kamuzu College of Nursing number on 0111873623.

Kuti mumve zambiri?

Ngati mufuna kumva zambiri imbilani Beatrice Gundo nambala ya lamya 0888 303 787 komaso Dr. Kabuluzi nambala ya lamya 0995 984 612

Kapena

The Secretariat, College of Medicine Research Ethics Committee

Private Bag 360, Blantyre, Malawi.

Nambala ya lamya 0111 871911

APPENDIX G: CONSENT FORM

Make sure you have read the above information before signing below if you are taking part in this study

- I have read the attached information sheet for this study and have understood the purpose of the study and the problems involved.
- I agree to voluntarily participate in the study and provide answers to the best of my knowledge. I understand that I am free to withdraw from the study any time and this will not influence anything.
- I know that I am not going to have any injury or harm during the research process. The information that I will give to the researcher should not be used against me in future.
- I understand that the information I give will be kept confidentially and will only be accessed by the researcher or those people directly concerned with this study.
- I understand that I will not benefit financially.
- I know how to contact the researcher if I need to.

I voluntarily agree/disagree to take part

Participant's Signature/Thumb print

Date

.....

Name of interviewer

Signature

Date

.....

THANK YOU FOR TAKING PART IN THIS STUDY

APPENDIX H: KALATA YA CHIVOMEREZO YOLOWELA MU KAFUKUFUKU

Onetsetsani kuti mwawerenga ndi kumvetsetsa zakafukufuku ameneyu musanasayinire

1. Ndawerenga kalata yolongosola za kafukufuku ali pamwambayu ndipo ndamvetsa cholinga cha kafukufukuyu ndizovuta zake.
2. Ndavomereza kutengapo mbali pa kafukufukuyu mosaumirizidwa ndi kufunsidwa mafunso amukafukufukuyu. Ndamvetsa kuti ndili ndi ufulu kusiya nthawi ina ili yonse.
3. Ndikumvetsa kuti zonse zomwe zamukafukuffukyu zidasungidwa mwachimsinsi ndikugwiritsidwa ntchito ndiopanga kafukufukuyi kapena okhuzidwa ndi kafukufukuyi.
4. Ndamvetsetsa kuti palibepo phindu la ndalama potenga nawo mbali mukafukufuku ameneyu.
5. Ndikudziwa mmene ndikapezere opanga kafukufukuyu ngati ndikofunika kutero

Ine ndikuvomeleza/sindikuvomeleza kutenga nawo mbali mukafukufukuyu.

Chitsindikizo cha kholo

Tsiku

.....

Dzina la opanga kafukufuku

Chitsindikizo

Tsiku

.....

ZIKOMO POTENGA NAWO MBALI PA KAFUKUFUKU AMENEYU

APPENDIX I: INTRODUCTION LETTER FROM KAMUZU COLLEGE OF NURSING



KAMUZU COLLEGE OF NURSING

PRINCIPAL
A. MALATA, DIPNURS. MRM
B.Sc., MN, PHD

P.O BOX 415, BLANTYRE, MALAWI
TELEPHONE: 01 871 644
FAX: 01 875 341
TELEGRAM: NURSING
EMAIL: viceprincipal@kcn.unima.mw

2nd April 2014

The Chairperson
COMREC
P/Bag 360
Chichiri
BLANTYRE 3

Dear Sir/Madam

INTRODUCTION OF MRS BEATRICE GUNDO

I write to introduce to you Beatrice Gundo who is a student pursuing Master of Science Degree in Child Health at Kamuzu College of Nursing. She is currently working on her research proposal and the title is **"Parents' Perception of Available Support following Diagnosis of Childhood Cancer at Kamuzu Central Hospital"**.

The study that she will conduct is very important and relevant to the Malawi situation. The findings of the study will assist health care planners on strategies to be used to support parents of children with cancer at Kamuzu Central hospital.

Thank you for your usual assistance.

Yours faithfully

Melanie Yandakale Hami
DEPUTY HEAD – MATERNAL AND CHILD HEALTH DEPARTMENT