



KAMUZU COLLEGE OF NURSING

**ASSESSING FAMILY INVOLVEMENT IN CHRONICALLY ILL CHILDREN'S
HEALTH CARE AT QUEEN ELIZABETH CENTRAL HOSPITAL, MALAWI**

MASTER OF SCIENCE (CHILD HEALTH NURSING) THESIS

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Declaration

I, **Anizia Kamwendo**, hereby declare that this thesis on family involvement in chronically ill children's health care at Queen Elizabeth Central Hospital is entirely my work. I have not submitted it or any part of it for any degree at any other university within or outside Malawi. All the sources of information quoted in this thesis have been acknowledged and added to the list of references.

Anizia Kamwendo

Legal full name

Signature

Date

Certificate of Approval

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

Signature_____ Date_____

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Main supervisor

Dedication

I dedicate this work to my husband Blessings and my sister Olive for their support during my studies.

Acknowledgement

I thank God for being with me throughout my studies. My special thanks should go to the following for their support:

- ELMA Foundation fund through Kamuzu College of Nursing
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Abstract

Family involvement has been recognized as the standard of care in caring for children with chronic illnesses. Studies have suggested that family involvement in child's care increases family understanding of the child's illness, management and sharing in decision-making between the family and the health care providers. In Malawi, though family members stay with their hospitalized children, they only played a role of providing food and supportive care due to cultural expectations and due to lack of available nursing care. Studies had revealed family members' desires to be involved in both the physical care of their children and in decisions regarding their care. However, there was no information regarding the perception of health providers on family involvement.

The aim of this study was to assess the perception of healthcare providers on the practice of family involvement in chronically ill children's health care at Queen Elizabeth Central Hospital. A descriptive qualitative study was done using semi structured interview guide to collect data from 16 health care providers working with children with cancer conditions. Thematic analysis was done guided by Collaizi's framework. Five main themes identified from the data were: perception of health care providers on family involvement in the care of children, health care providers' practice of family involvement in children's care, inadequate involvement of other family members, lack of care giving role negotiation, factors that facilitate involvement of caregivers in children's health care and challenges encountered by health care providers to involve families in children's health care.

From the study findings, it was found that there was a discrepancy between the health providers' perception and practice in regards to most of the areas of family involvement in child's care. For the few areas that the caregivers were involved, the health care providers only interacted with the caregiver who was available in the hospital with the child, the other family members were not involved. Furthermore, results have shown that health care

providers were not aware of their role of negotiating the caregiver role in caring for their children. Health care providers need to have the appropriate theoretical knowledge and practical skills to negotiate roles with the families.

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List of Abbreviations

COMREC:	College of Medicine Research Ethical Committee
HMIS:	Health Management Information System
KCH:	Kamuzu Central Hospital
KCN:	Kamuzu College of Nursing
QECH:	Queen Elizabeth Central Hospital

Operational Definitions

Health care provider: Any person that provides health care services

Child chronic illness: Diseases that affect a child for an extended period of time, often for life, and that require medical care and attention above and beyond the normal requirements for a child.

Family: A group of individuals who are bounded by strong emotional ties, a sense of belonging, and a passion for being involved in one another's lives

Family involvement: The act of family members being allowed to participate in their child's care to the degree that they desire.

Health care: Maintenance or improvement of health through diagnosis, treatment, and prevention of disease, illness, injury, and other physical and mental impairments in human beings.

CHAPTER 1

Introduction and Background of the Study

Introduction

The American Academy of Paediatrics defines childhood chronic diseases as illnesses that affect a child for an extended period of time, often for life, and that require medical care and attention above and beyond the normal requirements for a child (Geist, Grdisa & Otley, 2008). Family involvement refers to the act of family members being allowed to participate in their child's care to the degree that they desire (Shields et al., 2007). Shields et al. further stated that family involvement stresses the importance of health professionals considering families as partners and collaborators in the health care of children.

Family involvement is built around the empowerment, respecting personal autonomy and recognition of human rights (Majamanda et al., 2015). Family members must be empowered with knowledge and skills to enable them to participate in the care of their children (Gibson & Bowes, 2011). Family ideas and decisions are expected to be incorporated in child's care and their rights are respected (Majamanda et al., 2015). Additionally, care plans are also supposed to be made together with the families and clinical decisions should consider the context of the family (Kuo et al., 2012). In order to involve families in their children's care, Mullen and Pate (2006) suggest the development of the partnership between the family of a child and the health care professionals. Mullen and Pate further describe the partnership to include mutual interdependence and equal status between family and health professionals.

A diagnosis of a long-term illness in a child brings major upheaval in the lives of the whole family involved (Nuutila, 2006). Frequent and long time hospitalization interferes with the daily functioning of the family as a whole. Family members experience psychosocial adjustment problems related to the chronic illnesses of their children. Studies on the

psychological effects of chronic illnesses for example Wallander and Varni (2006) found major psychological problems of marked anxiety, depression and preoccupation with death to those caregivers who had chronically ill children. Curtis and Luby (2008), Cousino and Hazen (2013) also indicated that childhood chronic illness imposes significant stress on the family.

Family involvement has been recognized as the standard of care in caring for children with chronic illnesses. There is a large body of research that strongly suggest that family involvement increases understanding of the child's illness, management and sharing in decision-making (Kuo et al., 2012; Nuutila, 2006; Lam, Chang & Morrissey, 2006; Israels et al., 2008; Israels, Ribeiro & Molyneux, 2010). Attending to the impacts of chronic illness on the whole family is important because the physical and emotional health of family members have the potential to influence the health, welfare and successful rehabilitation of children with such chronic illness (Just, 2008).

Studies from Kristensson-Hallstrom (2008), Coyne (2011), Lam, Chang and Morrissey, (2006) revealed family members' desires to be involved in both the physical care of their child and in decisions regarding their care. Additionally, unpublished data from the study that was conducted at Queen Elizabeth Central Hospital on caregivers' perception regarding their participation in the children's care showed that caregivers viewed their participation as important. A qualitative study conducted by Coyne and Cowley (2006) found that health workers experienced difficulties in supporting families and facilitating family involvement in their children's care. Despite these challenges, parents were increasingly seeking to be included in the care of their children's health care. In addition, studies from Shields et al., (2007), Just (2005), Lam, Chang and Morrissey (2006) emphasized the need to involve family members in chronically ill children's health care.

There were several studies conducted on perception of family care givers on their involvement in the care of their children (Nuutila, 2006; Phiri, 2015; Ygge & Arnetz, 2008; Israels et al., 2008; Ygge & Arnetz, 2008; Coyne, 2011; Lam, Chang & Morrissey, 2006) but little was known on the perception of health workers on family involvement. Therefore, the researcher assessed perception of health workers on family involvement in chronically ill children's health care.

The study focused on health care providers caring for children with cancer as one of the chronic illness because the nature of the disease leads to repeated hospitalization for acute and chronic aspect of the disease and it was one among chronic illnesses associated with several impacts on the family. The study used chronic dimension framework developed by Olmen, Schellevis, Damme, Kegels, and Rasschaert in 2012. The model analyzes the characteristics of chronic illness, identifies and clarifies the needs for management of chronically ill patient and family. As such, in this study the model was used because it promotes patient and family involvement in their health care as one of the needs for management of chronically ill patients.

Background

Childhood cancer is one among the chronic illnesses experienced by significant number of children in Malawi. Globally, an estimated 175,000 cases of cancer are diagnosed annually in children aged younger than 15 years (Ward et al., 2014). The common types of cancer among children include acute lymphoblastic leukemia, brain and central nervous system tumours, neuroblastoma, non-Hodgkin lymphoma, Hodgkin lymphoma, Wilms tumours, and germ cell tumours (Jemal et al., 2011). The prevalence and burden of cancer are high in low-income and middle-income countries and is predicted to increase such that it is estimated that up to 70% of the predicted 24 million people that will be diagnosed with cancer annually by 2050 will reside in low-income and middle-income countries due to

urbanization, and globalization of risk factors (Kingham et al., 2013). The risk factors include exposure to pharmaceuticals (carcinogens), toxic and waste products (Sasco, 2008).

Literature is silent on the estimates of the people affected by cancer in Sub-Saharan African countries.

Malawi, a low-income country has two main referral centres for childhood cancer; Kamuzu central Hospital (KCH) situated in the administrative capital of Lilongwe and Queen Elizabeth Central Hospital (QECH) located in Blantyre, the financial and economic centre of the country. According to QECH Health Management Information System (HMIS), the paediatric oncology unit admitted approximately 231 children with different types of cancer in 2014. In 2015 the admissions increased approximately to 253. On average, the hospital admits 21 children with different types of cancer every month. These children are admitted at least five times in a year with hospital stay of not less than a month.

The diagnosis of cancer in children and adolescents is a life-altering event for them as well as their families as it requires long-term treatment and monitoring. Additionally, cancer survivors remain at risk of progression or recurrence of their disease as well as increased risk of developing subsequent malignant and functional impairments (Ward et al., 2014). As such there are a number of factors associated with the condition that results in poor child quality of life which requires proper collaboration between the health care professionals and the families. Additionally, Hamilton et al., (2006) suggested that managing childhood cancer just like any other childhood chronic illness requires a complementary relationship between the health care team and the family. This relationship is essential to supporting changes in family life in order to adapt to the chronic illness.

Family involvement in paediatric care has evolved over time. In the beginning, especially in developed countries like the United States, health care professionals were caring for children exclusive of their families (Kuo et al., 2012). Midway through the twentieth

century, with the increased recognition of child-family separation psychological trauma (the negative impact which includes anxiety to the children as well as the families), hospital policies were altered to allow for family members open visiting hours (Kuo et al., 2012). Then in 1980s, through research conducted by paediatricians, parents expressed the importance of partnership and joint decision-making between health care team and families regarding children's health care (Johnson, 2008).

In 2003, in United States it was recommended that conducting physician rounds (patient presentations and discussions) in the patients' rooms with the family present should be standard practice (Kuo et al., 2012). Over the past decade, reports worldwide have advocated for the presence of parents in the hospital in paediatric care. For example, the Platt report of 1959 states that parents should be allowed to stay with their children in the hospital whenever possible and to help with the care (Ygge & Arnetz, 2008). In addition studies from Swaziland and China revealed families' desires to be involved in both the physical care of their children and in decisions regarding their care (Ygge & Arnetz, 2008; Coyne, 2011; Lam, Chang & Morrissey, 2006).

Studies had found the importance of involving families in their children's health care. Nuutila (2006) in a study on parents' experiences of care of children with long term illness found that family involvement in child's care through information giving to the parent about their child's illness helps in parental coping and parents are able to organize their thoughts and learn how to deal with their own feelings such as depression. Nuutila further indicated that parents become aware of their ability to make sound decisions and react effectively according to the demands of a given situation. In addition, in a study done in China by Lam, Chang and Morrissey (2006), it was found that involving families in their children's health care enables parents to have a clear understanding of things that happening to their child and made them feel more in control of the situation. In another study on the guardians'

perspective on paediatric cancer treatment in Malawi and factors affecting adherence by Israels et al., (2008) and a review of studies by Israels, Ribeiro and Molyneux (2010) on Strategies to improve care for children with cancer in Sub-Saharan Africa, it was found that involving families in children's care through counselling and education enable them to have a clear understanding of the condition which promotes treatment adherence.

Despite evidence suggesting importance of family involvement in chronically ill children's health care, the role played by families of hospitalised children in Malawi was typically solely one of the physical support for the child in which there was no active exchange of information or collaborative decision making between families and health care providers (Hoffman et al., 2012). Therefore the researcher assessed the perception of health care providers on the practice of family involvement in chronically ill children's health care.

Problem Statement

Evidence suggests that family involvement is important for effective management of child chronic illness. In Malawi, though family members stayed with their hospitalized children, they only played a role of providing food and supportive care due to cultural expectations and due to lack of available nursing care (Hoffman et al., 2012). Yet despite the constant physical presence of families at the bedside, clinicians excluded family members from discussions and decisions regarding the child's health care such that there was no active exchange of information or collaborative decision making between families and health care providers (Tong et al., 2010). However, studies had recommended that the growing numbers of children with chronic illness necessitate well-defined clinical practices for how and to what extent parents should be involved in care processes and decisions. Studies conducted in other countries had revealed family members' desires to be involved in both the physical care of their children and in decisions regarding their care. In Malawi, studies had also found that families view their participation in their children's health care as important. However, there

was no information regarding the perception of health workers on family involvement.

Therefore, the researcher assessed the perception of health care providers on the practice of family involvement in chronically ill children's health care. The study used chronic dimension framework which promotes patient and family involvement in their health care.

Objectives of the Study

Broad objective.

To assess the perception of healthcare providers on practice of family involvement in chronically ill children's health care at QECH.

Specific objectives.

The specific objectives are:

1. To determine the perception of health care providers on family involvement in the care of chronically ill children.
2. To describe the health care providers' role in facilitating family involvement in the care of chronically ill children.
3. To describe the challenges and facilitators in involving families in chronically ill children's health care.

Research questions.

- How do health workers perceive the family involvement in chronically children's health care?
- What is the role of health care providers in chronically ill children's health care regarding family involvement?
- What facilitators and challenges do health care providers face in involving families in their chronically ill children's care?

Significance of the Study

Evidence suggests that family involvement is important for effective management of child chronic illness. Through family involvement in child's care, families have a clear understanding of the condition and management given to their child which results in treatment adherence. In addition, families become aware of their ability to make sound decisions and react effectively according to the demands of a given situation. In order for family involvement to be effective, there is need for information sharing between health care providers and families. In Malawi, studies had been done regarding caregivers perception on their role in children's health care. However, there was no information regarding the perception of health care providers on family involvement. Therefore, the study findings have provided information on how family involvement is practised. This information has helped to clearly define the health care providers' role regarding family involvement to improve the quality of paediatric service delivery.

CHAPTER 2

Literature Review

Introduction

This chapter contains the literature that was reviewed in relation to the study topic. Literature search was done using the electronic data base of HINARI, pubmed /MEDLINE, full free PDF for free scientific publications, Google and Google Scholar. The following search terms were used to search articles: family or parent AND family involvement, child chronic illness AND family involvement, perception AND health care providers AND family involvement, perception AND health care providers AND family role. The literature reviewed contained articles which were published from 2006 onwards. However some studies published before 2006 were included because they contained important and scarce information. The chapter first discusses the Chronicity Conceptual framework which was used to guide the study then review of studies related to the topic of study. Chronic conceptual framework was developed by Olmen, Schellevis, Damme, Kegels, and Rasschaert. The model analyzes the characteristics of chronic illness, identifies and clarifies the needs for management of chronically ill patient and family.

Chronicity Conceptual Framework

Chronic illness has been defined as life-long condition requiring long-term medical interventions, adherence to medication and adjustments in life (Olmen, Schellevis, Damme, Kegels & Rasschaert 2012). The definition highlights that people with chronic illnesses have to make adjustments in their life to remain as healthy as possible. Olmen et al., found that a big portion of care of chronically ill patients takes place outside the formal health care system. In this process, the involvement of the family in the patient hospital care becomes very crucial. Olmen, Schellevis, Damme, Kegels, and Rasschaert developed a chronicity

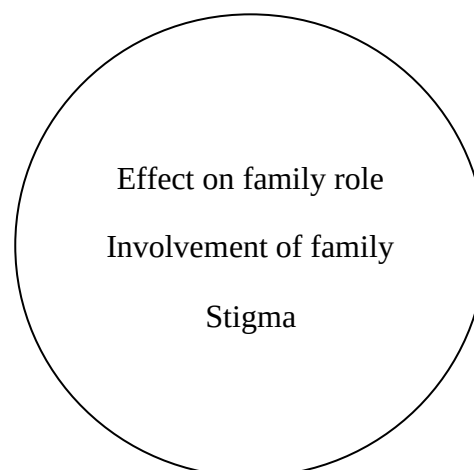
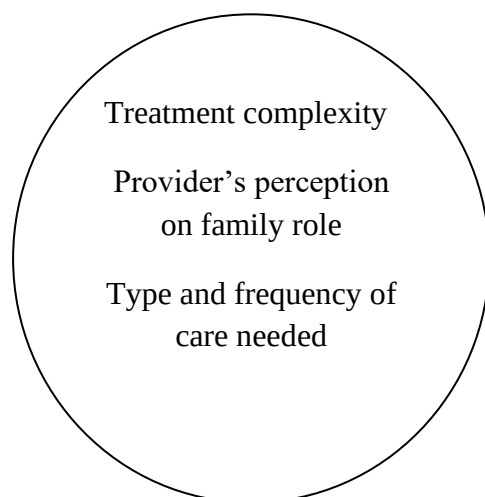
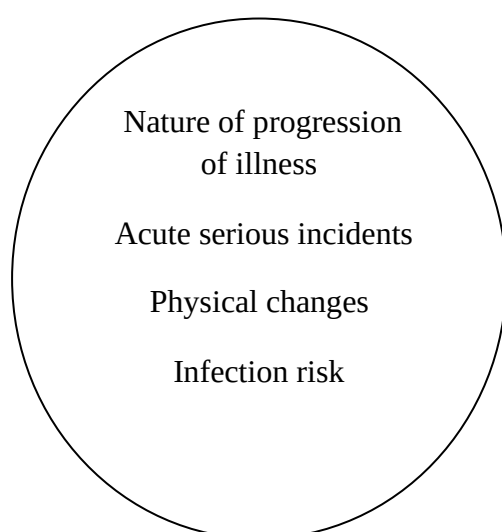
conceptual framework which promotes patient and family involvement in their own hospital health care.

The Chronicity conceptual framework was developed to fill the gap which was identified with the professionalized models of chronic care that do not adequately conceptualise the role of the patient and the family and they rely heavily on professional care, specialized staff, and medical technology (Coleman et al., 2009). Olmen et al., (2012) recognized that those models could not apply to low income countries as they are costly and need more staff to deliver the care.

The Chronicity conceptual framework's approach was designed to maximise the autonomy of people living with chronic illnesses and their families by empowering them with knowledge and skills to assume responsibility of participating in their own health care. Olmen et al., (2012) emphasized that patient and family involvement in care is not an alternative to medical care but rather supports the family to become an active partner with professional health care providers in managing their chronic conditions. Chronicity conceptual framework consists of four dimensions: patient, disease, health care provider, and environment (Figure 1). The dimensions have been described in the section that follows.

Disease dimension

Patient dimension



Health care provider dimension

Environment dimension

Source: Olmen et al., 2012.

Figure 1: The Chronicity Conceptual Framework describing four dimensions of chronic illness

Patient Dimension

The patient dimension entails the importance of involving patient in his or her own care. Olmen et al., (2012) stated that the long duration of the chronic illness and its impact patients experience becomes an opportunity for patients to gain knowledge in their condition and its management. Olmen et al., further indicated that in the course of their illness, patients gradually become experts on how to live with the disease, how the disease changes their lives and in gaining some control over the course of their illness. In this process, the patient involvement in making the best treatment decision is essential.

In addition, the patient dimension describes the crucial role that patients play in the management of their illness. Patients continuously make decisions that influence the course of their disease (Olmen et al., 2012). They also participate in care activities including treatment adherence, behavioural changes, disease monitoring and reporting and lifestyle adjustments in managing their own physical, mental and social wellbeing to avoid complications of their chronic condition. In this process, patient's learning and practicing skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition becomes crucial (Olmen et al., 2012).

In sum, the patient dimension involves the experience of the patient in relation to their illness, their way of coping with the illness, and their own role in disease management. For the sake of the study, the patient dimension was not used because children could not be able to express themselves and most of the care is done by the caregivers. Only three dimensions (Figure, 2) were focused; the disease dimension, the health care provider dimension and the environment dimension.

Disease dimension

Environment dimension

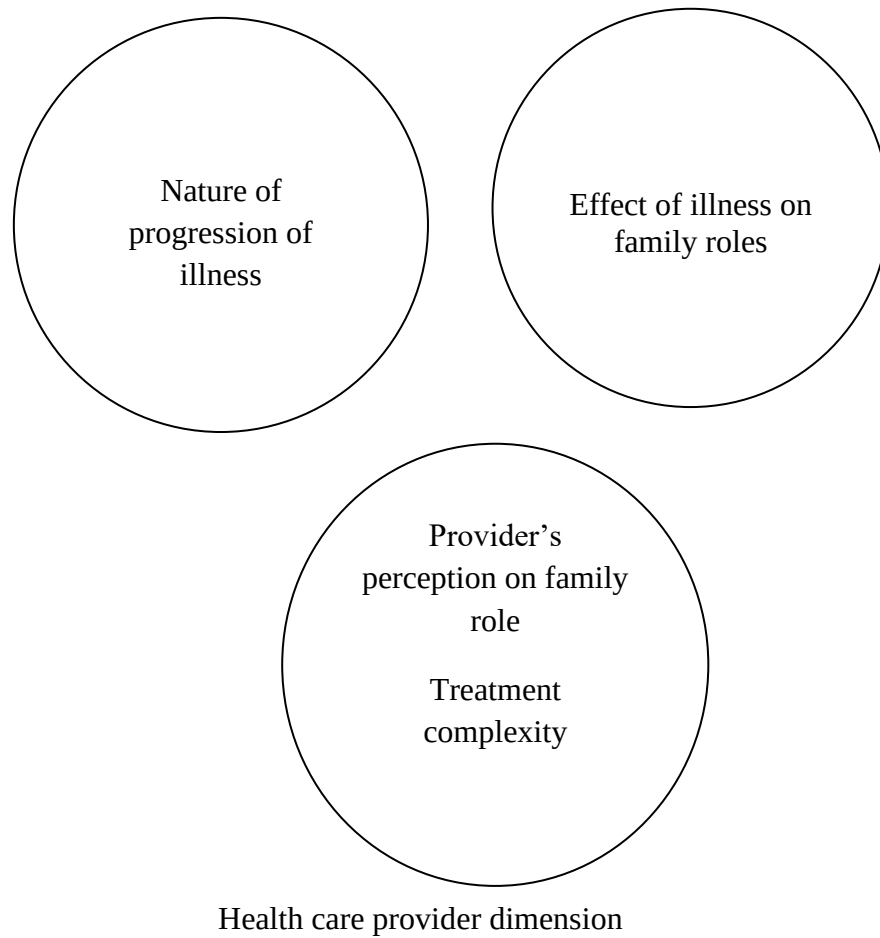


Figure 2: The Chronicity Conceptual Framework describing three dimensions of child chronic illness

Disease Dimension

According to the model authors, the disease dimension refers to the chronic illness which requires long-term medical interventions and adjustments in life. The disease dimension was described in terms of its biomedical characteristics which include the nature of progression of the illness, the risk for acute frequent illnesses, the physical changes associated with the illness and the risk of infection (Olmen et al., 2012). In this study, only one disease characteristic (nature of progression of the illness) was used.

The nature of progression of the illness.

Olmen et al, (2012) stated that chronic illness starts and progresses slowly, affecting multiple organ systems with advanced stages leading to increased morbidity and requiring different professional expertise. By the nature of the illness that it does not disappear, people have to make adjustments in their life to remain healthy. In this process, the involvement of family in the patient's hospital health care becomes very crucial as they play an active role in the management of the condition in homes. Families need to be empowered with knowledge and expertise in their children's condition which helps them in developing the skills to critically analyse situations and solving problems effectively as they are participating in the care (Olmen et al., 2012).

In this study, childhood cancer has been referred to the disease. Childhood cancer starts and progresses slowly requiring long term management. The family mostly stays with the child in homes. The family plays a crucial role in providing care to the child in homes as well as in the hospital. The care comprises physical care, giving drugs, and other technical care like feeding through nasogastric tube. For effective family participation in the child's health care to occur, it requires health care providers to provide comprehensive information regarding the nature of the child illness and their participation role. This knowledge will help the family to have clear understanding of the condition and their participation role. Therefore, the study identified the type of information that health care providers give to the families of cancer children regarding their participation in care.

Health Care Provider's Dimension

The characteristics of chronic illness have implication on the delivery of health care. It becomes apparent that patients and their families need support from health care providers that will facilitate their coping and life adjustment processes to gain mastery of their chronic condition (Olmen et al., 2012). Olmen et al., incorporated health care provider dimension

which entails the professional involvement with patients and their disease. The components of the health care provider dimension include treatment complexity, provider's perception on patient and family role in the management of the illness and the type and frequency of care needed. In this study, treatment complexity and providers' perception components under health care provider dimension have been used.

Complexity of treatment.

According to the model authors, chronic illness involves long term treatment which requires some professional expertise and training to handle them correctly. The crucial role of the health care provider is to administer the drugs, detect and manage the complications. Shared expertise between the health care providers and the family on drug administration, detection and management of complications is essential as it helps the patient and the family in the management of the treatment complications in homes.

In this study, children with cancer receive complicated and long-term treatment which is associated with several side effects for example; vomiting, diarrhoea, mouth sores (Cullen, Brunet & Martin, 2014). The health care providers administer the drugs, detect and manage the treatment side effects during the child's hospitalization period. Health care providers need to give information on giving medication and managing side effects to the family of the child to enhance their participation as they are also involved in the administration of drugs the time that they are in the home with the child. Therefore, the study identified the type of information that the health care providers give to the families regarding their participation in the care of their cancer children.

Health care provider's perception towards patient and family role.

Olmen et al., (2012) emphasized that people with chronic illnesses and their families should become the management centre of their own condition. They further indicated that patients should not only be at the centre of receiving care, but take full responsibility of their

chronic condition. In this process, it is important for the professionals dealing with the chronically ill patients to recognise the patient and family role in the care. Health care providers' understanding of the patient and family role in their own care influences the support given to the family on their role (Olmen et al., 2012).

In this study, families having children with cancer play important role in the child's care because they provide most of the care to the children in homes as well as in the hospital. Families need support on their role of participation in care. It is the role of health care providers to support the family role of participating in child's care. The support can only be provided if the health care providers understand and acknowledge the family role in the care of their child. Therefore, the study will assess the health care providers' perception on the family role in the care of their cancer children.

Environment Dimension

The model authors described environment dimension as people interacting with the patient. Olmen et al., (2012) emphasized that chronically ill patients have great impact on the people surrounding the patient. Due to the management needs of the chronically ill patient which include frequent and long hospital stay, the people's roles get affected. People need to understand their role and modify their family life in response to the demands of the illness. Health care providers have a role to make the people understand their role in the care of the patient.

In this study, the family members as environment for the child with cancer is greatly affected, especially the immediate circle of family life. The family spend a lot of time in the hospital with the child. Income generating activities are affected, jobs are lost and guardians express fear of their husband's unfaithfulness in their absence after staying longer in the hospital (Israels et al., 2008). This has resulted to some guardians abscond treatment in order to attend to other roles at home. Family members need to understand their role in the care of

the child in response to the demands of the child's illness. It is the role of health care providers to help the families understand their role in the child's care. Therefore, this study will describe the health care providers' role in promoting family participation in care of children with cancer.

Review of Studies

The literature review contains information on the perception of health care providers on family involvement in chronically ill children's health care, the health care providers' role in facilitating family involvement in chronically ill children's health care, the factors that health care providers experience in facilitating family involvement and challenges experienced by health care providers in involving families in their chronically ill children's health care.

Perception of Health Care Providers on Family Involvement in Chronically Ill

Children's Health Care

Perception has been defined as the way a person understands or interprets something (Collins, 2012). Researchers have described how health care providers understand family involvement in children's health care. Below are various descriptions of family involvement in children's health care found by different researchers.

Health care provider-family relationship.

Effective family involvement in child's health care requires excellent relationship between health care providers and the family (Corlett & Twycross, 2006). Studies done by Lee (2007), Barry and Edgman-Levitan (2012) and Mackay & Gregory (2011) found that the nurse-family relationship is an important aspect to consider for family involvement in child's care as it enhances the family's ability to feel comfortable voicing their opinions and concerns about child's care. The studies further found that the relationship enables the nurses

to be there for the family and being able to do things for the family which help the family to be free in expressing their emotions to the nurses.

Having interacting with families from various cultures and ethnic back grounds, Mackay & Gregory (2011) suggested that for successful nurse-family relationship, it is important for the health care provider to accept the families' culture, values, and beliefs. Nurses need to actively engage with the family in order to learn about their individual culture and beliefs. Further more, they need to respect family's strengths and build on the strengths to support the families in their care giving roles.

Though health care provider- family relationship has been viewed as essential in family involvement in the care of the child (Lee, 2007; Barry and Edgman-Levitan, 2012; Mackay & Gregory, 2011), some studies have found poor relationship between nurses and parents of hospitalised children (Paliadelis et al., 2005; Foster et al., 2010; Power & Franck, 2008; Coyne 2011; Hoffman et al., 2012). In their studies, Paliadelis, Foster et al., Power & Franck, and Coyne, nurses reported concerns about parents being uncooperative and not complying with nurses' expectations. In addition, Hoffman et al., (2012) found that poor relationship between the hospital staff and parents hindered the participation of parents in care-giving roles as there was limited negotiation of care roles.

Recognizing family role.

The family plays a critical role in the development and nurturing of the child (Denboba et al., 2006). In addition, the family is expert on the care of their child (Sarajärvi et al., 2006). Family involvement has been described as a method of care delivery that recognizes and values the vital role of the family in ensuring the health and wellbeing of the child (Shields et al., 2012; Coyne et al., 2013). Evidence suggests that participating in decision making process regarding the child's medical and nursing care above usual parenting tasks is a significant role of families because they know the unique needs of their

child (Barry & Levitan, 2012; Rachmani et al., 2012; Arnetz et al., 2010; Coleman et al., 2006; Weingart et al., 2011). Recognizing family role in the care of the child promotes active exchange of information and collaborative decision making between families and health care providers (Sarajärvi et al., 2006).

Though evidence suggest that participation in decision making process regarding the child's medical and nursing care is the family's significant role, some studies have found that health care providers perceive family role in child's care as provision of basic care to the child (Hoffman et al., 2012; Tong et al., 2010; Coyne 2013; Galvin et al., 2006). Galvin et al., found that working collaboratively with the parents in providing technical care and decision making about child's care is a threat to nurses' professional role. The participants felt that parents are there in the hospital to support the child in provision of basic care activities such as meeting hygiene needs, helping at meal times and meeting elimination needs. The participants talked about the importance of retaining their professional role because they felt involving parents in decision making and technical care means taking away their role and handing over to the parents.

Information sharing.

Family involvement in children's health care is based on the understanding that the family is the child's primary source of information on the unique needs of their child (Sarajärvi et al., 2006). Importantly, Sarajärvi et al., stated that there is a need for the health care professionals to value the information from the family about the child. Child's information from the family enables health professionals to identify respond to child's care needs (Rathert et al., 2013). Ladak et al., (2013) and Bruce et al., (2012) found that involving families in their children's health care, health care providers are responsible for giving the family honest and unbiased information about the diagnosis, monitoring and treatment of the child's disease at different stages throughout the treatment continuum. The studies found that

providing information about the child's diagnosis and treatment empowers the family's decision making and participation in care.

Though evidence suggest that family involvement in child's care requires active information sharing between the health care providers and the family, some studies have found that clinicians exclude family members from discussions regarding the child's health care such that there is no active exchange of information between families and health care providers (Tong et al., 2010; Mostert, et al, 2014; Ladak et al., 2013; Rathert et al., 2013; Bruce et al., 2012). In Malawi studies done on parental perception on their participation, families have expressed desires to be involved in discussions regarding their child's care (Hoffman et al., 2012, Phiri, 2015).

Shared decision making.

The Institute of Medicine described child's health care as care that is respectful and responsive to family needs and values and ensures that family values guide all clinical decisions. The definition highlights the importance of clinicians and families working together to produce the best outcomes possible. As the definition implies, the most important aspect of child's care is the active engagement of family when fateful health care decisions must be made. In such cases, family involvement in decision making adds substantial value (Barry & Levitan, 2012).

Research has found that in shared decision making, families understand the importance of their value in making the decisions that are best for the child (Higman & Shaw, 2008). In addition, families who actively participate in their children's healthcare decision making have more positive experiences of child's care (Rachmani et al., 2012; Arnetz et al., 2010; Coleman et al., 2006; Weingart et al., 2011). In their studies, Higman & Shaw (2008) and Meuthing et al., (2007) the participants suggested that a practical way to include the

family in decision making and keep them better informed is to involve them in patient ward rounds.

While studies have acknowledged families as being central in the decision making process regarding the care of their children (Barry & Levitan, 2012; Rachmani et al., 2012; Arnetz et al., 2010; Coleman et al., 2006; Weingart et al., 2011), some studies have found that parents are not considered when making decisions regarding child's care (Tong et al., 2010; Hallström & Elander, 2014; Barry & Levitan, 2012). A study conducted by Hallström & Elander on decision making during hospitalization: parents' and children's involvement, results showed that most decisions regarding the child's care are made by medical professionals. Parents are left just to stay with the child.

Health Care Providers' Role in Facilitating Family Involvement

Family participation in child's care requires the process of role negotiation (Corlett & Twycross, 2006). Reeves et al., (2006) defined role negotiation as the process in which health care providers discuss with the family the level of care that they are responsible for while in the hospital. It also includes discussing the plans for the child's care (Power & Frank, 2008). Studies by Hallström & Elander (2014); Coyne (2007); Sarajärvi et al., (2006) have found that when the health care providers negotiate parental role, parents are able to provide care to their hospitalised children according to the health care providers' expectations. In a study on the role of the nurse in family-centred care, Tedford and Price (2011) pointed out that professionals must recognise their duty to negotiate parental role in order to facilitate family participation in the child's care. Providing information, providing parents with skills and supporting family role are some of the identified roles of health care providers in facilitating family involvement. The roles have been described in the sections that follow.

Providing information.

Parental roles and responsibilities alter when a child is admitted in the hospital. Health care providers need to negotiate with parents what the parental role in the care of their hospitalized child will be (Corlett & Twycross, 2006; Bruce et al., 2012; Coyne, 2011; Coyne, 2013; Koller, 2006; Davies, 2012). In the absence of information about parental roles, parents just attend to their child's basic needs. In a study by Coyne (2015) on Families and health-care professionals' perspectives and expectations of family-centred care: hidden expectations and unclear roles, it was found that there was inadequate information on parental roles in regards to the care of the child. Parents were uncertain about how their role fitted in with nurses' roles and some were afraid of breaking the hospital rules by doing certain care to their child. Parents perceived that there could be greater sharing of information from nurses to assist them in child's caring role. Based on the study findings, it was recommended that families should be educated about the essential role they play in participating in child's care.

Similarly, in another unpublished study by Phiri (2015) on caregivers' perception regarding parental participation in care of hospitalised children at QECH, it was found that parents were unsure of their role because there were not given any information regarding their participation in the care of their children. The study findings further indicated that nurses assumed everyone knows what to do when they are in the hospital with their children. However, the caregivers indicated that it would have been better for them to be given the information on their role regarding child's care from admission because hospital was a strange environment for them.

Providing parents with skills.

Chronic illness is a life-altering event for families as it requires long-term treatment and monitoring. Research has shown that parents of chronically ill children are willing to learn the care of their children because the care is continued at home (Coyne, 2015).

Empowering families with skills on how to perform care procedures on the child is beneficial to the families as it is easy for them to deliver safe and recommended care to their children at home (Lee, 2007). However, studies have found that nurses experience problems with providing skills to parents. In a study by Koller (2006) on parental involvement in paediatric hospital care and Hallström & Elander (2014) on Decision-making during hospitalization: parents' and children's involvement, nurses demonstrated reluctance in passing on skills to a child's parent and reported that this is very time-consuming for them and stressful for families.

Supporting family role.

Participating in child's care can be stressful for families (Coyne, 2007; Ygge & Arnetz, 2006) and the provision of support contributes towards positive interactions between families and health care providers. McKivergin and Daubenmire (2014) found that when the health care workers provide support to the family role, the family gain more insight into the child's care. Furthermore, the parents are able to become partners with the medical staff in making decisions about child's care. In their studies, Coyne et al., (2013); Bruce et al., (2012); Bruce & Ritchie., (2007); Letourneau & Elliott (2006) results showed providing support for family role was found to be frequently practiced. The participants indicated that providing support was a means to enhance family participation in child's care.

Though evidence has suggested that providing support to family's role is essential in family participation in child's care, some studies have found that parents were not supported in their role to their hospitalised child (MacKean, Thurston & Scott, 2005; Aein et al., 2009; Gill et al., 2014). MacKean, Thurston & Scott, Aein et al., and Gill et al., found that parents felt stressed and abandoned by the health care providers because they were not supported in their role in caring for their hospitalised children.

Challenges Experienced by Health Care Providers' in Involving Families in Chronically Ill Children's Health Care

Although family involvement has become a cornerstone of health care systems globally, it has encountered numerous difficulties in effective implementation (Foster, Whitehead, & Maybee, 2010; Harrison, 2010; Mikkelsen & Frederiksen, 2011). Studies have found challenges experienced by health care providers in involving families in their children's health care. Below are some of the identified challenges experienced by health care providers in involving families in their children's health care.

Time constraint.

Several studies have found time constraint as a barrier to involve families in their children's health care (MacKay & Gregory, 2011; Foster et al., 2010; Power & Franck, 2008; Paliadelis et al., 2005; Coyne 2015). In their studies, Foster et al., Power & Franck, Paliadelis et al., Coyne and MacKay & Gregory, lack of time was the main barrier to involve parents in their children's health care. It was found that paediatric nurses were involved in many different treatments procedures such that everyone in the ward was running around trying to meet the basic needs of the patient and could not have time to sit with the family and listen to what they say or to focus on the psychosocial and educational needs of the family.

Parental illiteracy.

Parental illiteracy has been reported to be a challenge to involve parents in their children's health care. In studies done by Hoffman et al., (2012), Barry & Levitan (2012), Lipstein (2013) and Paliadelis et al., (2005), health care providers indicated that they experienced problems to give information about child's care to parents because of parents' inability to understand the information regarding child's care. Evidence indicates that parental illiteracy lead to the parents giving inappropriate care to a child (Lee et al., 2009).

Poor relationships.

Difficult working relationships between the health care providers and families have been reported as a barrier to involve families in their children's health care. In studies conducted by Paliadelis (2005); Foster et al., (2010); Power & Franck (2008); Coyne (2011) and MacKay & Gregory, (2011), participants reported concerns about parents being uncooperative. The study revealed that some parents neglect health care providers' advices in regards to the children's health care which has been said to occur when the family does not trust the medical staff. Coyne further found that poor relationship between the health care providers and the families occur due to contradictions between nurses and families. It was indicated by the participants that the contradictions come when the nurses do not agree with the family's religious beliefs or did not understand the logic behind the family's beliefs. Poor relationship resulted to nurses getting disappointed and focus on the patient issues rather than working together with the family in the management of the child.

Lack of hospital guidelines.

Lack of hospital guidelines has also been found to hinder health care providers in involving families in their children's health care. In a Qualitative study that explored Family-Centered Care among Paediatric Oncology Nurses in Canada, nurses highlighted lack of hospital guidelines or policies regarding family involvement in children's care hindered having the families participate in their children's care (MacKay & Gregory, 2011). This finding is also supported by the findings of the study by Ygge and Arnetz (2006) that explored parental involvement in paediatric hospital care which found that checklists and clinical guidelines are useful tools for achieving health care providers' understanding of how to work with families.

Despite the challenges, parents are increasingly seeking to be included in the care of their children's health care. In addition, studies from Shields et al., (2007), Just (2005), Lam,

Chang and Morrissey (2006) have emphasized the need to involve family members in chronically ill children's health care.

Summary

In summary, evidence suggests that family involvement is important for effective management of child chronic illness. Various studies had illustrated that families were mainly involved in providing physical care to their hospitalised children. It had been documented that health care providers provide insufficient information about children's conditions and treatment to families and they exclude them from discussions and decisions regarding the child's health care. In addition, literature emphasized that it is the role of health care providers to support the family role in order to facilitate their participation in the child's care. However studies from other countries have found that parents are not supported in their role to their hospitalised child. In Malawi, studies that had been done regarding caregivers perception on their participation in children's health care had revealed caregivers' desires to be involved in both physical care of their children and in decisions regarding their care. However, there was no information regarding the perception of health care providers on family involvement in children's care. Therefore, it was the aim of this study is to assess the perception of health care providers of family involvement in chronically ill children's health care among health care providers.

CHAPTER 3

Methodology

Introduction

This chapter describes details of the study design; place where the study was conducted; population; sample size and sampling methods; recruitment criteria; data collection procedure, data management and analysis. Issues pertaining to ethical considerations and dissemination of research findings have also been elaborated.

Study Design

The study used descriptive qualitative design to assess the perception of health care providers on family involvement in chronically ill children's health care at Queen Elizabeth Central Hospital. Holloway (2005) explains that a qualitative approach is used to explore the behaviour, perspectives, feelings and experiences of people and what lies at the core of their lives. Therefore, the design was the best approach in this study since it assisted in assessing the perception of health care providers on the practice of family involvement in chronically ill children's health care.

Study Setting

The study was conducted at QECH Paediatric department, paediatric oncology ward where children with cancer are admitted. QECH is one of the central hospitals offering tertiary care, located in Blantyre district, in the southern region of Malawi. The hospital was chosen because it is a major referral hospital for various district hospitals and other central hospitals for children with cancer. According to QECH HMIS, approximately 90% of children admitted in the paediatric oncology ward are referred from various district hospitals and central hospitals.

Study Population

The target population in this study was health care providers (nurses and clinicians) working in paediatric oncology ward. Those working under palliative care but in oncology ward were also invited to participate. These health care providers were capable of providing rich information regarding their experience of caring children with cancer as one of the chronic conditions.

Sampling Technique

Purposive sampling was used to pick a sample that has desirable characteristics for a study. Purposive sampling is defined as a technique in which people from a specified group are purposely sought out and sampled (Gerrish & Lacey, 2006). According to Creswell (2013), it is essential that all participants have experience of the phenomenon being studied. Therefore, nurse midwives technicians, registered nurses and clinic officers were intentionally selected by the researcher as they were more likely to contribute appropriate data in terms of relevance.

Inclusion and Exclusion criteria.

Health care providers who had worked in paediatric oncology ward for a year and above were invited to participate as they were likely to give appropriate data according to their experience of caring for chronically ill children. Health care providers who had worked less than a year were excluded as it was felt that participation for them would not give appropriate data because they did not have enough experience in caring for chronically ill children.

Sample Size

The sample size was determined based on informational needs, and the guiding principle in sampling was data saturation, that is sampling to the point at which no new information is obtained and redundancy is achieved. Sixteen (16) health care providers

participated in the study. According to Remsherdt & Flowers (2007) there are no set rules or criteria for sample size because sampling depends on data saturation. However, the small sample size is suitable because of the potentially detailed data that can be generated from each participant (Polit & Beck, 2010).

Data Collection

Semi-structured interview guide was used (Appendix 3) to collect data. The guide contained open-ended questions that were formulated according to the study objectives. In this study, the design of semi-structured interview guide was for the purpose of health care providers to give rich information about their experience. In addition, Polit and Beck (2010), indicate that semi-structured interviews allow the researcher to have a framework in which open-ended questions are posed to encourage the participants to talk freely about their experiences.

Pretesting was done at Queen Elizabeth Central Hospital children's neurological ward in which four participants were interviewed. Neurological ward was chosen for the pre-test of the interview guide because it is also one of the wards where children with chronic conditions are admitted. The guide was pretested in order to identify problems, rectify the questions and to improve clarity of the questions before the actual data collection.

Data Collection Procedure

The researcher with the assistance of unit matron and nurse ward in charge identified potential participants. Then the researcher approached the health care providers, explained the purpose and goals of the study, and requested their permission to participate in the study. The participants were given detailed written information about the study (Appendix 1) and the consent form to read, understand and sign to indicate their willingness to participate (Appendix 2). The interviews were conducted in English because the health care providers were able to speak and understand. Interviews were conducted at the hospital in a private

room in order to maintain confidentiality and anonymity. Time for the interview ranged from 40 to 59 minutes. Field notes were taken during the interview and questions and responses were audio taped.

Data Analysis

In qualitative studies, the significance of data analysis is to discover themes and links among the themes (Polit & Beck, 2010). In this study, data was analyzed using thematic analysis guided by Collaizi's (1978) framework. The following process was followed.

Stage 1: Reviewing raw data

Reviewing raw data was being done after each interview whereby the researcher listened to the audio taped data in order to verify if all important information had been captured. The recorded interviews were then transcribed word for word verbatim and read the data several times to gain familiarity with ideas presented.

Stage 2: Extracting significant statements

From each transcript, significant statements and phrases that sum up what has been said in the text during the interviews pertaining to the phenomenon being studied were extracted. The extracted statements were written on a separate sheet of paper.

Stage 3: Spelling out meaning from significant statements

The extracted significant statements were reviewed and meanings were then formulated from the significant statements. Each underlying meaning was coded with one category.

Stage 4: Organizing the formulated meanings into clusters of themes

The formulated categories from the significant statements were then grouped into broader categories called themes.

Stage 5: Integrating results into an exhaustive descriptive of the phenomena under study

In this process, the researcher wrote rich and exhaustive description of the health workers perception on family role from this the essential structure of the phenomena was formulated. Each theme was supported with statements from the interviews that reflected participants' ideas.

Stage 6:

At this stage, the results were organized so that they flow logically and make sense

Data Management

The data files and recorder was being locked in the drawer of the researcher's study table and were only accessible by the researcher. The electronic data was being kept in researcher's computer with a pin code which was known to the researcher only.

Ethical Consideration

To ensure that ethical standards were followed, the research proposal was submitted to College of Medicine Research and Ethical Committee (COMREC) for approval.

Permission was sought from the Director of QECH and Paediatric department to conduct the study at the hospital (Appendix 5 and 6). Participants were asked to sign a written informed consent prior to participation in agreement to their willingness to participate. The consent form (Appendix 2) contained information on the purpose, benefits, and risks of the study. Participants were informed of their right to refuse or withdraw at any point of the study and that no penalty will be granted upon such a decision.

Participants were duly informed that there were no benefits for taking part in the study but that their information will contribute to the quality of care of chronically ill children and their families in the hospitals. Participants were also assured that their identification will not be known on publication or presentation of the findings. Furthermore, participants were informed that the study does not have any foreseeable physical harm (risks) to the

respondents, however in cases of any emotional or psychological harm participants were informed to refuse to answer questions or withdraw at any point.

The participants were assured that their responses will be handled in a confidential manner in order to protect their identity. Privacy was maintained throughout the research process. Names were not used, and the information was not available to anyone except the researcher and the supervisors in order to protect their privacy and confidentiality. Gathered information was stored by the researcher, and after data analysis, the data collection materials were destroyed by burning.

Research Dissemination

Dissemination of the results will be done to health care providers through a meeting which will be held at the departmental level and during national and international nursing conferences. The study will possibly be published as a journal article where it may be accessed by paediatric nurses and other health professionals in practice and education. Report will be submitted to COMREC, Queen Elizabeth Central Hospital and Kamuzu College of Nursing library

CHAPTER 4

Presentation of Findings

Introduction

This chapter presents the findings of a study that aimed at assessing the perception of health care providers on family involvement in chronically ill children's health care. The specific objectives of the study were to: determine the perception of health care providers on family involvement in care of chronically ill children, describe the health care providers' role in facilitating family involvement in the care of chronically ill children and describe the challenges and facilitators in involving families in care of chronically ill children.

The findings are presented in two sections. The first part contains demographic information of 16 participants who were recruited from oncology ward and children's palliative care at Queen Elizabeth Central Hospital. The health care providers had worked in paediatric oncology ward and children's palliative care for at least one year and above. The second part presents the analysis of the qualitative data obtained through in-depth interviews using semi-structured interview guide. Direct quotes from participants have been used to show what was said. The participants have been identified using the serial numbers which were given to them during the interview.

Demographic Characteristics of the Participants

Demographic information of the participants is summarised in table 1. The table shows that most of the participants were female health providers with age ranging from 20 to 60 years. There were 3 Enrolled Nurses, 5 Nurse and Midwife Technicians, 4 Registered Nurses and 4 Clinical Officers. Almost all participants were Christians. Half of the participants had worked for 1 to 5 years and five participants had worked for 6 to 10 years.

Table 1: Demographic information of participants

Characteristic	Number
Age in Years	
20-30	4
31-40	3
41-50	5
51-60	4
Sex	
Male	4
Female	12
Religion	
Christian	15
Muslim	1
Position	
Enrolled Nurses	3
Nurse Midwife	5
Technician	4
Registered Nurses	4
Clinical Officers	
Duration of work	
1-5	8
6-10	5
11-15	0
16-20	3

Results from Qualitative Data

Findings from in-depth interviews with participants on assessing family involvement in chronically ill children's health care are presented under the following themes: perception of health care providers on family involvement in the care of children, health care providers' practice of family involvement in children's care, inadequate involvement of other family members, lack of care giving role negotiation, factors that facilitate involvement of caregivers in children's health care and challenges encountered by health care providers to involve families in children's health care.

Perception of Health Care Providers on Family Involvement in the Care of Children

Participants were asked how they understood family involvement in children's health care. Overall, the participants described family involvement in terms of areas of care that the families were supposed to take part in caring for their hospitalised children. Most participants stated that family involvement is important in the delivery of children's health care. Their responses are presented according to the following sub themes: performance of physical care activities, sharing of information between the health care providers and the family and provision of emotional support to the child and the family.

Performance of physical care activities.

This sub theme concerning family's performance of physical care activities for the children came up during all interviews. All participants explained that involving family in child's care refers to the family performing physical care activities to their hospitalised child. The physical care activities include: feeding the child, bathing the child, taking the child to the toilet, cleaning child's bed, changing child's nappies and washing child's clothes. The participants felt that these activities are part of child's health care because they facilitate healing of child's condition. One participant explained:

I think family involvement in child's care is when the family takes part in child's care in terms of feeding the child, bathing the child and doing other physical care activities for the child. These activities are part of treatment for the child. For example feeding the child helps the child to stay healthy and promotes healing of the child's condition. And bathing the child helps the child to look clean and prevents infection that could delay healing (Participant # 6).

Sharing of information.

Majority of the participants described that family involvement in child's care involves the health care providers giving the family information about the child's condition and

treatment. The participants explained that information is a major need for the families caring for a child suffering from cancer. They indicated that giving information about the child's condition and treatment facilitates family's understanding of the child's problem and ability to provide recommended care to the child. One participant illustrated this:

I think involving family in child's care is when the family is given information about the condition that the child has and the hospital care that will be given to the child by the medical people in the ward because through that the family can be able to follow whatever is happening to their child and being able to take care for the child properly. For example may be the child has developed a danger sign whilst in the ward, if the family has been given information about that condition and those expected signs, they can easily rush and report to the medical personnel and the child can be helped quickly (Participant # 9).

A few participants explained that involvement of the family in child's care includes the family's responsibility of providing information to the health care providers through presenting child's problems during assessment for proper planning of child's care. One participant said:

...and also the family presenting problems that they have noticed from their child to us during child assessment because the child's diagnosis and plan of care is based on what they tell us as well as what we find on the child during examination (Participant # 10).

Provision of emotional support to the family and the child.

A few participants described family involvement in children's health care as provision of emotional support to the hospitalised child by the family. In regards to the provision of support to the child, the participants explained that it includes family's availability in the

ward for the child as well as showing love to the child. The participants said that providing support to the child helps the child to have a feel of being cared for thereby reducing the worries that they have. One participant illustrated this:

What I see from the children who are older, when they have been admitted in the ward, they have worries so the family's presence and love reduce the child's worries (Participant # 16).

In regards to provision of support to the family, participants explained that it can be provided through responding to the family's concerns, addressing family's questions concerning child's condition and care and showing love to the family during the child's care. The participants said that providing support to the family promotes the family's coping with the child's condition. One participant said:

From how I understand it, family involvement in child's care is not just us the health workers concentrating at eliminating the child's condition, but also looking at the welfare of the family because the family gets affected psychologically with the child's condition (Participant # 4).

Health Care Providers' Practice of Family Involvement in Children's Care

In regards to the practice, when participants were asked how they involve families in their children's health care, it was found that only provision of physical care to the child was in line with their perception. However, in addition to provision of physical care to the hospitalised children, it was found that caregivers are also involved in providing basic nursing care activities to their children mainly due to health care providers' workload. Results further showed a discrepancy between the health providers' perception and practice on sharing of information between the family and the health care providers. Despite the participants perceiving that in family involvement there is sharing of information between the health care providers and the families, in practice this was not done. The participants'

responses were according to the following sub themes: Provision of physical care, performance of basic nursing care, lack of information giving, inadequate participation in discussion and decision making

Provision of physical care.

In line with their perception, all participants mentioned that every caregiver was involved in performing physical care activities for their hospitalised children like feeding the child, bathing the child, taking the child to the toilet, cleaning child's bed, changing child's nappies, and washing child's clothes. The participants explained that these activities are roles of the caregivers such that they were supposed to be doing that for their hospitalised children. One participant said:

In this ward the caregivers do everything about the physical care for their children because to us it is their responsibility to be doing that for the children (Participant # 11).

Performance of basic nursing care activities.

Apart from the caregivers providing physical care to their children, the participants said that the caregivers performed basic nursing care activities like draining urine from catheter bags, doing physiotherapy activities and giving oral medication to the children. It was indicated that caregivers performed those basic nursing care activities because mostly the health care providers were busy giving chemotherapy. One participant said:

When they are in the ward, for example may be the child is suppose to be getting acyclovir which is given five times a day, we prefer giving the drug to the caregiver to be giving the child on her own because for us it is easy to miss the dose because most of the times we are busy administering chemotherapy to children so it is difficult to remember giving the drugs every 5 hours (Participant # 10).

Lack of information giving.

Much as majority of the participants perceived that family involvement in child's care involves giving the family information about the child's condition and treatment, most of the participants explained that in practice, they did not give information about the child's condition and treatment to the caregivers. One nurse illustrated this:

Caregivers are not given information about the child's condition and treatment, for example sometimes when we have inserted a cannula for giving medication, after few hours you see the care giver coming saying take out the cannula, my child is crying with it. This means information about the cannula and its use is not given to the caregiver when it is being inserted because had it been the caregiver is told and has understood she can not be coming to ask for the removal (Participant # 8).

The participants indicated that they did not consider giving information about child's condition and treatment to the caregivers as important.

We don't even explain to the caregivers about the drugs that we are giving, we just hang the drips. When the caregivers try to ask, we don't really take that as important like people who do not know (Participant # 6).

The few participants who gave information to the caregivers gave basic information because of problems with translation of words from English to Chichewa for caregivers to clearly understand.

We try to give them information about the condition that the child has for the caregivers to know what to do when caring for the child. However we experience a challenge with that because we don't clearly explain to them in Chichewa for them to understand because most of the words that we use are difficult to translate from

English to Chichewa. So, what we do mostly, we don't go in detail telling them about their child's condition, it is really difficult for us, instead we just give them basic information that we know that they will understand (Participant 12).

Inadequate participation in discussion and decision making.

Most of the participants explained that caregivers were not involved in the health care providers' discussions and decision making about the child's care. It was indicated that at times caregivers were only told the already planned child's care. One participant explained:

Mostly the discussions and decisions are done by us the health care workers, sometimes we just tell them what we have planned (Participant # 9).

A few participants said that caregivers were only involved in discussion and decision making when the child's condition is going to end of life. It was explained that when the child's condition is getting worse the caregiver was asked to make a decision on whether she can take the child to be taken care of at home. One nurse illustrated this:

To say the truth, in this ward caregivers have been coming to us nurses and complain that they are not given that chance to participate in the decision making. For example caregivers have complained that they are only told to make a decision when the child's condition is becoming worse or going to end of life. So caregivers have been complaining that why are they not being told in the first place when they have just come because what they are told when they have come mostly is that we are going to help your child and he will be well but they get surprised when the child's condition is becoming worse and they are being told to decide to take the child home because they can not cure the condition. This means that caregivers are not given that chance to participate in the discussion of the child's progress such that they do not follow what is happening to their child (Participant # 8).

Reasons for inadequate involvement of caregivers in discussion and decision making.

Illiteracy.

Participants reported that they did not involve caregivers in discussion and decision making because most of the caregivers were illiterate such that they could not be able to make a decision about child's care. One participant said:

From my experience, most of the caregivers that we usually have here are illiterate and they do not have that capacity to make decision on what the child should get, it is like they just receive anything that has been said by the health care providers (Participant # 9).

It was further found that some children came in the ward with their grand mothers who took care of them during the hospitalization period as such it was difficult to discuss the child's care with them because understanding to them was a problem. One participant explained:

Sometimes we have grand mothers who are very old taking care of the child so it becomes difficult to be discussing child's care or having them make a decision about the child's care (Participant # 3).

Lack of Time.

Some participants said that it was difficult to involve the caregivers in discussions because most of the discussions were done during ward round and doctors had a lot of patients to see such that they were doing the ward round in a faster way to finish.

Our ward rounds happen in a faster way for the doctors to finish so it takes time because we usually have a lot of patients so it is difficult that we should be discussing the child's care with the caregivers (Participant # 5).

Inadequate Involvement of Other Family Members

Participants were asked how they involved other family members in the care of the sick children. The results showed that involvement of other family members depended on the condition of the child. Usually, the health care providers interacted with the caregiver who was available in the hospital with the child. It was indicated that the other family members were not involved because they were just coming in to visit the child. Though the other family members just came to visit the child, the health care providers did not make an effort to include them in the care of the child. It was further found that, at times a caregiver was requested to make difficult decisions about child's care before she can consult her family members. One nurse explained:

I would really say we are concerned much with those that are available in the hospital, we don't really look much at those that are just coming in and going out, so we just concentrate on who has come with the child, who is staying with the child. Even with other care like surgery, it is the available caregiver who is asked to give the consent without consulting other family members. For example may be the doctors have assessed that the child needs amputation so when they explain to the available caregiver she may say let me discuss with other people at home, but that is not accepted, instead she is told that your are the caregiver here and you are the one to give us the consent (Participant # 8).

Other participants reported that other family members were only involved when the child's condition is worsening. One participant said:

Other family members are only involved when things are not ok, when the condition of the child is worse it is when you would see the doctors asking about the other family members so that they can discuss on how to manage the child (Participant # 8).

Lack of Caregiving Role Negotiation

The results showed that most of the health care providers did not consult the caregivers to discuss the caregiver role in caring for the hospitalised children. It was the participants' expectation that the caregivers knew their role in regards to the hospitalised child. One participant explained:

We don't discuss anything about their role in caring for the child, we just feel like its automatic that they know what they are supposed to be doing when they are in the ward, I think we don't really see that as a necessity (Participant # 14).

When participants were asked what they did to facilitate family participation in child's care, almost all the participants explained that they did not do anything. The participants indicated that their role in the ward was just to provide technical care to the patients. One participant said:

The role of us...(Check number of dots to be used according to APA) all what we do is to give them the chemotherapy and giving the other drugs but looking at their day to day life, mostly it's done by themselves (Participant # 2).

Only one participant reported that apart from providing technical care to the patients, she taught the caregivers about their role in caring for the children. The participant felt that this is important because the caregivers did what they had been told to do and the health care providers did not find problems with the caregivers in regards to child's care. However the participant said that she did not do this to every caregiver because caregivers came differently in the ward and she could not manage to have time for everyone such that some caregivers stayed in the ward without being prepared of their role. One participant explained:

We teach them what they are supposed to know for them to be doing that for the child, like teaching them on how they should be giving the drugs, how to turn the child when it is indicated and other things that we need them to be doing for the child. When they have been taught it becomes easy for them to know what to do in caring for their child. However, we do not do that to everyone that comes in the ward because other caregivers find us in the ward when we are very busy that we can not manage to teach them all these things (Participant # 16).

Factors that Facilitate Involvement of Caregivers in Children's Health Care

Results show that in practice, the caregivers were involved in some areas of child's care in the ward. When participants were asked about the factors that made them to involve the caregivers in the areas that they mentioned, the following factors were identified: continuity of care at home, reducing health care providers' workload and poor child's condition.

Continuity of care at home.

Majority of the participants reported that they involved the caregivers in their child's care for easy continuation of child's care at home. It was indicated by the participants that most of the times the child stayed home with the caregiver so it was necessary that the caregivers learn how to take care of the sick child while in the hospital so that they should not have problems when they were discharged home. One participant explained:

Because we are talking of the chronic illness and its not all the times that the child stays in the hospital with us the health workers, sometimes the child is home with the caregiver and in this case if the caregiver is not involved in the child's care, the caregiver may not take care of the child properly when at home. For example, these children usually are discharged with drugs to be taken home so if the caregivers are not involved in the care of the children they may not be able to

administer the drugs to the child at home properly as a result the child may not respond to the treatment (Participant # 7).

Reducing health care providers' workload.

Most of the participants explained that mostly the caregivers were involved in providing basic nursing care activities to reduce the burden of workload that they had. For instance, participants indicated that some drugs like morphine which were being administered frequently to the children were given to the caregivers to be giving to the child on their own. It was indicated that the health care providers were mostly busy attending to the children's crucial needs. One participant explained:

For the issues like doing the physiotherapy activities and administration of drugs like morphine we prefer teaching the guardian for them to be doing on their own because health workers we are most of the times busy with other activities such that its difficult to have time of doing those activities (Participant # 3).

Poor child's condition.

Poor condition of the child made the health care providers to involve the caregivers decision making about child's care. It was indicated by the participants that when the child's condition was going to end of life, caregiver was asked to participate in making decision on whether she can take the child to be taken care of at home. One participant illustrated this:

It is not to everyone being asked for their input in decision making or having a discussion with us about the child's care. Most of the times we do ask for the caregiver's input in the decision when the child doesn't respond to treatment so we try to reason together with the family that the child should be taken care of at home. So that's one of the situations that we ask for the family's input in decision making. But

for the other cases we just explain to them that your child has cancer and will receive treatment, and they accept that (Participant # 15).

Challenges Encountered by Health Care Providers to Involve Families in Children's Health Care

When asked about the problems that they experienced in involving families in their children's health care, all participants explained that they experienced challenges working with caregivers in caring for the children. Apart from caregivers' illiteracy and lack of time, the participants explained the following challenges: language barrier, associating child's condition with witchcraft, inavailability of caregivers in the ward, poor caregiver- health care provider relationship and poor relationship among health care workers.

Language barrier.

Apart from the English language barrier, participants reported that they experienced problems with communication of child's problems to the caregivers due to difference in language. It was found that the unit admitted patients from other countries who could not speak the local language or English so that hindered communication of child's care between the health care providers and the caregivers. One participant said:

We get patients from all over Malawi and even Mozambique, so for example we get a patient with the caregiver from Mozambique who do not speak English or Chichewa, they speak their languages that not any of health workers or guardians understand, so its even difficult to work with those people because we cant communicate so it's very challenging because for us to work together effectively we need to communicate.

Associating child's condition with witchcraft.

Participants mentioned that some caregivers did not understand the problem of the child. They associated the child's condition with witchcraft. One participant said:

Some of the caregivers when they are coming with the patient, they would associate the child's sickness with witchcraft so when your explaining to them that this is cancer, they would still have that element that someone else from their home is taking part in making the child sick because it's what stuck in their minds so its really a challenge (participant # 2).

Inavailability of caregivers in the ward.

The results show that health care providers experienced problems in involving the caregivers in their children's healthcare due to their inavailability in the ward. It was reported that sometimes caregivers leave the children alone in the ward and go out mostly to do piece works as a result health care workers fail to provide care to the child. One participant explained:

Another thing is that due to long stay in the hospital these caregivers lack different material resources for example food, money as a result they tend to leave the child alone in the ward and go out to do piece works to find money, because of that they are not able to take care of the child as they are suppose to be doing, and at the time that they are out, the child may need a certain type of care from us the health workers for example to give the child drugs so it means we may not give the medication to the child in absence of the caregiver (Participant # 7).

Poor relationship between health care providers and caregivers.

Most of the participants indicated that they experienced problems with caregivers' conduct in the ward. It was explained that at times caregivers neglected health care providers' advice in regards to the children's health care which led to poor working relationship between the health care providers and the caregivers. One participant said:

The problem with caregivers is that sometimes whenever we are advising them something about the child's care, they want to show us that they already know the things when they don't know anything so because of that we just leave them (Participant # 5).

It was also found that poor relationship between the health care providers and the caregivers affected the assessment and planning of the child's care. One participant explained:

Sometimes may be during the ward round when you ask the caregiver the child's problems, they don't say anything, they just say there is no problem but whenever a different person goes there, they present lots of problems so I don't really know why they do that (Participant # 9).

Poor relationship among health workers.

Participants reported that they experienced problems working with their colleagues and this affected the children's care. It was found that nurses were underrated by the doctors such that they were not allowed to explain issues about the patient to the caregivers. This led to the nurses keeping information to themselves instead of giving that information to the caregivers to facilitate their participation in care. One participant explained this:

Sometimes us nurses we may want to tell the caregivers issues about their children's conditions and management, but you see the doctor asking you why were you telling them that, so that brings us back. For example there was time when the doctor decided to send a child for surgery and us nurses assessed that the surgery will not bring any good to the child, so we explained to the caregiver and let her decide whether to proceed with surgery or not, so the caregiver went to the doctor and tell him that my child is no longer going for surgery because such a nurse has advised me. So the doctor was angry with us, so with that we choose to stay quiet (Participant 8).

CHAPTER 5

Discussion of Results

Introduction

This chapter presents the discussion of the study findings. The study sought to assess the perception of health care providers on family involvement in chronically ill children's health care. The objectives of the study were to: Determine the perception of health care providers on family involvement in care of chronically ill children; describe the health care providers' role in facilitating family involvement in care of chronically ill children; describe the challenges and facilitators in involving families in health care of chronically ill children.

The discussion is based on the themes that came out of the data analysis. These are: health care providers' perception and practice of family involvement in children's health care, lack of care giving role negotiation, inadequate involvement of other family members, and challenges encountered by health care providers to involve families in children's health care.

Health Care Providers' Perception and Practice of Family Involvement in Children's Health Care

The study findings showed that participants perceived family involvement as family's performance of physical care activities, sharing of information between the health care providers and the family and provision of emotional support to the child and the family. However, in practice results showed that only provision of physical care to the child was practiced.

Performance of physical care activities.

In regards to the family's performance of physical care activities to their hospitalised children, it was mentioned that families are responsible for feeding the child, bathing the child, taking the child to the toilet, cleaning child's bed, changing child's nappies and

washing child's clothes. In line with their perception, in practice it was found that every caregiver was involved in providing physical care to their hospitalised children.

Studies from other countries have also found that parents provided usual child's care to their hospitalised children (Coyne, 2015; Hoffman et al., 2012; Tong et al., 2010; Coyne 2013; Galvin et al., 2006). This means that it is commonly expected that caregivers should continue doing parenting tasks that they normally do at home when they are in the hospital with their children. In their studies, Aein et al., (2009), and Smith, Cheater & Bekker, (2013) found that parental performance of caring routines strengthened parent-child attachment. This entails that this finding is positive and should be encouraged at QECH.

Apart from the caregivers' provision of physical care to their children, the study findings show that caregivers performed basic nursing care activities. The basic nursing care activities included draining urine from catheter bags, doing physiotherapy activities and giving oral medication to the children. It was found that caregivers performed those basic nursing care activities because of health care providers' workload. Hoffman et al (2008) found that in Malawi the health care provider to patient ratio is 1:2771 and the physician to patient ratio is 1:50, 0004. This study findings are similar to the growing body of literature which found that health care providers shift their responsibilities to parents for their children's care to relieve their workload (Coyne 2015; Hoffman et al., 2012; Aein et al., 2009).

Despite the reason of reliving workload, involving families in basic nursing care may be beneficial in the care of cancer children as the care continues in the home. Evidence suggests that care-giving such as providing medical and nursing interventions above usual parenting tasks is a significant feature of living with a child with a long-term condition for families (Cashin, Small & Solberg, 2008; Smith, Cheater & Bekker, 2013; Wennick & Hallström, 2007). The families develop considerable expertise in managing their child's long term condition and they do not experience problems in providing the care in homes

(Dickinson et al., 2006; Nuutila & Salanterä, 2006). The chronicity framework emphasizes the need to provide training and skills to the family members for safe delivery of medical and nursing care to the chronically ill children at home (Olmen et al., 2012). However, in this study it was found that though caregivers were involved in providing the basic nursing care to their children, they were not trained the skills to provide basic nursing care to their children.

Discrepancy between perception and practice on information giving.

Findings from this study showed a discrepancy between perception and practice in regards to information giving. The health care providers perceived family involvement in child's care as giving the family information about the child's condition and treatment. Information was viewed as a major need for the families caring for children with cancer conditions. It was outlined that giving the family information about the child's condition and treatment facilitates family's understanding of the child's problem and their ability to provide recommended care to the child. This is in line with findings from Bruce et al., (2012), Sarajärvi et al., (2006), and Lee (2007).

Although health care providers perceived family involvement in child's care as giving the family information about the child's condition and treatment, the findings of the study demonstrate that in practice this was not done. This is similar to other studies that illustrated that professionals treating children with cancer provide insufficient information to families (Mostert, et al, 2014; Sarajärvi et al., 2006; Ladak et al., 2013; Rathert et al., 2013; Bruce et al., 2012). Evidence suggests that providing information about child's condition and treatment is essential to families living with children with long-term conditions (Cashin, Small & Solberg, 2008; Smith, Cheater & Bekker, 2013; Wennick & Hallström, 2007). In order to identify and respond to illness symptoms in their children, the families need knowledge of the condition and its management (Gallo et al., 2013; Nuutila & Salanterä, 2006). In addition, chronicity framework illustrate the need for the health care providers to

give adequate information on child's condition and management to the family of the child to enhance their participation as they are also involved in the administration of child's treatment at home (Olmen et al., 2012).

Lack of information about the child's condition and treatment affects the family's ability to comply with child's treatment plan. In a study on the guardians' perspective on paediatric cancer treatment in Malawi and factors affecting adherence by Israels et al., (2008) and a review of studies by Israels, Ribeiro and Molyneux (2010) on Strategies to improve care for children with cancer in Sub-Saharan Africa, it was found that guardians could abandon their child's treatment because they could not follow what was happening to their children. Caregivers caring for cancer children at QECH may lack knowledge of their children's illnesses and treatment. This may result to abandoning the child's treatment though in this study it was not reported whether caregivers abandoned their children's treatment or not.

The health care providers identified to lack of time as the reason for not providing information about child's condition and treatment to the caregivers due. It was indicated that the health care providers were most of the times busy with other activities. Several other studies have found time constraint as a barrier to involve families in their children's health care (MacKay & Gregory, 2011; Foster et al., 2010; Power & Franck, 2008; Paliadelis et al., 2005; Coyne 2015). In their studies, MacKay & Gregory, Foster et al., Power & Franck, Paliadelis et al., and Coyne found that paediatric nurses were involved in many different treatments procedures such that everyone in the ward was running around trying to meet the basic needs of the patient and could not have time to sit with the family and give them information about their children's conditions. In contrary, in a study by Ygge & Arnetz (2006) on perceptions of parental involvement among oncology, surgery and neurology staff found that oncology staff gave information to the parents about their children's conditions

and treatment despite being involved in several activities. The study indicated that the unit had established routines for parental involvement, thereby experiencing less work strain in their interactions with parents. Similarly, staff working at QECH paediatric oncology can establish routines for caregivers' involvement because the caregivers require knowledge of their children's conditions and management for their effective participation in child's care.

Caregivers' lack of understanding was also reported as another reason for not giving information about the child's condition to caregivers. It was found that caregivers were associating the child's condition with witchcraft as a result understanding of the child's problem was difficult despite being given the explanation. This finding is consistent with findings from Banerjee et al., (2011), Mostert et al., (2014) and Tran, Kaddatz, & Allard (2005) where people attributed their child's cancer conditions to religious and cultural beliefs.

Misconceptions regarding childhood cancer may have implications for treatment adherence (Banerjee et al., 2011). In a study by Mostert et al (2014) on contributors to abandonment of childhood cancer treatment in Kenya, many parents abandoned treatment to seek help from traditional healers due to the belief that their children were bewitched. This implies that in the absence of clear information and advice from health professional cultural beliefs influence parent's attitudes to decision making for management. This demonstrates the need for knowledge about childhood cancer and treatment in communities.

Study findings also showed that health care providers experienced problems with communication of child's problems to the caregivers due to language differences. It was found that the unit admitted patients from other countries who could not speak the local language or English and that hindered communication of child's care between the health care providers and the caregivers. Reports from other studies have also indicated that health care providers identified difficulties communicating with non English speaking parents and had

concerns about parents' inability to understand the information regarding child's care (Coyne 2011; Paliadelis et al., 2005; Abbe et al., 2006).

Language barrier between clinicians and parents is associated with provision of insufficient information and little opportunity for discussion (Nuutila, 2006; Wennick & Hallström, 2007; George, Vickers, Wilkes & Barton, 2006) resulting in the family's dissatisfaction with the care. In addition, parents give inappropriate care to the child due to limited communication of child's care between the professionals and the parents (Abbe et al., 2006). However, evidence suggests that use of interpreters reduces language barriers between professionals and parents having language differences (Abbe et al., 2006). Abbe et al., indicated that interpreters may help the parents understand key medical terms and concepts of their children's problems and care to facilitate their participation in care.

Perception on provision of emotional support.

Provision of emotional support to the family was viewed as involving the family in their children's health care. It was indicated that emotional support could be provided to the family through responding to the family's concerns, addressing family's questions concerning child's condition and care and showing love to the family during the child's care. The findings illustrate that provision of emotional support to the family promotes the family's coping with the child's condition. This finding is also similar with other study findings where provision of emotional support to the family helped the family to gain more insight into the child's care (McKivergin & Daubenmire, 2014; Coyne et al., 2013; Bruce et al., 2012; Bruce & Ritchie., 2007; Letourneau & Elliott, 2006).

Previous studies suggest that families caring for cancer children experience stressors and challenges such that their participation in child's care becomes more stressful (Mackay & Gregory, 2011; Coyne, 2013; Haapamäki, & Paavilainen, 2006). This implies that providing emotional support to the families enhances their participation in care. Evidence indicates that

paediatric oncology nursing care is focusing on implementing provision of emotional supportive care as a means of enhancing patients' and family's quality of life (Cantrell, 2016). Therefore, practice of this finding may be beneficial to the families caring for cancer children at QECH.

The study further found that involvement of the family in child's care includes the family's responsibility for providing emotional support to the hospitalised child. The support includes caregiver's availability in the ward for the child as well as showing love to the child. It was indicated that parental emotional support helps the child to feel secure, comfortable and free from worry. Other studies have found that hospital environment is a traumatic experience for the child and parental presence in the ward was viewed as helping, providing reassurance, comfort and security to the child (Coyne, 2015; McKivergin & Daubenmire, 2014; Coyne et al., 2013; Bruce et al., 2012; Bruce & Ritchie., 2007; Letourneau & Elliott, 2006). In addition, the studies indicated that children were happier, more cooperative and recovered quicker because of the parental support. This implies that this finding is positive and it should be practised.

Lack of participation in discussion and decision making.

The findings of the study show that health care providers did not involve the caregivers in discussion and decision making about their children's care. The findings are consistent with the growing body of literature which indicates that despite the constant physical presence of families at the bedside, clinicians exclude family members from discussions and decisions regarding the child's health care (Tong et al., 2010; Hallström & Elander, 2014; Barry & Levitan, 2012). However, the chronicity framework and literature emphasizes that actively involving parents in care decisions is essential in the context of children with long-term conditions as the day-to day management of the child's condition is primarily the responsibility of the family (Olmen et al., 2012; Smith & Swallow, 2015;

Lipstein et al., 2012; Smith, Cheater & Bekker, 2013). Families who actively participate in their children's healthcare decision making have been found to have better understanding of their children's condition outcomes (Olmen et al., 2012; Rachmani et al., 2012; Arnetz et al., 2010; Coleman et al., 2006; Weingart et al., 2011) and more positive experiences of care (Weingart et al., 2011).

Caregivers' limited literacy on child's medical care was found as one of the reasons indicated for not involving caregivers in discussions and decision making. Sanders et al., (2009) defined limited health literacy as an individual's inability to obtain, process and understand health information and services needed to make appropriate health decisions. Findings indicate that caregivers lacked this capacity to make decisions about child's care and that hindered their participation in decision making. Findings from Hoffman et al., (2012) on a study of utilization of family members to provide hospital care in Malawi: the role of hospital guardians found that over 70% of guardians were illiterate. This made their ability to make decisions about child's care problematic. This entails that the findings from this study are true with QECH.

Parental limited health literacy is associated with adverse child health outcomes (Gallo et al., 2013). Studies indicate that children with chronic illness may be at greater risk for poor health outcomes if their caregivers have limited health literacy (Barry & Levitan (2012; Lipstein, 2013). However, evidence has shown that providing detailed and clear information on child's condition and treatment to the caregivers facilitates their ability to decision making (Adams, Boulton & Watson, 2009; Gallo et al., 2013; Nuutila & Salanterä, 2006). In a Review of Peadiatric Decision Making by Lipstein, (2013) parents perceived a key role for health care providers as providing parents with the information needed to participate in decision making about child's care. Such information included condition prognosis and treatment plan. In addition, Barry & Levitan (2012) emphasized the need for

families to be educated about their essential role in participating in decision making on child's care.

Understanding how parental literacy relates to children's health processes may have important implications for how medical and nursing professionals communicate with families and how the needs of those illiterate parents can be better met (Lee et al., 2009). Lee et al., stated that because adherence to instructions is dependent on understanding what is involved, it is incumbent on health care providers to recognize illiteracy as a widespread problem and to maximize opportunities for parent and patient understanding and education. This may involve low literacy verbal explanation of the diagnoses and instructions to parents thoroughly.

The study further found that health care providers did not involve the caregivers in discussions and decision making because the discussions were done on ward round and it was being done in a faster way to finish such that it was difficult to include the caregivers. In contrary, in their studies, Higman & Shaw (2008) and Meuthing et al., (2007) the participants suggested that a practical way to include the family in decision making and keep them better informed is to involve them in patient ward rounds. The studies found that by involving the family in discussions and decision making during ward rounds, they fostered attitudes of respect and interest in the concerns and opinions of families. QECH Paediatric oncology unit has a bed capacity of 24 and their ward round takes approximately 2 hours (Anecdotal report). This implies that it is possible for the doctors to take more than two hours during ward round in order to involve the caregivers in discussions and decision making during ward rounds.

Lack of Caregiving Role Negotiation

The study findings show that health care providers did not consult the caregivers to discuss family role in caring for their hospitalised children even though the care givers were

involved in providing technical care to their children. It was the participants' assumption that the caregivers knew their role in regards to the hospitalised child. This finding is also similar with other study findings which found that there was none or minimal discussion about parental roles regarding child's care. (Hughes, 2007; Gill et al., 2014; Coyne, 2015; Bridgeman, 2009; Corlett & Twycross, 2006; MacKean, Thurston & Scott, 2005; Phiri, 2015).

Evidence has shown that parental roles and responsibilities alter when a child is admitted to hospital (Corlett & Twycross, 2006; Bruce et al., 2012; Coyne, 2011; Coyne, 2013; Koller, 2006; Davies, 2012). Importantly, their participation in child's care requires the process of negotiation by health care providers (Phiri, 2015). In addition, chronicity framework emphasized that people with chronic illnesses and their families need support on their role of participation in care because they provide most of the care to the child in homes as well as in the hospital (Olmen et al., 2012). Studies from Hallstro & Elander (2014); Coyne (2007); and Sarajärvi et al., (2006) found that when the health care providers negotiate parental role, parents are able to provide care to their hospitalised children according to the health care providers' expectations. However, as reported by the participants, it is clear that health care providers in this study did not negotiate with the caregivers regarding their roles in caring for their sick children.

Literature has documented that professionals usually have clear expectations of the activities they want parents to be involved and are in a powerful position to negotiate this parental role of participating in those expected activities (Smith & Swallow 2015; Gallo et al., 2013; Theofilou, 2013). In addition, in a study on the role of the nurse in family-centred care, Tedford and Price (2011) pointed out that professionals must recognise their duty to negotiate family role in order to facilitate the parental participation in the child's care. However, findings from this study show that the health care providers did not play their role

of negotiating the caregiver role even the technical care that the caregivers were providing to their children. The health care providers indicated that their role in the ward was just to provide technical care to the patients. This might be the reason why there was no negotiation of the caregiver role in participation in care. It is therefore follows that health care providers caring for cancer children at QECH need to be aware of their role of negotiating parental participation role. As recommended by Corlett and Twycross (2006), health care providers need to have the appropriate theoretical knowledge and practical skills to communicate and negotiate with parents.

Negotiation process of parental role requires good relationship between the family and health professionals (Coyne, 2015). This study findings showed that there was poor relationship between the caregivers and the health care providers. It was found that even communication between health care providers and the caregivers was poor. Findings further indicate that sometimes caregivers neglected health care providers' advices in regards to the child's care because of the poor relationship. This might be another reason why in this study there was limited negotiation between the health care providers and the caregivers. The findings are similar with findings from Hoffman et al., (2012) Paliadelis et al., (2005); Foster et al., (2010); Power & Franck, (2008) and Coyne (2011) who found that poor relationship between the hospital staff and the guardians hindered the participation of guardians in care-giving roles as there was limited negotiation of care roles.

Cancer management requires the establishment of a long-standing and trusting relationship between parents and professionals (Dickinson, Smythe, & Spence, 2006; Swallow, Lambert, Santacroce, Macfadyen, 2011; Swallow, Macfadyen, Santacroce & Lambert, 2012). Barry & Levitan (2012) and Mackay & Gregory (2011) found that developing effective parent-professional relationship enhances the parental ability to feel comfortable voicing opinions and concerns about child's care. It is evident that in this study

caregivers were not open to express their concerns or opinions in regards to the child's care because of the poor relationship that they had with the health care providers.

Poor relationship was not only between the health care providers and the caregivers but also among health care workers. It was found that nurses were underrated by the doctors such that they were not allowed to explain issues about the patient to the caregivers. This led to the nurses keeping patients' information to themselves. However, literature emphasizes that effective relationship among health care providers promotes shared decision making and improves patient care (Mitchell, 2012). It is evident that in this study patients' care was affected because nurses were excluded from discussions of patient issues.

Manias & Street (2011) suggested that health care providers require an understanding of the roles and expertise of different professions in the health care service for effective relationship among them. Manias & Street further indicated that this understanding makes the professions to value each individual's opinion and contribution in the service. It is therefore follows that health care providers caring for cancer children at QECH have an understanding of each one's role in the care of the patient and value their opinions for the successful delivery of quality care to the children.

Inadequate Involvement of Other Family Members

The study findings show that there was inadequate involvement of other family members in the care of children with cancer. It was found that the health care providers only interacted with the caregiver who was available in the hospital with the child. This is contrary to the concept of family centred care practice where family involvement is an integral part. Family centred care practice acknowledges the family as a complete unit and encompasses care of the family as a whole (Coyne, 2015).

Family members were not involved because they were just coming in the ward to visit the child. Though this was the case, the health care providers did not make an effort to

include them in the care of the child. Sadly, it was further found that, at times a caregiver was requested to make difficult decisions about child's care before she can consult her family members. This is contrary to the chronicity framework which states that chronic illness has a significant impact on every family member of the patient and that they perceive a need for their involvement in the health care of the patient (Olmen et al., 2012). Furthermore, studies provide evidence that decisions about treatment and care of chronically ill patients are often made in the context of family (Adams, Boulton & Watson, 2009; Smith, Cheater & Bekker, 2013). It is therefore important that the other family members should be involved in the care of the children.

Treatment adherence of chronically ill patients has been attributed to the available social support (Trevino, Fasciano & Prigerson, 2013; Adams, Boulton & Watson, 2009; Smith, Cheater & Bekker (2013)). Encouragement from family members improves adherence to medical regimens. For instance, supportive family members may remind patients to take medication or attend hospital appointments and thus enhance treatment compliance. It is therefore important that at QECH family members of cancer children be involved in the care of the children for their effective participation in the care of the child at home.

Adams, Boulton & Watson (2009) suggested that oncology practice need to pay greater attention to providing information on supportive care to family members of the cancer patients to promote their participation in the care of the patient. Rutten et al., (2005) identified treatment-related information, rehabilitation information, prognosis information and coping information as information needs for the family members as part of their involvement in the care. In this study, it is evident that the other family members of cancer children at QECH lacked knowledge of their needs to help them participate in the child's care effectively because they were not involved in the children's care. It is therefore important that

health care providers consider the information needs of other family members to aid their participation in care of the children.

Additional Challenge Experienced by Health Care Providers to Involve Families in Children's Health Care

In availability of caregivers in the ward.

The study findings show that health care providers had problems to involve the caregivers in their children's healthcare due to their inavailability in the ward. It was found that caregivers were leaving the sick children alone in the ward and go out to do piece works outside the hospital to find money for their help during hospitalization period. This finding supports the findings of Israels et al., (2008) who found the economic burden as the main concerns of the guardians during their hospital stay. In the study, guardians explained that due to the child's long hospitalization, they lacked money to buy additional food while staying in hospital.

Evidence indicates that QECH provides meals which include breakfast, lunch and supper to the patient and one guardian for free (Hoffman et al, 2012). From the current study findings, it can therefore be concluded that nutrition support given to these caregivers was inadequate to keep the caregivers and their children in the hospital. It is therefore necessary to consider providing adequate nutritional support when offering prolonged treatment to the cancer children that require long hospital stays in resource poor settings like Malawi where patients sorely depend on the hospital food.

Findings from this study further indicate that due to the caregivers' inavailability in the ward, health care workers failed to provide care to the child. In addition findings indicate that other caregivers absconded treatment because of financial constraints. The findings clearly demonstrate the negative effects of the economic burden that families caring for cancer children experience. It is therefore important for the hospital to develop measures for

supporting caregivers who care for children with cancer during hospitalization period so that parents do not have to leave children in the ward to search for money. This will help the caregivers to provide adequate care to the children in the hospital.

Conclusion

This chapter presented the discussion based on the study findings in relation to the conceptual framework of the study. Results have showed a discrepancy between the health providers' perception and practice in regards to most of the areas of family involvement in child's care. For the few areas that the caregivers were involved, the health care providers only interacted with the caregiver who was available in the hospital with the child, the other family members were not involved. Furthermore, results have shown that health care providers were not aware of their role of negotiating the caregivers' role in caring for their children.

Recommendation

The findings of this study have shown that health care providers do not give adequate information to caregivers concerning their children's conditions and treatment and there is no collaborative decision making between families and health care providers. Families need adequate information about their children's conditions and treatment and they need to be involved in decisions regarding their children's care. There is a need for the Paediatric oncology ward staff to develop the leaflets containing information on different types of childhood cancer. This helps to reduce the time for giving information in settings where there is staff shortage. On the other hand, management should consider providing adequate staff in the ward because nursing shortages means nurses do not have time to speak and listen to the families. There is evidence that adequate staff led to improved quality of care for hospitalized children (Coyne 2011).

Study findings have further shown that the other family members were not involved in the children's health care. It is important that the other family members should be involved

in the care of the children because family members work together caring for the child. The health care providers should be utilizing the opportunity that the other family members visit the children to include them in the care of the child. It is also important that health care providers consider the information needs of other family members to facilitate their participation in care of the children.

The health care providers did not consult the caregivers to discuss family role in caring for their hospitalised children. Information, communication and clarification of expectations are essential pre-requisites for effective family participation in child's care. Further, poor relationship between health care providers and caregivers contributes to the limited negotiation of roles. For this to change health care providers need to negotiate and communicate with parents more effectively. The health care providers need to have the appropriate theoretical knowledge and practical skills to communicate and negotiate with parents

Areas of Further Research

- Strategies to support parents in their role in children's health care
- To understand and identify ways of improving the delivery of information in Paediatric oncology
- Factors that contribute to inadequate role negotiation between health care providers and families

Study Limitations

The study was conducted at QECH and small sample size was used hence findings can not be generalised to the whole population in Malawi. The limitation resulted from time and financial constraints of the researcher. The study was done as part of the researcher's school and had time limit. The financial constraint was due limited funding for the study.

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Appendices

Appendix 1: Participants information sheet

Dear participants

My name is Anizia Kamwendo and I am currently registered as a student at the University of Malawi, Kamuzu College of Nursing for the Master of Science degree in Child Health. I am conducting a research on **“Assessing family involvement in chronically ill children’s health care at Queen Elizabeth Central Hospital.”** I write this letter to ask you to participate in the study. The aim of the study is to assess the perception of health care providers on the practice of family involvement in chronically ill children’s health care at Queen Elizabeth Central Hospital. You have been asked to participate in the study because you’re a health care provider caring for chronically ill child.

Participation in the study is entirely voluntary which means you may choose to participate or not. Furthermore, the study does not have any foreseeable physical harm (risks); however, in cases of any emotional or psychological harm, you can refuse to answer questions or withdraw at any point.

The findings of the study may not be beneficial to you individually but the knowledge gained from assessing the perception of health care providers on the practice of family involvement in chronically ill children’s health care will assist in improving standard and quality of care given to the families with chronically ill children.

No names will be used but codes as such no reports in this study will identify you in any way and results of the study will be given to you should you so wish. Should you agree to participate, I will ask you to sign a consent form or put a finger print on the space provided to

indicate that you have accepted to be interviewed. The interview will be conducted at a time that is most suitable and convenient to you in a quiet environment to avoid any disturbances.

Thank you for taking time to read this information letter.

Should you require any further information regarding the study or your rights as study participant you are free to contact me on the following number: 0881428567 or The chairperson, COMREC Secretariat, P/Bag 360, Chichiri, Blantyre 3 or you may call on 01989766.

Appendix 2: Participant Consent Form

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

I..... (Name), voluntarily give permission to participate in the study.

I have read or they have explained to me and I understood the content of the information letter and I have been given the opportunity to ask questions where necessary and ensure that questions have been answered to my satisfaction. I understand that the information I give will be kept confidential and will only be accessed by the researcher and/or those people who are directly concerned with the study. I know that I will not suffer any injury or harm during the research process and the information that I will give to the researcher will not be used against me in future. I can refuse to answer questions or withdraw from the study at any point.

.....

Participant's Signature

Date

.....

Researcher's Signature

Date

Should you have any further inquiries please contact: The Chairperson, COMREC Secretariat P/Bag 360, Chichiri, Blantyre 3 or you may call on 01989766.

Appendix 3: Interview Guide for Health Care Providers

Date of interview.....

Participant's number.....

Starting time.....Finishing time.....

SECTION A: DEMOGRAPHIC DATA:

Age.....

Sex: Male ☐ Female ☐

Religion.....

Qualification.....

How long have been working in the ward.....

SECTION B: IN-DEPTH INTERVIEW GUIDE

1. What is your experience working with children with chronic illnesses and their families?
2. From your perspective, how do you understand family involvement in chronically children's health care?

PROBE

How important is family involvement in chronically children's health care?

Caregivers always stay in the ward with their sick children, how are they involved in the care of their children?

Do they ever participate in other aspects of care (being involved in the discussion regarding child's care, involved in children's care plan, decision making, given information on child's treatment)?

What else do they do?

Does the participation in those aspects of care apply to everybody?

3. What role do you play in facilitating family involvement in chronically ill children's health care?

PROBE

How important is this role in the care of the chronically ill child?

What information do you give to families regarding family involvement in children's health care?

How does the information given?

When is the information given?

How important is this information during the care of the child?

4. What facilitators do you experience in involving families in the children's care?

PROBE

Do you experience any challenges in involving families in the children's care?

If yes, what are they?

How do you address the challenges?

**Appendix 4: Approval Certificate from college of Medicine Research Ethics Committee
(COMREC)**



Appendix 5: Permission Letter to Conduct Research at QECH

Telephone: (265) 01 874 333 /877 333
Facsimile: (265) 01 876928
Email: queenshosp@globemw.net



All communications should be addressed to:
The Hospital Director

In reply please quote No. QEC/GEN/2

QUEEN ELIZABETH CENTRAL HOSPITAL
P.O. BOX 95
BLANTYRE
MALAWI

3rd April, 2017

Anizia Kamwendo
Kamuzu College of Nursing
P.O. Box 415
BLANTYRE

Dear Sir/Madam

**RE: PERMISSION TO CONDUCT A RESEARCH STUDY AT QUEEN ELIZABETH
CENTRAL HOSPITAL**

Reference is made to your letter dated 24th March, 2017 requesting to conduct study titled "**Assessing family involvement in chronically ill children's health care**" at Queen Elizabeth Central Hospital, paediatric oncology ward.

This letter serves to inform you that Management has no objection for you to conduct the said study. Please remember to provide us with a copy of the results after the study.

Yours faithfully,


Linly Chewere
DEPUTY HOSPITAL DIRECTOR

Appendix 6: Permission Letter to Conduct Research at QECH in Paediatrics

Department

Telephone: (265) 01 874 333 /877 333
Facsimile: (265) 01 876928
Email: queenshosp@globemw.net



In reply please quote **No. QEC/PAT/4**

QUEEN ELIZABETH CENTRAL
HOSPITAL
P.O. BOX 95
BLANTYRE
MALAWI

12th April 2017

The chairman,
COMREC,
P/Bag 360,
Chichiri,
Blantyre 3.

RE: ASSESSING FAMILY INVOLVEMENT IN CHRONICALLY ILL CHILDREN'S HEALTH CARE AT QECH BY ANIZIA KAMWENDO

We are writing in support of the above mentioned study that will be led by Anizia Kamwendo in partial fulfillment of her masters in child health course. It is well known that family involvement is important for effective management of childhood chronic illness. In Malawi even though family members stay with their hospitalized children their main role is providing the physical and emotional support to the child they are not involved in the clinical decisions making process for their child. The clinical decisions are mostly made by clinical staff and many times there is no active exchange of information or collaborative decision making between families and health care providers.

The department of paediatrics at QECH is trying to establish clinical practices for how and to what extent parents should be involved in care processes and decisions and therefore this study will provide us with the necessary information as to what the normal practice is at the moment. We will use results from the study to formulate the guidelines.

We therefore fully support the study

Yours sincerely,

A handwritten signature in dark ink, appearing to read 'Queen Dube'.

Dr Queen Dube
Clinical Head Paediatrics and Child Health
Queen Elizabeth Central Hospital



KAMUZU COLLEGE OF NURSING

ACTING PRINCIPAL
Prof. E. Chirwa, Dip Nurs, MRM, B.Sc., MN, PhD

PO BOX 415, BLANTYRE, MALAWI

TELEPHONE: 01 873 623

FAX: 01 875 341

TELEGRAM: NURSING

EMAIL:

viceprincipal@kcn.unima.mw
23rd March 2017

The Chairperson
COMREC
P/Bag 360
Chichiri
BLANTYRE 3

Dear Sir/Madam,

**SUBMISSION OF RESEARCH PROPOSAL FOR REVIEW FOR ANIZIA
KAMWENDO**

I write in support of Anizia Kamwendo's submission of her research proposal "**Family Involvement in Chronically Ill Children's Health Care at Queen Elizabeth Central Hospital**" in partial fulfilment for the award of a Masters degree in Child Health and Nursing.

The results of the study will give information on what families encounter when caring for chronically ill children and how they can be supported in order to provide adequate care to their children.

I, therefore, strongly support the submission.

Yours faithfully,

Belinda Gombachika, PhD
DEAN, POSTGRADUATE STUDIES