



Kamuzu College of Nursing

CAREGIVERS' PERCEPTION REGARDING PARENTAL PARTICIPATION IN
CARE OF HOSPITALISED CHILDREN AT QUEEN ELIZABETH CENTRAL
HOSPITAL, MALAWI.

By

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Declaration

I, Lophina Phiri, hereby declare that this dissertation on caregivers' perception regarding parental participation in the care of hospitalised children at Queen Elizabeth Central Hospital is entirely my work. This thesis has not been presented for any award at any university within or outside Africa. All the sources of information that have been quoted have been acknowledged and added to the list of references.

Lophina Phiri

Signature

Date

Certificate of Approval

The undersigned approve that this dissertation represents the students own work and has not been presented anywhere else in or outside Africa

Signature_____ Date_____

Dr Angela Chimwaza, PhD (Associate Professor)

Main supervisor

Dedication

This thesis is dedicated to my Husband Patrick for his untiring support and my two sons
Wonderful and Hope.

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Abstract

Parental participation is one of the cornerstones of pediatric practice. Evidence from literature has shown that effective parental participation depends on caregivers' preparedness, adequate communication between caregivers and Health Care Workers (HCW) and the negotiation process. Queen Elizabeth Central Hospital (QECH) is the major referral hospital for the country and caregivers stay with their children in the hospital and participate in the care. However, little is known about the perception of these caregivers regarding their participation in the care of their hospitalised children.

The study aimed to explore caregivers' perception regarding parental participation in the care of their hospitalised children at QECH. A descriptive qualitative design using a semi-structured interview guide was used to collect data from 20 caregivers in the pediatric department and thematic analysis was done guided by the Colaizzi method. Seven main themes emerged from the data and these were lack of role negotiation by health care workers, inadequate role preparation for caregivers, care given by caregivers to their hospitalised children, poor HCWs- Caregivers communication, benefits of caregivers' participation in the care of hospitalised children, needs of caregivers participating in the care of hospitalised children and overall impression of caregiver's participation.

The study findings showed that caregivers view their participation in hospitalised child care as appropriate, important and satisfying. However, gaps exist in the way caregivers participate in the care of their hospitalised children due to inadequate role negotiation, role preparation for caregivers and inadequate information for caregivers. Given this, it is recommended that management should develop protocols and guidelines

for the implementation of parental participation in the care of hospitalised children to promote best practices.

List of Abbreviations

AJOL:	African Journal Online
CINAHL:	Cumulative Index to Nursing and Allied Health Literature
COM:	College of Medicine
COMREC:	College of Medicine Research and Ethics Committee
FCC:	Family Centred Care
HCW:	Health care worker
HINARI:	Health InterNetwork Access to Research Information.
IFCC:	Institute of Family Centred Care
KCN:	Kamuzu College of Nursing
KCH:	Kamuzu Central Hospital
NAWCH:	National Association of Welfare of Children in Hospital
PICU:	Pediatric Intensive Care Unit
PP:	Parental participation
QECH:	Queen Elizabeth Central Hospital

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Definition of Terms

Caregiver: Any person who was the guardian of the admitted child

Child: Any person below the age of 12.

Hospital: An institution that provides health care services.

Participation: The process of taking part or getting involved in decision making
process or delivery of service.

Perception: The way of understanding, interpreting and conceptualizing or
viewing phenomena

CHAPTER 1

Introduction and Background of the Study

Introduction

Parental participation (PP) in the care of hospitalized children has become one of the cornerstones of pediatric nursing practice (Power & Frank, 2008). It is viewed in terms of the partnership between health care professionals and caregivers in the care of children in a hospital setting (Lam, Chang & Morrissey, 2006). Power and Franck (2008) defined parental participation as allowing caregivers to visit or stay with their children in the hospital and take part in the child physical, psychological and social activities with or without collaborations and negotiation with health care workers (HCWs) to improve the health and psychological wellbeing of the children. In this view active parental participation in the care of hospitalised children is essential for child physical, psychosocial and emotional welfare (Harrison, 2010; Just, 2005; Power & Franck, 2008). In this regard, caregivers are viewed as experts in the care of the child with HCWs acting as consultants as such their knowledge and skills are acknowledged and respected within the health care system (Irlam & Bruce, 2002; Shields, Zhou, Pratt, Taylor, Hunter & Pascoe, 2012;).

Parental participation is one of the core concepts of family-centred care (FCC) which forms the framework for pediatric nursing care. The other components include collaboration, information sharing as well as respect and dignity for families (Institute of Family Centred Care (IFCC), 2013). There is evidence that PP in the care of hospitalized children is beneficial to both caregivers and children (Coyne & Cowley, 2007; Lam et al.,

2005; Power & Franck, 2008). As such allowing caregivers to participate in care activities alleviate anxiety for both caregivers and children, promotes the emotional welfare of children besides caregivers experience the continuity of parental role and enhanced coping skills (Ames, Rennick & Baillagen, 2011; Just, 2005; Lam, et al., 2005; Paliadelis, Cruickshank, Wainohu, Winskill & Stevens, 2005; Power & Franck, 2008). Furthermore, PP reduces the workload for the nurses and helps in the provision of the best care possible for hospitalised children (Ames, et al., 2011; Coyne & Cowley, 2007). Parental participation is therefore viewed as an essential element of quality care for hospitalized children (Coyne & Cowley, 2007; Soderback & Christensson, 2008).

However, there is variability in how PP is being implemented ranging from caregivers taking the passive role to total responsibilities in the care of their children (Ames, et al., 2011; Power & Frank, 2008). Studies have shown that caregivers desire to participate in the care process and decision making by their desire to do so and at a level of their own choice (Pongjaturawit & Harrigan, 2003; Power & Franck 2007; Soderback & Christensson, 2008; Ygee & Arnetz, 2004). These findings suggest that the need for role preparation, good communication and negotiation of caring roles between caregivers and HCWs about the nature and extent of parental participation are important for effective PP (Davies, 2010; Shields, et al., 2012). However, role preparation, negotiation of care roles, communication between caregivers and HCWs does not routinely happen (Corlett & Twycross, 2006; Roden, 2005; Soderback & Christenssen, 2008; Ygee & Anertz, 2004)

HCWs assume that all caregivers are willing to participate in the caring process because they are available (Coyne & Cowley, 2007; Reeves, et al., 2006; Ygee & Anertz, 2004).

HCWs need to appreciate that caregivers differ in terms of the amount of participation they want to have. Thus, PP needs to be individually negotiated and mutually agreed upon with every caregiver (Corlett & Twycross, 2006; Hopia, et al., 2005; Reeves, et al., 2006).

The researcher investigated the perceptions of caregivers regarding parental participation in the care of their hospitalized children. This was because In Malawi and at QECH to be specific caregivers stay with their children in the hospital however it was not known how caregivers were prepared for their role, how the caregivers' caring roles were negotiated and the extent to which information was shared.

Background

Parental participation in child care in the hospital setting has been accepted in pediatric nursing (Polkki, et al., 2002). Historically, caregivers were not allowed to stay with their children in the hospital. The visiting hours were restricted and the responsibility for care was solely for the hospital staff (Davies, 2010; Paliadelis, et al., 2005; Priddis & Shields, 2011). The attitude started to change in the 1950s when it was believed that separation or denial of a warm intimate and continuous relationship with the caregiver resulted in serious developmental, emotional and psychological consequences for the child (Spitz, 1945; Bowlby, 1951; Bowlby & Robertson, 1953). Maternal care was therefore viewed as essential for the mental health and normal development of a child. It was then recommended that separation should be avoided and mother or caregivers be allowed to room-in when the child is admitted to the hospital (Bowlby, 1951). Following these recommendations, the Platt report was published in 1959 which

was a milestone in child health care. It advocated for unrestricted visiting time for the caregivers whenever they can as well as an admission of caregivers with their children and that caregivers should participate in the care of their children (Davies, 2010; Ygee & Arnetz, 2004).

After the Plat report, HCWs were not in support of caregivers participating in the care process as they felt it was much easier for them to care for children in absence of their parents (Brain & Maclay, 1996). Caregivers were still being blocked to visit and room in (Hunt, 1978; Brain & Maclay, 1996). In the 1960s group of mothers published a letter describing their attempts to visit their children which was blocked by medical staff (Davies, 2010). Hundreds of women responded which led to the formation of the National Association for the Welfare of Children in Hospital (NAWCH) which advocated for the caregivers to be allowed unrestricted visiting time, stay with their children in the hospital, participate in the care and policy change (Palmer, 1993; Davies, 2010). Nurses and other HCWs started to change their attitudes towards PP gradually and expected parents to perform some physical activities that they perceive as mothering tasks (Derbyshire, 1995). Parental participation was then seen as valuable and feasible and they were satisfied with what caregivers were doing. This led to the realization that parental participation can improve the quality of care that was offered to children (Priddis & Shield, 2011).

In parental participation, the caregivers are encouraged and supported to participate in care and decision-making at the level they choose (IFCC, 2010). Studies have shown that caregivers participate in basic activities such as feeding, toileting, bathing, providing emotional support and decision making (Blower & Morgan, 2000;

Paliadelis, et al., 2005; Power & Franck, 2008). However, HCWs delegate some of the nursing tasks such as administering oral medication, feeding through a nasal gastric tube, instilling nasal saline drops, draining urine from urine bag, monitoring fluid intake and monitoring technical child condition (Avis & Reardon, 2008; Paliadelis, et al., 2005; Power & Franck, 2008).

Research has proved that parental participation is beneficial for both the parent and child (Coyne & Cowley, 2007; Harrison, 2010; Lam, et al., 2005; Power & Franck, 2008). The child emotional stress is reduced and feels secure (Power & Franck, 2008). Also, the competence of the caregiver in dealing with the child illness is strengthened and caregivers experience continuity in their role as a caregiver (Lam, et al., 2005). However, HCWs find it difficult to integrate caregivers into the care process (De Lima, Rocha, Scochi, & Callery, 2001).

Caregivers have always been expected and encouraged to stay with their children and participate in the care of their hospitalised children to provide physical, emotional and psychosocial well being (Blower & Morgan, 2000; Coyne & Cowley, 2007; Lam, et al., 2005; Pongjaturawit & Harrigan, 2003; Soderback & Christensson, 2008;). However, studies have shown that they often experience inadequate information leading to a feeling of anxiety, loneliness and lack of support (Polkki, et al., 2002; Pongjaturawit & Harrigan, 2003; Ygee & Anertz, 2004). Corlett and Twycross (2006) reported that caregivers want to participate in the care but HCWs lack of communication and limited negotiation prevent them from participating effectively. HCWs spend less time with parents to discuss their caring roles (Polkki, et al., 2002).

Caregivers involved in the care of hospitalised child require negotiation of caring roles. Negotiation depends on nurses' ability to understand caregivers' expert knowledge and recognition of parental roles. This enables parents to participate in the care process effectively to improve quality care (Reeves, et al., 2006). Despite this evidence, the literature shows that HCWS make assumptions that if caregivers are present should take on caring roles (Avis & Reardon, 2008; Reeves, et al., 2006). HCWs appear to have clear ideas about the activities caregivers should be involved in and do not routinely negotiate with them (Corlett & Twycross, 2006). This may result in placing a lot of responsibilities on the caregivers as parents become unclear about their expected roles (Just, 2005; Reeves, et al., 2006).

HCWs often manage the amount of participation by controlling the amount of information, the support they provide and the extent of communication with the caregivers as well as the way they negotiate the caring roles with caregivers. Ygee (2004) in her study on the implication of parental involvement found that HCWs were unwilling to share their power, were rejecting parents input and not taking their suggestions. Similarly, Corlett and Twycross (2006) also found that HCWs controlled PP by deciding whether or not to negotiate with caregivers and they acted as gatekeepers. But in PP HCWs need to give out a degree of control and negotiate the caring roles with parents and involve them positively in selective intellectual and physical activities that parents are willing and competent to do (Ames, et al., 2011).

Avis and Reardon (2008) in their study on understanding the views of parents on the nursing and medical care the child is receiving found that nurses were perceived by caregivers as having no time and motivation to support parental participation in the care

of the hospitalised child. Also, caregivers perceived their participation as being assumed rather than negotiated which is being perceived as a lack of attention on the HCWs' part (Avis & Reardon, 2008; Ygee & Anertz, 2004).

Given the above literature, it was evident that for effective PP, there was a need for role preparation, negotiation of caring roles, communication and information sharing. However, as most of these studies were conducted in the developed, western world and elsewhere in Africa, it was difficult to generalise the findings and make conclusions to Malawi hence this study was necessary.

Statement of the Problem

Parental participation is one of the cornerstones of pediatric nursing and medical practices. It has been documented to be beneficial as it promotes physical, emotional and psychosocial wellbeing of both the caregiver and the child (Coyne & Cowley, 2007; Harrison, 2010; Lam, et al., 2005; Power & Franck, 2008). Literature has shown that parental participation is based on the assumption that all caregivers are willing to participate in the care of their hospitalised children (Avis & Reardon, 2008; Coyne & Cowley, 2007; Reeves et al., 2006; Ygee & Anertz, 2004). However, for PP to be effective, it depends on caregiver's preparedness to participate in care as well as the extent to which caregivers and nurses can communicate and negotiate the caring roles for the hospitalised children (Paliadelis, et al., 2005; Power & Franck, 2008; Ygee & Anertz, 2004). A literature review has shown that PP is done with inadequate role preparation, negotiation of caring roles and information sharing between HCWs and caregivers leaving the caregivers with a lot of responsibilities (Paliadelis, et al., 2005; Reeves et al.,

2006; Ygee & Anertz, 2004). At QECH caregivers stay with their children in the hospital but little was known on how caregivers perceived their participation in the care of their hospitalised children hence this study. This study aimed to investigate perceptions of caregivers regarding parental participation in the care of their hospitalized children with the view of identifying areas that need improvement in the delivery of pediatric care thereby promoting quality care.

Significance of the study

Parental participation is a way of improving quality care for children. Allowing caregivers to participate in the care process assist in promoting the physical, emotional and social wellbeing of both child and caregiver. For PP to be effective good communication, information sharing, role preparation and role negotiation are prerequisites. In Malawi, little was known on how the caregivers participate in the care of hospitalised children. Describing the perceptions of caregivers' who accompany their children admitted to the pediatric ward at QECH regarding their participation in the child care process has assisted in identifying gaps that exist in the provision of child care thereby providing recommendations for medical and nursing practice to improve parental participation. The findings have also provided knowledge and understanding which will guide the implementation of parental participation in the care of hospitalised children to ensure caregivers satisfaction. It may also be utilised by health care managers in the development of appropriate protocols and guidelines for the implementation of parental participation to improve quality care.

Objectives of the Study

Broad objective.

To explore caregivers' perception regarding parental participation in the care of hospitalized children at Queen Elizabeth Central Hospital.

Specific objective.

The specific objectives of the study were to:

- Describe how caring roles are negotiated between HCWs and caregivers caring for hospitalised children.
- Identify the care that caregivers provide to their hospitalised children.
- Describe how information is shared between HCWs and caregivers in the care of hospitalised children.
- Determine views of the caregiver's concerning their participation in the care of hospitalised children.

CHAPTER 2

Literature Review

Introduction

A literature review is a way of examining what others have done in similar, though not necessarily identical areas (Leedy & Ormrod, 2010). The aim is to lay the foundation for the new study because it generates an understanding of what is known in a particular situation (Burns & Groove, 2009). In this chapter, the researcher outlines what is already known on the care that caregivers perform on their children when hospitalised, role negotiation and HCWs- caregivers' communication. The literature also highlights the views of caregivers regarding their participation in the care of hospitalised children.

The researcher only reviewed studies in English and those which were done from 2003 onwards. However, studies that were done earlier but contained important and scarce information were included in the review. A literature search was done using the following databases: African Journal Online (AJOL), EBSCO Host, Google Scholar, Pubmed, Pubmed central Medline, CINAHL, Cochrane and HINARI. The following search terms were used to generate articles containing information relevant to this study: caregivers or parents AND parental participation; caregivers AND hospitalised children; caregivers AND parental participation AND hospitalised children; perception AND caregivers AND parental participation; caregivers AND role preparation; role preparation AND parental participation; caregivers AND role negotiation; role negotiation AND parental participation; caregivers AND communication AND HCWs; benefits AND parental participation.

The literature review contains information on care given by caregivers on their children, role negotiation, communication between HCWs and caregivers and views of caregivers regarding parental participation in the care of hospitalised children.

The care given by caregivers to their Hospitalised Children

Parental participation is seen as most critical in the care of hospitalised children. Power and Franck (2008) defined parental participation as “allowing caregivers to visit or stay with their children in the hospital and take part in their children’s physical, psychological and social activities with or without collaborations and negotiation with health care workers (HCWs) to improve the health and psychological wellbeing of children. Parents view their children’s hospitalisation as the most critical event regardless of the child condition and period of hospital stay (Abdelkader, et al., 2013; Lam, et al., 2006; Power & Franck, 2008). Abdelkader, et al. (2013) used phenomenological design to describe mothers experience when their children were admitted to the hospital and to capture mother’s perspectives on their participation in Jordan. The study recruited 8 mothers at the pediatric ward in a tertiary metropolitan hospital in Amman. The results showed that parents saw staying with their hospitalised children as an unconditional aspect of being a parent. They left their commitments, family needs and their basic physiological needs to accompany their sick children 24 hours per day and participate in the care.

Researchers have described how caregivers participate in the care of their hospitalised children (Coyne & Cowley, 2007; Espezel & Canam 2003; Pongjaturawit & Harrigan, 2003; Roden, 2005; Tourigny, et al., 2005; Ygge & Arnetz, 2004). Roden

(2005) conducted a study that aimed at examining both parents' and nurses' expectations and attitudes towards parental participation in the care of ill children at a community hospital in Australia using a qualitative research study with 14 parents and two focus group discussions with nurses. The results showed that mothers felt that their role was to do the mothering tasks. Mothers explained that to them mothering meant doing things that they would normally do when at home such as changing nappies, giving fluids, stopping a child from getting out of the cot and pulling out the intravenous line whereas nurses did things such as making sure that the child received the correct amount of medication, did dressing and fixing intravenous fluids. Similarly, Tourigny, et al. (2005) found that in Canada, parents' activities largely consisted of basic mothering tasks like bathing, feeding, changing leaving more technical tasks to nurses.

Mothers viewed technical care as solely the responsibility of the HCWs. This is because HCWs have knowledge and expertise from their training (Coyne & Cowley, 2007; Espezel & Canam, 2003; Pongjaturawit & Harrigan, 2003; Tourigny, et al., 2005). Coyne and Cowley (2007) conducted a study in the United Kingdom aimed at exploring children, parents' and nurses' views on participation in care in the health care setting using grounded theory. Results showed that parents were willing to provide basic child care but generally reluctant to perform technical nursing care. They were anxious about performing the technical nursing care due to their lack of knowledge about medical and nursing matters which could cause harm to their children. In that study, parents viewed technical nursing care as the nurse's responsibility because of their training and expertise. This is contrary to what Pongjaturawit and Harrigan (2003) found in Thailand. They found that caregivers provided both basic care and technical care and they felt confident

and comfortable with all the care they were providing to their children. It was difficult to tell whether or not caregivers of hospitalised children at QECH were confident and comfortable with the care they provided to their children. This was the subject of this research.

Role Negotiation.

Parental participation requires the process of negotiation between HCWs and caregivers which results in shared decisions making about what child care will be and who will provide the care (Corlett & Twycross, 2006). According to Corlett and Twycross, the negotiation of caring roles allows parents to feel in control over what their participation in their children care would be. Role negotiation in care provision is the process in which HCWs discuss with caregivers the level at which caregiver's want to participate in the care of their hospitalised children while in the hospital. This also includes discussing the plan of care for the child (Reeves, et al., 2006). Newton (2000) reported that negotiation in parental participation required an open relationship in which roles could be agreed upon without the individuals involved imposing their expectations onto others. HCWs need to be aware of how they can interact with caregivers and how parental participation can be realistically negotiated from the beginning of their contact with the caregivers (Corlett & Twycross, 2006).

Studies show that HCWs make assumptions that if parents are available in the hospital they would participate in the care of their hospitalised children (Avis & Reardon, 2008; Coyne & Cowley, 2007; Power & Franck, 2008; Ygee & Anertz, 2004). Ygee and Anertz (2004) did a study in Sweden aimed at gaining an understanding of factors that

influence parental involvement and clarifying parental role in care. The study used qualitative methods. They found that nurses took it for granted that if parents were available they would participate in the care. This was also the case even if the child was going for an unpleasant procedure. The parents were never asked whether they wanted to participate or not. In another study by Avis and Reardon (2008) parents expressed that there was an unspoken assumption that parents would be available to assist in their child's care because HCWs were often too busy or understaffed. The nurses were not only busy, but they also seemed to be very hurried or impatient. This may suggest that understaffing could be one of the factors that prevent HCWs to negotiate with HCWs. However, it was difficult to conclude this situation at QECH. This was the subject of this research.

Literature shows that negotiation of care is not routinely planned or conducted but happens in an ad-hoc manner (Corlett & Twycross, 2006). Corlett and Twycross, (2006) conducted a systematic study whose aim was to review research published from 1991 to 2006 about how children's nurses negotiate with parents concerning family-centred care. The results showed that nurses had clear expectations of what activities they felt parents were to be involved in. The study also reported that nurses were in a powerful position to ensure that parents comply with their expectations. In that study, nurses were more comfortable with parents doing basic caring activities such as bathing and feeding but reluctant to relinquish more technical task. Nurses in that study also felt their expectation was appropriate because some parents may not be skilled enough to undertake technical tasks although some parents were willing to undertake technical tasks. However, it was reported that the decision to determine the level of parental participation rested entirely

with the nurses with little or no consultation or negotiation with the caregivers. This may suggest that the nurses control the nature of parental participation. As a result, the caregivers might not have the choice of what activities to be involved in.

Studies have shown that culture influences parental participation (Lam, et al., 2006; Pongjaturawit & Harrigan, 2003; Soderback & Christensson, 2008). In a study from Thailand, Pongjaturawit and Harrigan (2003) explored parental participation in the care of hospitalised children in Thai and western cultures. They conducted a systematic review of 12 articles on parental participation in the care of hospitalised children from 1996-2002. Then research articles were systematically analysed and reported using a qualitative descriptive approach. Although there was a willingness to participate in the care, Western parents always participate by choice, unlike Thai parents. The conclusion was that parents from Eastern cultures have always been expected to play a role in the care of a hospitalised child. In that part of the world parental participation was viewed as a routine expectation.

Similarly, Lam, et al. (2006) conducted a study which aimed at describing the Chinese parents experience in their participation in the care of hospitalised children in Chinese pediatric hospital care. They also compared the cultural differences with Western countries in communication and ways of giving support and ways of seeking care. Results showed that Chinese parents participated in care by choice. The results indicated that even though the caregivers needed support from the HCWs, they often avoided taking an initiative to seek help because they perceived the nurses as always busy and unapproachable. Besides, the parents failed to express the need for communication and support because they believed that the nurses' concern would be focused on the sick

child. The study further reported that the parents avoided conflict to maintain harmony. Similarly, Soderback and Christenssen (2008) did a study in Mozambique in which they found that family caregivers had no choice in participation. The family caregivers did not want to be involved or participate in frightening procedures with the child but preferred to leave that to the staff. However, in those situations, they did not have any choice because of the shortage of staff. This suggests that parental participation was regarded as a means of relieving the hospital staff of their workload. However, this was difficult to generalise the situation at QECH and was a subject for this study.

Communication Between HCWs and Caregivers During Parental Participation

Communication is crucial to effective parental participation in the care of patients in the hospital. Melo et al. (2014) conducted a study in which they wanted to explore the involvement of parents in health care provided to hospitalised children in three hospitals in Portugal using an exploratory design which was based on the conceptual framework of pediatric health care and qualitative analysis. They found that the presence and participation of parents in the care provided to hospitalised children enabled them to draw closer to HCWs, a situation in which communication was the key. Evidence shows that when communication between HCWs and caregivers is good, caregivers experience less anxiety and become more inclined to get involved (Espezel & Canam, 2003). This further encourages their autonomy, treatment adherence and coping process (Melo et al., 2014). Ames, et al. (2011) conducted a study to explore parents' perception of the parental role in Canadian University-affiliated hospital's paediatric intensive care unit (PICU). The study found that caregivers value information and anticipatory guidance on what to

expect in their child recovery to reduce stress, anxiety and sense of helplessness. Parents described how being educated about medical interventions such as intubation, sedation, Opioid use, intravenous lines and chest tubes led to an understanding of their child's appearance and behaviours. This, in turn, helped to moderate their emotional reactions and allowed them to care for their child effectively.

Conversely, poor communication had been a common theme in many studies (Lam, et al., 2006; Hoffman, et al., 2012; Melo, et al., 2014; Roden, 2005; Soderback & Christenssen, 2008; Ygee & Anertz, 2004). Roden (2005) in a study involvement of parents and nurses in the care of acutely ill children in non-specialist paediatric setting reported that mothers were not happy with hospital doctor's communication which was attributed to talking down to the mothers and not providing adequate information. Further to this, the nurses were insensitive, unsympathetic and rude to them. This led to mothers feeling as being a nuisance. Similarly, Lam, et al. (2006) found that there were a few HCWs who were perceived as rude.

Literature also shows that parents lack adequate information about their child condition, treatment plan and what to expect (Ames, et al., 2011; Haskell, et al., 2013; Pongjaturawit & Harrigan 2003; Soderback & Christenssen, 2008; Ygee & Anertz, 2004). Hallstrom, Runeson and Elander (2002) found that parents were unable to participate effectively due to inadequate information or unsatisfactory communication. Similarly, Pongjaturawit and Harrigan (2003) found that caregivers lacked information especially related to child condition, treatment and care needs.

Soderback and Christenson (2008) conducted a cross-section study to articulate family caregivers' expressed needs, expectations and experiences of hospital care and

hospital staff using a questionnaire in Mozambique. The findings showed that the caregivers lacked information before and during admission as well as during the caring process. The caregivers explained that not knowing what will happen to them or their children in the hospital made them feel neglected. They experienced difficulties in understanding and engagement in what was going on regarding the care of their sick children. The participants also indicated that they were not receiving information on the state of the sick child or the cause of the child's death. This made family caregivers feel abandoned.

Studies have shown that parents need information about their children illnesses, treatment plan ongoing basis (Ames, et al., 2011; Shurdy, 2006; Tourigny, et al., 2005; Vasli & Salsali, 2014). Ames, et al. (2011) found that parents wanted to know about their child physiological status and test result, what treatment they are receiving and reasons for the treatment. It can be argued that parents need information and detailed instruction is paramount. Without information about the child's illness and medical needs, parents may feel that they are not in control. Vasli and Salsali (2014) conducted a study to define parents' participation in taking care of hospitalised children which were analysed using the hybrid model in three phases. The first phase literature review, the second phase fieldwork and the last phase combination of literature review and fieldwork. The study recruited 11 nurses who were working in two educational pediatric centres affiliated to Tehran University of medical school. The study found that to achieve trust and mutual patient cooperation there should be mutual communication between HCW and parents. Having a hospitalised child is a great source of stress and anxiety as they face role change. This is when they need help to overcome their role in taking care of their

hospitalised children. This open and mutual communication helps parents to reach peace. Parental participation is impossible without the exchange of information. Access to information about child diagnosis and treatment helps parents to feel in control and secure and adapt to their child hospitalisation and have a greater share in the child's care. Similarly, Hopia, et al. (2005) found that tailoring information according to family needs and situation proved to be important to family wellbeing. Some families were unable to absorb the information initially about their children situation, for some families access to information was the most important means of coping throughout the child's hospitalisation. Little was known on how HCWs and caregivers share information during the care of hospitalised children at QECH. This was a subject for further research.

Haskel, et al. (2013) reported that parents should be able to expect complete and up-to-date information to make informed decisions about care. Medical staff should take time to educate parents objectively about the plan for differential diagnosis, and full options, including the option of comfort care, once a diagnosis has been established. It is helpful to be prepared with written material to help parents understand the child's illness and treatment and to allow sufficient time with the family to answer questions and allay anxiety. Abdelkader, et al. (2013) also found that mothers emphasized that HCWs should take more initiative in reporting the child's condition to them. It was important to keep caregivers informed about everything that concerns the child. However, it was difficult to conclude the situation at QECH. This was a subject of this study

Views of Caregivers Regarding their Participation in Care of Hospitalised Children

It may be concluded from the literature that admission of a child is an agonising experience for both the child and parents. Parents fear for their child's survival, and in a foreign and highly technical environment. Children fear pain, separation from loved ones, strange environment and disruption of their routines (Coyne, 2006). Studies have confirmed that parents desire to participate in the care of their hospitalised children. They feel compelled to be there for the child and being responsible for their child care (Ames, et al., 2011; Coyne & Cowley 2006; Power & Franck, 2008; Ygee & Anertz, 2004). Coyne and Cowley (2007) conducted a study that aimed at exploring parents and nurses' views on participation in health care settings. The data was collected using an in-depth interview with ten parents and twelve nurses from four pediatric wards in two hospitals in England. The findings showed that the parents felt the need to be with their children in the hospital because of the concern for the child's welfare. They justified their presence as an unconditional aspect of being a mother and loving one child. Parents were concerned about their children's emotional welfare and felt that their presence would provide reassurance for their children. Parents emphasized that normalizing the child's emotional welfare would help in a child's recovery from illness. This finding is consistent with the findings of Ames et al. (2011) in Canada. Ames et al found that parents explained that being there was a source of comfort for the child. This meant watching over him, praying with him, talking to him and touching his hand. Roden (2005) found that most parents believed that it was a top priority to be with their child while in the hospital because children need their mothers close to them to cuddle, kiss and reassure them.

Aein, et al. (2009) conducted a study to explore the parents and nurses experience of parental participation in child care in a hospital in Iran. The study used qualitative methods and data was collected using in-depth interview on 14 parents and 11 nurses. The data was analysed using thematic analysis. The results showed that parental presence meets the needs of the child, increases child cooperativeness and decreases behavioural issues. Parents felt that being at the bedside was more imperative but at the same time parents cited not feeling comfortable that nurses would be available for their child constantly due to their heavy workload of the ward. This made them be worried that their children needs may not be met and found their presence essential. This suggests that the caregivers do not have trust and confidence in the HCWs. This situation was difficult to conclude for QECH. This was a subject of this study

Literature has shown that parents feel that their participation in child's care is very important and beneficial to the child, to HCWs and themselves (Abdelkader, et al., 2013; Aein, et al., 2009; Ames, et al., 2011; Coyne & Cowley, 2006; Espezel & Canam 2003; Lam, et al., 2006; Roden, 2005; Tourigny, et al., 2005; Ygee & Anertz 2004). Ames, et al. (2011) conducted a study that aimed at exploring the parents' perception of the parental role in tertiary care at Canadian University affiliated to the pediatric intensive care unit (PICU). The study used descriptive interpretive design using semi-structured interviews with seven mothers. The analysis was done using the constant comparative method. The study found that parents believed that as a parent they had knowledge about the child's nature than the HCWs. As such sharing, that expertise with the HCWs was an important parental role. Parents felt that they shared their child likes and dislikes with the nurse about what would make the child comfortable. Similarly, Just

(2005) conducted a study in which she found that children benefit from contact with their loved ones and also when caregivers form a partnership with the HCWs. When caregivers share their unique knowledge about their children with HCWs and participate in decision making regarding their children's health the child benefit from individually tailored care designed to meet his or her specific needs. Without parental participation, HCWs may not be able to deliver custom made care that truly makes a difference.

Again, parents participate in the care to provide individualised care to their children. Abdelkader, et al. (2013) in their study to describe mothers experience when their children are admitted to the hospital and to capture the mother's perspective of their participation in Jordan. The study used a phenomenological design with 8 mothers at the pediatric ward in a tertiary metropolitan hospital in Amman. The study found that when children were hospitalised their day to daycare needed to be readjusted to fit into the hospital routine such as feeding schedule, bathing. All mothers in that study believed that their child was different from the other so that he or she could not be able to fit into the hospital routine. Moreover, mothers view herself as the only one who knew the emotional, character and behaviour and feared that HCWs might not understand their child's needs. Besides, the mothers' presence was to meet the emotional needs of the children. According to the mothers' narrative children were afraid of the HCWs and regarded them as a symbol of giving the injection. Mothers also wanted to provide a sense of security to their children especially when undergoing for unpleasant procedures such as a collection of blood or insertion of intravenous infusion. Further mothers felt that a caregiver was the first person to notice the change in child condition. As a result, he or she could report to the nurses promptly so that immediate action could be taken.

Although most studies show positive views on parental participation, some literature shows that parents have a negative attitude towards parental participation in the care of hospitalised children. Power and Franck (2008) conducted systemic research in which they wanted to report parent participation in the care of hospitalised children. Twenty-one descriptive studies were reviewed. The studies that were reviewed were conducted in North America, Europe and Australia. The negative feelings include incompetence or a sense of overwhelmed because of a lack of knowledge or skill to participate in the care. Parents were afraid of making mistakes and that the HCWs would disapprove of their participation. Furthermore, parents who took on technical care felt overburdened because nurses assumed that they would do the majority of care for their child without negotiation. Specifically, parents felt unhappy when they thought that nurses expected them to participate in painful procedures without their choice. These findings are similar to what Pongjaturawit and Harrigan (2003) found in Thailand. Thai parents expressed the feeling of stress, anxiety, discomfort. The additional concerns included being afraid of making mistakes and feeling that the nurses could do a better job. Studies on perceptions of caregivers on parental participation in the care of hospitalised children in Malawi have received little attention, thus research was needed to understand how the phenomena are perceived by caregivers.

Summary of Literature Review

Literature has shown that parental participation is considered a practice by caregivers. Studies have described how caregivers participate in the care of their hospitalised children. The activities include both basic and technical. However, it has

been shown that caregivers are more reluctant to do the technical task because of their lack of knowledge and skills. In turn, they want to leave these activities for the HCWs. However, situations such as a shortage of staff cause parents to have no choice but to participate in those activities.

It has been documented in the literature that some caregivers participate in care without negotiation. HCWs assume that if parents are available in the ward they will participate in the care. It has also been reviewed that culture influences how parents participate in care. In other cultures, caregivers participate by choice, unlike others. In a culture where they do not participate by choice, it is taken as a routine expectation that caregivers should participate in the care. However, parents experience lack of information regarding their childrens' status. This may pose a challenge in how caregivers participate in the care.

Parents' views on parental participation seem to be positive in most of the studies. Parents feel compelled to be with their children at the hospital because children want their parents near them. In addition, parents feel that their presence as a means of providing comfort to the child in the form of cuddling, kissing and providing reassurance. Conversely, there were other studies in which caregivers had feelings of stress, anxiety and afraid of making mistakes as they were providing the care. They also had a feeling that the HCWs could do a better job because of their knowledge and expertise.

CHAPTER 3

Methodology

Introduction

This section describes the methodology that was followed when conducting this research. It contains study design, study setting, study population sampling method, sample size inclusion criteria, pretesting of data correction tool, data correction method, data management, data analysis, the trustworthiness of data and ethical consideration.

Study Design

This study used a descriptive qualitative design to explore perceptions of caregivers on parental participation in the care of hospitalised children at QECH. According to Burns and Grove (2005), qualitative research is a systematic research approach to describe life experiences and give them meaning. In this study, the researcher collected information from caregivers about how they were prepared for their role and how the information of hospitalised children was shared between HCWs and caregivers and caregivers perceptions regarding their participation in the care of hospitalized children. The caregivers were interviewed using a semi-structured interview guide with probes.

Study Setting

The study setting is the physical location where individuals live, experience life and where the data collection takes place (Polit & Beck, 2010). The study was done at Queen Elizabeth Central Hospital (QECH), pediatric department. QECH serves as a

referral hospital for children and adults with varying conditions across Malawi. The pediatric department at QECH is composed of seven sections namely: Pediatric Special Care, Surgical, Orthopedic, Oncology, Medical, Nursery and Nutrition Rehabilitation Unit. The setting was chosen because it is a place where children with complicated conditions are admitted and they stay in the hospital for more than one day. This implies that caregivers of these children had some experiences with hospitalisation and participation in care which the researcher wanted to explore.

Study Population

A study population is defined as the entire population in which the researcher would generalise the results (Polit & Beck, 2010). The target population in this study was caregivers who were taking care of children admitted to all sections of the pediatric department at QECH to have a broader understanding of caregivers' perceptions regarding their participation in the care of hospitalised children.

Sampling Method

Sampling is defined as the process of selecting a portion or subset of the designated population to represents the entire population (Wood & Haber, 2006). Purposive sampling was used to recruit participants for this study based on the inclusion criteria. The participants were selected because they were knowledgeable and had the experience of the phenomena under study. The researcher believed that the participants with the characteristics described in the inclusion criteria would contribute to the

information needs of the study. All caregivers who met the inclusion criteria had a chance to participate in the study.

Sample Size

A sample is part of the targeted population comprising of individuals that represent the characteristics of the target population (Burns & Grove, 2009). Twenty caregivers were recruited and interviewed. Holloway and Wheeler (2002) indicate that in qualitative studies a sample of ten or less is adequate especially when the researcher is using homogenous participants. Nevertheless, the sample may increase or decrease depending on data saturation. In this study, data saturation was reached during an interview with the 20th participant.

Inclusion Criteria

The inclusion criteria included the following:

- Caregivers who spent more than 48 hours in the hospital with the child and the child condition was stable
- The participants volunteered to participate in the study and were able to communicate in Chichewa.

Pre-Testing of Data Collection Instrument

The pretesting of the interview guide was done with five caregivers at Kamuzu Central Hospital in Lilongwe after seeking approval from authorities (Appendix I). KCH is the main referral hospital in the central region. This pre-testing setting was therefore

much similar to the actual study setting, QECH. After pretesting objectives and the interview guide were modified to suit the study direction.

Data Collection methods

Data collection tool

Data was collected using face to face in-depth interview with the aid of the semi-structured interview guide (Appendix A & D). The researcher used a semi-structured interview guide because she wanted to be sure that the area under study was well covered (Burn & Grove, 2005). According to Polit and Beck (2010) using a semi-structured interview guide, the researcher has questions to ask but cannot predict the answers. In this view, the developed open-ended questions with probes to obtain more information from the participants about the phenomena under study. The interview guide was formulated in English then translated to Chichewa the language that the majority of Malawians can speak. The interview guide contained two sections namely demographic data for caregivers and interview guide for the qualitative data (Appendix A & D). Section A contained demographic information such as age, gender, level of education, relationship with the child and religion of participants. Section B contained qualitative information. The variables under examination were guided by the study objectives. Data were collected on the care the caregivers provided to their children. Further, the interview guide sought information on how the caring roles were negotiated between the HCWs and caregivers and how the caregivers were prepared for their role. Additionally, the guide has sought information on how the caregivers perceived their participation in the care of hospitalised children. The questions that were included were on benefits of

caregiver's participation, caregivers' needs and how appropriate was their participation in the care of hospitalised children. Probes were also used to prompt the participants to give adequate information that was needed on their perception regarding their participation in the care of their children.

Data collection procedure

The researcher started data collection after obtaining ethical approval from COMREC. The researcher then obtained permission to start data collection from the hospital director of QECH. Following that, the researcher reported to the head of the pediatric department section and the Chief Nursing Officer of the pediatric department. The researcher also reported to the Unit Nursing Officers to make the personal introduction and explain the intention to start data collection. The Unit Nursing Officers introduced the researcher toward in-charges of each department. After briefing the ward in-charges about the study and its aim, the in-charges introduced the researcher to nurses and caregivers and gave the researcher a go-ahead to look into the files and select the potential participants. The researcher checked the files of the patients in the nurses' office and if the owner of the file meets the inclusion criteria, the researcher would go to the bedside to introduce herself, confirm the child's name and do a quick assessment of the child condition. Then the identified participants were given a full explanation of the study (Appendix B & E). Those who consented were asked to sign a consent form (Appendix C & F). Consent was also obtained from the participants to have the interview tape-recorded. Data was tape-recorded using the voice recorder. Each interview took 45 minutes.

Data Management

The researcher was the in-charge of all written and tape-recorded information from the interviews. Data collection and analysis were done simultaneously to identify the point of data saturation. At the end of each interview, the researcher would listen to the tape-recorded information to check that the data collected was relevant. Besides the data was checked for accuracy and completeness. The recorded data were then transferred and stored on the computer. Following this, the data was then transcribed word by word in Chichewa. The researcher then proofread the written transcripts against the recorded information simultaneously to avoid distortion of data. Then the researcher translated data into English. Later on, an independent person translated the English version back to Chichewa to ensure that the original information was not lost. Throughout the study, the transcripts, written field notes and tape-recorded data were kept under a lockable cupboard for safety. On the other hand, the electronic data were assigned a password that was only accessible to the researcher. The audio recorded data and transcripts will be kept for five years after which data will be erased from the recording devices and hard copies incinerated.

Data analysis

Demographic data were analysed using descriptive statistics. Qualitative data were analysed using the Colaizzi method of analysing data. Colaizzi method has seven steps which are reviewing the data, extracting significant statements, spelling out the meaning of each significant statement, organizing the formulated meanings into the

cluster of themes, integrating results into an exhaustive description of the phenomenon under study, extraction of fundamental structures and member checking.

Stage 1: Reviewing the raw data.

The process started immediately after each interview whereby the researcher listened to audiotaped information to verify if all important information had been captured. Then the audiotaped data were transcribed verbatim and all textual data were read line by line. Since the interview was done in Chichewa it was then translated to English and then an independent person translated back to Chichewa to ensure that the meaning was not lost. Each transcript was read and re-read to have a general sense of the whole content

Stage 2: Extracting significant statements.

There was a lot of data that was obtained however the researcher tried to condense the data to have the more significant data that was related to the phenomenon under study to extract significant statements. For each transcript, significant statements were extracted. These statements were written on separate sheets of paper. This stage was undertaken after all the interviews were completed.

Stage 3: Spelling out the meaning from extracted statements.

The researcher revisited the significant statements from each participant and put them in context. Meanings were formulated from those extracted significant statements.

Each underlying meaning was coded with one category as they reflect an exhaustive description.

Stage 4: Organizing the formulated meanings into a cluster of themes.

The researcher grouped all the formulated meanings into categories that reflected a unique cluster of themes. Each cluster of the theme was coded to include all the formulated meanings related to that group of meanings. After that, the group of clusters of themes that reflected a particular issue were incorporated together to form a distinct construct of a theme.

Stage 5: Integration of results into an exhaustive description of the phenomena under study

All the emergent themes were defined as an exhaustive description. After merging the entire theme the whole structure of the phenomena was extracted. During the report writing the researcher supported each theme with the statements from the interviews that reflected participant's feelings and ideas on a particular theme.

Stage 6: Identifying fundamental structures.

At this stage, the researcher removed redundant or misused descriptions from the overall structure to emphasize only on fundamental structure. Lastly, the researcher organized the results so that they flow logically and make sense.

Stage 7: Member checking.

This stage aimed at validating the findings using the member checking technique. This stage required the researcher to go back to the participants to check if the results truly reflected what they said. However, in this study, this was done after each interview knowing that it would have been impossible for the researcher to take back the findings to the participant.

Trustworthiness of Data

Trustworthiness can be measured using many ways. In this study, the researcher used the framework that was developed by Lincoln and Guba (1985) which used credibility, dependability, confirmability and transferability as standards for measuring trustworthiness.

Credibility.

According to Guba and Lincoln credibility refers to confidence in the truth of the data and interpretation of them (Polit & Beck, 2007). Several steps were taken to ensure credibility. Firstly the tool was pretested to check if the information that it will solicit will be the intended one before the actual study. This allowed the researcher to modify the objectives and data collection tool.

An in-depth interview was used to obtain a real understanding of the study. The researcher also used prolonged engagement with the participant to have an in-depth understanding of the caregivers' perceptions to achieve the purpose of the study and to test misinformation and distortions. Open-ended questions were used during data

collection using the questions which were relevant to the study to allow the participants to give as much information as possible. Probes were also used to prompt the participants to give relevant and true information. After each interview, the researcher summarized the information and checked with the participants to verify what they said. Direct quotes from the participants have been used to anchor the report.

Dependability.

In the framework, Guba & Lincoln dependability is the stability of the data over time and conditions. It is also a way of checking whether all methods and decisions are documented in the audit trail (Polit & Beck, 2007). It aims at ensuring that the study findings should be replicated with the same participants in the same context. The researcher had documented methodology step by step so that other researchers may repeat the process and produce a similar finding in the same context. The verbatim quotes from the participants were used to ensure the authenticity of the findings. The field notes and transcripts were prepared using standardized methods.

Confirmability.

According to Guba and Lincoln, Confirmability is a means of checking whether the findings are grounded in the data. The criterion is concerned with establishing that the data represents the information that the participants provided and that the interpretations are not figments of the researchers' imagination (Polit & Beck, 2007). In this study, the researcher tape-recorded the interview and replayed them to the participants. She used the responses from the participants in her report and kept the records of the transcribed data.

The researcher supervisor reviewed the transcripts and findings to check for objectivity and to determine if the conclusion is supported by data (Polit & Beck, 2010). Besides, the researcher used the participant's narrations to reflect the participant's voice.

Transferability

In Guba and Lincoln, transferability is a means of checking whether findings are transferable to other setting given an adequate description of the context. To ensure transferability, the researcher ensured the correct selection of participants to present viewpoint and experiences that reflect key issues in the research problem. Additionally, the researcher has provided sufficient descriptive information of the participants and their perception to reflect what is happening on the ground. The findings and recommendations will be given to the hospital management and head of the pediatric department so that they can evaluate the findings and the recommendations with what is on the ground to see if the findings can be generalised. Since this study captured caregivers from all the sections of the pediatric department, the findings can be generalised to the entire pediatric department.

Ethical Consideration

The researcher ensured that participants' human rights were respected throughout the research process: the right to self-determination, anonymity, privacy, confidentiality and protection from harm. The proposal was presented to the College of Medicine Research and Ethics Committee (COMREC) through Kamuzu College of Nursing (KCN) for ethical approval (Appendix J). Furthermore, permission to conduct a study at the

pediatric department of QECH was obtained from the hospital director (Appendix G) and Head of the Paediatrics Department (Appendix I).

During the actual data collection, all caregivers were given an equal opportunity to participate in this study using the chosen sampling technique. There was no discrimination in terms of sex, religion, age, race or any other parameters not mentioned in the inclusion criteria. No one was forced or coerced into the study. Informed consent was obtained from each participant (Appendix C & F). Obtaining informed consent was essential for the conduct of ethical research and a prerequisite for all research involving identifiable subjects (Burns & Groove, 2009; Speziale & Carpenter, 2007). The details of the study were explained clearly to the participants before obtaining the consent (Appendix B & E). The participants were given information about the study and their participation. Participants were informed about their right to participate or withdraw and that no penalties were attached to such decisions (Appendix).

Participants were informed that there were no direct benefits for their participation in the study however the study findings might assist in improving how PP was being implemented in future patients. Furthermore, the participants were informed that there was no direct physical harm in participating in the study however they may have psychological fear that they may be known and may not feel comfortable to answer some questions they may not feel comfortable. The participants were assured that information was confidential and that no health care workers would know what they said. Furthermore, the interview was conducted in a private room within the ward to ensure participants privacy. No names and identifiable data were used throughout the data collection and analysis of the findings instead serial number was used. A tape recorder,

field notes as well as transcripts were kept in a lockable cupboard only accessible to the researcher. The electronic data were secured with the password on the researcher's laptop.

CHAPTER 4

Presentation of Findings

Introduction

This chapter presents the findings of a study that aimed at investigating the perceptions of caregivers regarding their participation in the care of hospitalised children. The specific objectives of the study were to: Describe how caring roles are negotiated between the HCWs and caregivers caring for their hospitalised children, describe the care caregivers provide to their hospitalised children, describe how information about hospitalised children is shared between HCWs and the caregivers and determine views of the caregiver's regarding their participation in the care of their hospitalised children.

The findings are in two sections. The first part contains demographic information of 20 caregivers who were recruited from all sections of the pediatric department at Queen Elizabeth Central Hospital. The caregivers had stayed in the wards for a minimum of 3 days to a maximum of 6months. The second part presents the analysis of qualitative data which were obtained through in-depth interviews using a semi-structured interview guide. From the analysis, seven themes emerged. Direct quotes from participants have been used to illustrate what was said. Of importance to note was that caregivers used the term “doctors” and “nurses” to refer to any health care worker. As such, there is no segregation of health care workers in regards to cadres and profession. No names have been used instead the participants have been identified using serial numbers which were assigned to them during the interview.

Demographic Characteristics of Participants

Table 1 presents demographic information of 20 caregivers who participated in this study. The table shows that most of the caregivers were female with the age ranging from 21 to 43 years. Half of the participants (n=10) had attended secondary education. In regards to the relationship with the children, the majority (n=16) of the participants were biological mothers and a few (n=3) were fathers and one aunt. Almost all participants were Christians (n=19).

Table 1: Demographic information of caregivers who participated in the study

Characteristic	N
Age in Years	
20-24	4
25-29	6
30-34	3
35-39	4
40-43	3
Gender	
Male	3
Female	17
Level of Education	
None	1
Primary	8
Secondary Education	10
College Education	1
Relationship to the sick child	
Mother	16
Father	3
Aunt	1
Religion	
Christian	19
Moslem	1

Results from Qualitative Data

The qualitative data were analysed using thematic content analysis (TCA) which was guided by the Colaizzi method and the main themes that emerged were: (1) Lack of role negotiation by HCWs, (2) inadequate role preparation for caregivers, (3) care given by caregivers on their hospitalised children, (4) poor HCWs-Caregivers communication, (5) benefits of parental participation in the care of hospitalised children, (6) needs of caregivers participating in the care of hospitalised children and (7) overall impression of caregivers' on their participation in the care of hospitalised children. These themes have been described in the sections that follow.

How Caring Roles were negotiated between HCWS and Caregivers Caring for their Children

The first objective captured information on how the HCWs negotiated the caring roles with the caregivers. Participants were first asked to explain whether the caregiving roles were negotiated by HCWs or not. Finally, the participants were asked to explain how HCWs prepared them for their role. Two themes came out of this objective. These were: lack of role negotiation by HCWs and inadequate role preparation for the caregivers

Lack of Role Negotiation by Health Care Workers

The results showed that the majority of participants (n=16) were not consulted on caring roles. The HCWs assumed that every caregiver would take care of his or her child. One participant said: "They (HCWs) already know that every guardian is supposed to

take care of his or her own child” (Participant # 19). Some participants (n=4) indicated that they were told by HCWs that they were supposed to be taking care of their hospitalised children. They were given the tasks that they needed to be doing on their children such as encouraging them to eat or take the medication in case the child was refusing without discussing with them. One participant said:

A Doctor (HCW) told me that I am supposed to take care of the childlike a parent by doing the activities for the child such as encouraging the child to eat when is refusing and encouraging the child to take medication if the child is refusing so that the child should get better fast (Participant # 3

These participants said that they did everything for their children because they were not given the choice of activities. They also reported that when they refused to do some of the care, HCWs stopped paying attention to them. This was illustrated by one participant in this way:

We (caregivers) do everything that we are asked to do because if we refuse sometimes the nurses tell us that it is our child so we are supposed to take care of him or her ourselves. It’s my responsibility to take care of him.....if we refuse to do what they have asked us to do sometimes they stop paying attention to us they say we are troublesome (Participant # 5).

Two other participants indicated that they were told to observe what fellow caregivers were doing in regards to what activities to do for their children while in the hospital. As such they just followed what other caregivers were doing because they had found them already doing the same things like feeding, giving medication. One participant said:

They told me that you will see what your friends are doing.... Some of the things that they said are that when it is in the morning you should go to receive the porridge and give the child, in the afternoon when you receive food to give him but if you have maize flour or other things you can go to the guardians' kitchen to cook the food and give the child. You will see what your fellow mothers are doing for their children or you may ask them to tell you (Participant # 8).

Inadequate Role Preparation for Caregivers by Health Care Workers

Most of the participants (n=13) said that they were not prepared for their role and the HCWs did not teach them how to carry out various tasks on their sick children more commonly the basic task. They reported that HCWs assumed that everyone knew how to carry them out. One participant said: “We did not discuss anything that I know is that they just come and ask me how the child is this morning and give us medication that’s all” (Participant # 7)

Other participants (n=3) indicated that it would have been better for them if they were prepared for their role from admission because they were in a strange environment. Their role automatically changed from a mother to a guardian. However, they mentioned that HCWs did not pay attention to this fact. One participant said: “I did not know where to get things for my child care. I relied on my fellow mothers for guidance. Being in a strange environment changed my role of a mother to a guardian” (Participant # 1). The participants reported that role preparation would enable the caregivers to know how to take care of their children. The participants said that this would have enabled them to provide the care properly and would have prevented them from making mistakes.

Furthermore, caregivers were afraid to do some of the things because they were not sure whether the HCWs would be happy with what they were doing or not. One participant illustrated this: “It is good for us to be prepared because we should know how to take care of the child as a patient” (Participant # #).

Another participant said:

It is the responsibility of the doctors to prepare us caregivers on how we can care for our patients because when they prepare us we know that what we want to do the HCWs will be happy with that. If we are taking care of the child in our ways sometimes it may be possible that we are afraid that may be what we are doing may be the doctors may not be happy with. They may shout at us (Participant # 9).

However, there were other participants (n=7) who said that they were informed how to carry out various tasks but this was only done when the caregivers wanted them to carry out those tasks more especially the technical tasks such as drug administration, feeding through the nasogastric tube and doing passive exercise for the child. One participant said

I was told that the shunt that they inserted on the child, I should not let him sleep on that side because the wound has not healed but also I should protect him well on the wound, water should not enter. I was also told that I should not put him to sleep on the wound site because if I let him lie on that side may experience pain. So I also put him to sleep slowly so that should not feel pain. When the wound got healed they also told me to let him lie on that side. They explained how I should

do it. They also taught me how to feed the child through the nasogastric tube (Participant # 6).

Description of the Care Caregivers Provide to Their Hospitalised Children

The second objective captured information on the care that the caregivers provided to their hospitalised children. The participants were asked to describe the activities which they did for their children. They were further asked to explain why they were doing those tasks for their children. One theme that came out of this objective was the care given by caregivers to their hospitalised children.

Care Given by Caregivers to their Hospitalised Children

This theme was characterised by caregivers describing the care and tasks they performed when caring for their hospitalised children. Three subthemes emerged under this theme as follows: Basic care, technical care and caregivers' reasons for taking up the caring roles.

Basic care

All participants mentioned that they bathed their children, wiped them, washed clothes for them, cleaned the place where the children were sleeping, changed them whenever they had soiled themselves, fed their children at mealtimes and took the children to the toilet. There were other participants (n=2) who mentioned that they did whatever the child wanted to make him/her happy and allay anxiety by chatting with the

child, reading stories, playing with him/her on the see-saw. For example, one male participant explained:

I don't go far from him when he wants to go out to play, I take him to the see-saw, putting him on my back some times, walking around with him, playing with him, I try to make him happy so that should forget his illness (Participant # 4)

Technical care

The results show that participants were involved in the technical care that was meant to be done by the HCWs. Almost all the participants (n=19) mentioned that they were involved in the administration of oral medication. Some tasks included escorting their children to the X-ray department, simple wound dressing, collecting urine specimen, feeding children through the nasogastric tube (NGT) and doing a passive range of motion exercises for their children. Besides, they said that they monitored the child's condition and progress and informed the HCWs about change in the child condition. A few others (n=4) indicated that they were told to hold the child when the HCWs were putting up the intravenous line (IV), NGT and injecting (Intramuscular injection) the child with the medication. Besides, they said that they were also told to support the child arm when the IV infusion was running so that the cannula did not dislodge. They also said that they monitored the intravenous fluids by checking whether it was flowing or had finished and reported to the HCWs. However, the participants said that some of these technical tasks were the HCWs responsibility like wound dressing. One participant said:

But some of these tasks that they give us are supposed to be done by the “nurses”.
However, we don’t refuse because they shout at us that it is what we are here for yet I came here to find help from them (Participant # 5).

Reasons for taking up the caring roles

The main areas that came out under this subtheme were: Parental responsibility and child reliance on the parent.

Parental responsibility

Most participants (n=14) reported that they were doing the tasks for their hospitalised children because they felt responsible for their child’s care. They further said that it was their child and that there was a need for them to be taking care of the child whilst in the hospital. They also said that every caregiver was responsible for his or her child care as was expressed by one participant: “It is my responsibility.....there is no one who can take part in taking care of my child because the child is mine and everyone takes care of his or her child in this ward” (Participant 20). Besides participant’s said that the HCWs were not doing some of the tasks for the children mostly basic care like bathing, changing children when soiled, feeding and most of the care was done by the caregivers. The participants said that this was because HCWs had a lot of tasks. After all, children were many in the ward, so it was the caregivers’ responsibility to see that most of the care was done by themselves on their children. One participant said: “There is no one who can care for him and the nurses do not always like bathing the children and most of the times the patients are cared for by their guardians” (Participant 2). Another participant said:

“Nurses have a lot of tasks to do and it is my responsibility to see that everything has been done on this child” (Participant # 5).

Children reliance on caregivers

A few participants (n=4) indicated that children could not manage to care for themselves because they were too sick or too young. They relied on their parents (caregivers) to take care of them. One participant illustrated this:

The child relies on you as a parent like a person who can take care of him. That is why I saw that when the child was sick there was the need for me as a parent that I should take part in caring for him (Participant # 9)

How Information about Children is Shared between HCWs and Caregivers

The third objective was to describe how information was shared between caregivers and HCWs. The caregivers were asked how HCWs passed information to them, what type of information they received from the HCWs and how the HCWs talked to them. One theme that came out of this objective was poor HCWs-Caregivers communication.

Poor HCW-Caregivers communication

Under this theme, three sub-themes emerged namely: Mode of communication, inadequate information from HCWs and manner of communication.

Mode of communication

The majority of respondents (n=19) indicated that communication was largely verbal and was done in Chichewa. Some caregivers needed written information concerning their children illnesses but were not available. One participant said:

When they want to give us the information they do explain it to us. They have never given us any written materials on disease conditions so that we can read. This would have helped us to understand what is happening to our children that because sometimes when we are seeing them face to face we fail to ask them questions because we are shy or are in a hurry (Participant # 6).

Some participants (n=5) said that other HCWs wrote the information in the patients' case notes. These participants said that the HCWs only explained if they had been asked by caregivers for the information that has been written in the case note. This was illustrated by one participant who said: “Some HCWs write in the file. They only explain to me if I ask them. If I don’t ask them, they don’t tell me” (Participant # 14).

Inadequate information from HCWs

Two categories emerged from this subtheme namely: Incomplete information about child diagnosis and incomplete information about the child treatment plan.

Incomplete information about child diagnosis

The majority (n=17) of the participants reported that they were given incomplete information about their childrens’ illness. They were told by the HCW diagnosis of the

child but the HCWs did not explain to them what it was, the cause of the illness and the possible complications. For example, one participant said, “I was told that the child has cancer but they did not explain to me what cancer is” (Participant 3). A few participants (n=3) complained that they were never told about their childrens’ diagnosis. They attributed this to the fact that HCWs were always busy and in a hurry at all times. It was reported that the HCWs did not spend much time with caregivers so that they could see other patients. One participant said: “We did not discuss my child’s illness because when they come they do not spend much time. They do ward round and do things in a hurry so that they should also see other patients” (Participant # 6).

Incomplete information about the child treatment plan

Similar to information on childrens’ diagnosis all participants (n=20) reported that they received incomplete information about their children treatment. They said that they were told the treatment that the children received but not detailed. For example, the HCWs told the caregiver that the child is on medication, he or she is not told the name of the medication, mode of action, side effects, duration and frequency. One participant said:

I was not told the names of drugs that the child is on, the times for the medication. I go every time the nurse is calling caregivers to receive their childrens’ medication only to be told that the child has no medication at that particular time and that will receive medication at another time (Participant # 10).

The only exception was for caregivers from the oncology department who were told the frequency, duration and side effects. One participant said:

I was told that the child will be receiving the medication. They did not tell me the names but they said that will be taking three times a day another one five times and will take them for the whole year. They said that the medication that the child is taking is very powerful and the child may fall very sick, may develop alopecia and these are the things that are happening to my child. That is all that but they did not tell me what to do if the child develops this. I hope I should be coming to the hospital (Participant # 2).

The manner of communication by HCWs

Three categories emerged under this subtheme. These were: appropriate communication, inappropriate communication and communication without privacy.

Appropriate communication

The majority of participants (n=13) said that some HCWs talked to them calmly, nicely with respect. They said that these HCWs did not shout at them. These “nurses” or the “doctors” were not insulting. One participant said: “HCWs talked to us peacefully and calmly realizing that they are talking to other human beings” (Participant # 12). The participants said that when the caregivers had made a mistake the HCWs corrected them and advised them with respect without shouting at them. This was viewed as an appropriate way of communication by the participants. One participant illustrated this way: “They talk to us nicely... There are some who are nice when you make a mistake, they say that is not good you could have done this, they say this with respect” (Participant # 9).

Inappropriate communication

The other participants (n=7) said that some HCWs talked to caregivers inappropriately. These HCWs were insulting such that when the caregivers had made a mistake they shouted at them. Besides these HCWs talked rudely to caregivers which made the caregivers fear them. It was reported that these HCWs called the caregivers names and used inappropriate words on them like mad man, stupid, people who do not think properly. For example, one participant who was insulted by the nurses was a male caregiver. “He said: I was called a mad man who does not think properly by the nurse. She was shouting that everyone heard her. This made me feel shy because she was talking in front of many caregivers both male and female” (Participant 9). Nevertheless, one participant tried to justify why HCWs shouted at them. She said these HCWs only shouted when they saw that there was a problem. She said this:

Other HCWs do shout yes but one cannot just shout without any problem. If one does not understand what they are saying you can see them as if they are shouting because some are difficult. If you don’t understand what they are saying when they tell you to give the child medication at such a time and you give it your own time when they call you to receive the medication you are not going at that time you see them as difficult and bad if they shout at you (Participant # 19).

Communication without privacy

Almost all the participants (n=19) indicated that the HCWs communicated information to them during ward rounds at the bedside where there was no privacy. The HCWs gave them information about their children openly where everybody could hear. They said that at times caregivers failed to ask questions because they did not want other

caregivers to know their problem. One participant said: “a doctor explained to me concerning my child after they had examined him but there was no privacy. He was just explaining that we have found such a problem on the child” (Participant # b1).

Views of Caregivers on their Participation in Caring for their Hospitalised Children

This objective captured information on how caregivers perceived their participation in the care of hospitalised children. They were asked to explain what they viewed were the benefits of their participation in the care. They were further asked what were the things that they needed while in the hospital in regards to their participation in the care of their hospitalised children. The participants were asked about the appropriateness of their participation in the care. Finally, they were asked to explain whether they were satisfied with the level of their participation in the care of their hospitalized children. Three themes emerged under this objective. These were: benefits of caregivers’ participation in the care of hospitalised children, caregivers’ needs when caring for their hospitalised children and overall impression of caregivers’ participation in care.

Benefits of caregivers participating in the care of hospitalised children

Five subthemes emerged under this theme. These were: caregiver’s knowledge of child condition, meeting the medical and physical needs of the child, meeting

psychosocial needs of the child, relieving the HCWs of their tasks and provision of information to the HCWs.

Caregiver's knowledge of the child's condition

A few participants (4) indicated that when they participated in the care, they knew their child illness better although it was not detailed except for those who had asked the HCWs for details. One participant said:

I learnt a lot from the HCWs about my child illness since I was able to ask the question and were answered. This enabled me to understand what was happening to my child when the HCWs were giving treatment to him (Participant # 12).

These participants felt that knowledge of their children's illness would help them after the child is discharged from the hospital. One participant said,

I came to the hospital for assistance here and the HCWs could not follow me home after discharge. With the knowledge I have gained I will not have problems to care for my child at home. I learnt a lot from the HCWs during my participation.... For example, I was taught how to give medication to the child which I might also do at home (Participant # 16).

Meeting medical and physical needs of the child

Under this subtheme, two categories emerged. These were the provision of comprehensive care and the provision of attention to the child.

Provision of comprehensives and individualised care to children

Some participants (n=10) said that their participation ensured that children received comprehensive and individualised care. Firstly, they ensured that the child had received medical care so that he or she should get better and be discharged home. One participant said: “When the HCWs had forgotten to give the child medication, I would remind him or her (Participant 17). Secondly, they made sure that their children basic needs have been met like bathing, eating, elimination and making sure that children slept in a good place. One participant said:

The HCWs do not do most of the basic things for the children. These things are done mostly by caregivers. For example, the child may have diarrhoea so it is the caregiver who cleans the child and washes for him or her, the HCWs do not clean them (Participant # 15).

Provision of attention to the child

Two participants said that the HCWs did not pay attention to the children. If they wanted to give children medication, they did not take time to make sure that children had taken the medication. They just forced them to take the medication or at times they left medication at the bedside. One participant said:

If I give the child medication myself, can know whether the child has taken the medication or not while them (HCWs) just come giving the child medication forcefully. It is good that they should take the medication I should give him myself because they can take and give him violently or they may just leave it on the bedside without knowing whether the child has taken the medication or not.

Yet if I take the medication to give him, I will take my time till the child takes the medication ... HCWs don't have time for the children (Participant # 18).

Meeting psychosocial needs of the child

Other participants (n=3) reported that they cheered their children so that the child should not be in pains. They also played with them and also comforted them during the painful procedures. These participants said that they also showed love to their children by not abusing them. They said that some HCWs were abusing the children by shouting at them if they had done something that was not pleasing to them but a parent (caregiver) talked to the child with love without shouting at him/her. They said that this made the children realise that their parents loved them as they were taking good care of them during the time of illness. This was illustrated by one participant who said: "HCWs do shout at our children when they have done something bad. They abuse them. We parents handle them with love because they are our children" (Participant # 15).

Relieving HCWs of their tasks

Some participants (8) reported that parental participation also benefits the HCWs. HCWs had a lot of tasks to complete for many patients. This made them (HCWs) fail to attend to every child one by one and carry out all the necessary care. The participants reported that the HCWs delegated some of the technical tasks such as collecting urine specimen to caregivers so that things are done fast and on time. In this regard, the HCWS were helped with the tasks that they were otherwise supposed to do. One participant said:

We help the busy HCWs who have a lot of tasks because what they could have done we do them, for instance, if the child is supposed to give urine specimen the nurses just give us the bottle and we collect the urine ourselves (Participant # 20).

Provision of information to the HCWs

Some participants (n=4) said that they were informing the HCWs of any problem that they noticed on their children or change in the child's condition. This enabled the HCWs to come fast and assess the child properly. It was reported that in this way their children received timely treatment. One participant said:

The child gets treatment fast and gets better early for example if the child condition has changed, I can inform the HCWs early and they come immediately to assess the child and give him or her the treatment that the child needs (Participant # 20).

Needs of the Caregivers regarding their Participation in Care of their Hospitalised Children

This theme was characterised by participants describing the needs which they expected to be met during their stay in the hospital. Three subthemes came out under this theme which was the need for information, need for supervision and need for material support.

Need for information

Two categories emerged under this subtheme namely: Information about child condition and information about how to care for children.

Information about child condition

Some participants (n=3) reported that they needed the HCWs to give them comprehensive information about their children illness for them to participate in the care of their children effectively. They explained that the HCWs were supposed to tell them everything that was happening to their children. They further said that this should have been ongoing as they also wanted to know the progress of their children. One participant said: “They should give us information about our children illness now and then” (Participant # 13). Another participant said: “When there is a problem there should be nothing to hide they are supposed to reveal everything that is happening to my child....I do not see them being free sometimes” (Participant # 12).

Information about how to take care of children

Other participants (n=5) said that HCWs should give them proper information so that they should participate effectively. They said that they needed advice on how they could have taken care of their children whilst in the hospital in particular how to carry out various tasks. For example, one participant said: “I needed information on what I was supposed to be doing as was taking care of my hospitalised child from the time I arrived. This could have enabled me to take care of my child properly” (Participant 1). Another participant said:

I needed to be prepared for my role as the caregiver. The HCWs gave me some of the tasks to do which I did not know how to do it. It is the HCWs who know their training. They needed to transfer that knowledge to me so that I should have

carried out the task that they gave me properly like collecting the urine specimen (Participant # 4).

Need for supervision

Some participants (n=6) said that they wanted to be supervised by the HCWs on the task and the care they were providing to their children. The participants said that most of the care was done by the caregiver so they expected the HCWs to come and see how the care was being provided to the children to prevent or correct mistakes at the same time giving correct instruction. One participant said:

“When the HCW has given me tasks they should have come to see if what I am doing is right. When the HCWs gave me the task to do they did not come back to see how I have done it. I expected them to come and see how I have done it (Participant # 4).

Besides the participants said that they needed the HCWs to supervise them because they had observed some caregivers who could not provide some of the care to their children. One participant said:

They should come to see how we are caring for our children....they do not come visiting us that they should see how we are carrying out the tasks like has the child taken medication because other mothers keep the medication at the side when the child is refusing. They should supervise and instruct us so that we should be able to do the way they want us to do it (Participant # 11).

Need for material support

The majority of the participants (16) indicated that the HCWs did not provide them with the materials for use when caring for their children. They indicated that it could have been appropriate if they were provided with the necessary materials (resources) that they could have used when caring for their children. They mentioned things like soap, bathing basins, cups, plates that they needed most. They further said that some of the caregivers came from far and others were poor who could not manage to bring all the necessary resources. They further said that others stayed in the hospital for a long time and run short of necessary material so they needed to be provided with these things. One participant illustrated this way:

They should have the cups that the children should use when taking the medication. Some of the people come here referred from far hospitals so it may be possible that they come to the hospital with nothing even money they don't have to buy cups for example. If you don't have one feels like a fool to be borrowing from friends now and then the friends also get tired. They should give us everything that we are supposed to use because it is not everyone who can manage to buy, other people are poor like me. When I do not have money I send message home so that they should sell things at home like maize for me to have money to buy the necessary things like soap (Participant # 11).

Overall Impression of Caregiver's Participation in Care of Hospitalised Children

Two sub-themes emerged under this theme as follows: Appropriateness of caregivers' participation in the care of hospitalised children and caregivers' satisfaction with their participation in care.

Appropriateness of caregivers' participation in the care of hospitalised children

The majority of the participants (n=19) viewed their participation as appropriate for them. These participants said it could not take somebody's parent to come and care for their children. It takes his or her parent to care for the child. These participants said that it could have been possible for them to leave everything for the HCWs that they should be taking care of the child and not participate. However, this would have given HCWs a lot of responsibilities. One participant said:

It is proper that I should participate because this is my child. It cannot be possible for somebody's parent to come from there to take care of my child. It requires me as the owner who gave birth to this child like the parent to be the first to take part. It is right and proper that the first care should come from me so that other people who are helping should just be helping but the first care should come from me the owner. I am not feeling any pain when caring for my child and I know that the child is mine (Participant # 12)

Another participant said:

It is very good that nurses and caregivers should be helping each other caring for children who are hospitalised because we can come here to the hospital and it may be possible leaving our children to the nurses and doctors that they should be taking care of them and be outside and yet on their own may not manage to care for the child. The child may trouble them that I want my parents, I want my father

or I want my mother and we may give them a lot of task struggling with the child so that they should be able to care for him (Participant # 9)

Also, these participants said that children were free with their parents if they wanted something. They could not have been able to express themselves in the absence of the caregiver because all the people around them were strangers who accept the caregiver. Besides their caregivers knew their children better than the HCWs so it was proper for them to participate. This was illustrated by one participant:

It is proper that we should participate in the care of my child because when he wants something he or she is free to tell me the parent than the nurses because they are strangers to him/her. But also I am the one who knows my child better than nurses so the nurses rely on me that I should tell them about my child but also the child cannot explain on his own (Participant # 14).

Caregivers' satisfaction with their participation in the care

When the participants were asked whether they were satisfied with their participation in the care of their hospitalised children, it was found that despite the problems that the caregivers encountered during their participation, they all indicated that they were satisfied with the way they were participating in the care of their children. This was attributed to the fact that the care that they were providing was what they wanted to be doing for their children. The participants saw their participation as a continuation of their parental role and it was not a hard task for them to complete. Again they were satisfied because during their participation they could see and understand what was happening to their children and appreciated the change in their child condition unlike if they were not participating in the care. One participant illustrated this: “Am satisfied in

the way am participating because I can see the change in my child condition because am taking part in the care unlike if I was not participating I could have not seen this change” (Participant # 10).

CHAPTER 5

Discussion of Results

Introduction

The discussion section describes the meaning of the results of the study, how the study relates to the findings of other research and the implication that they have on clinical practice. The findings are of the study titled perceptions of caregivers on parental participation in the care of hospitalised children at Queen Elizabeth Central Hospital in Blantyre. The specific objectives of the study were to: (1) describe how caring roles were negotiated between the HCWs and caregivers caring for hospitalised children (2) describe care that caregivers provide to their hospitalised children (3) describe how information about hospitalised children was shared between HCWs and caregivers caring for hospitalised children and (4) determine views of the caregiver's concerning their participation in the care of hospitalised children.

The discussion will be based on the main themes that came out of the analysis. These were: (1) lack of role negotiation by HCWs (2) inadequate role preparation for caregivers (3) care given by caregivers to their hospitalised children (4) poor HCWs-Caregivers communication (5) benefits of caregivers' participation in the care of hospitalised children (6) needs of caregivers participating in the care of hospitalised children and (7) overall impression of caregiver's participation in the care of hospitalised children. Demographic information is incorporated into the discussion. Recommendations for the improvement in the practice of parental participation in the care of hospitalised children are also discussed together with areas for further study.

Demographic Characteristics of the Participants

Age of the participants

The findings showed that all the caregivers were between 20 and 43 years of age. This indicates that caregivers were mature and of childbearing age.

Gender of the participants and their relationship with children

The findings showed that 85% (n=17) of caregivers were female family members and 80% (n=16) were mothers of the hospitalised children. This may not be surprising in Malawian culture because most mothers remain the primary caregivers of their children when sick. Literature elsewhere also demonstrates that the majority of the caregivers were mothers of the hospitalised children (Abdelkader et al., 2013; Hoffman et al., 2012; Tourigny et al., 2012; Roden, 2005). Similarly, Shields et al. (2008) found that 81% of the respondents were mothers of hospitalised children in Australia.

Level of education of the participants

The findings showed that 95% (n=19) of the participants attended school from primary, secondary and college level. This implies that most of the caregivers were literate although this was at different levels. Literature indicates that literacy is a positive precursor for caregivers' participation in health care issues. Furthermore, literate family members have an upper hand in terms of understanding health issues over their illiterate counterparts (Ishikawa & Yano, 2008). According to Ishikawa and Yano, when family

members are literate, there can comprehend much of the health information and become empowered rather than being confused.

The religion of the participants

The findings showed that all participants 95% of the participants were Christians.

How Caring Roles were Negotiated Between Health Care Workers and Caregivers

Caring for their Children

Lack of Role Negotiation by Health Care Workers

The results showed that caregivers were not consulted by HCWs to discuss the activities that they were supposed to do whilst in the hospital regarding the care of their children. It was reported that HCWs assumed that the caregivers would participate in the care of their children. The findings also show that some were told by HCWs that they were supposed to be taking care of their hospitalised children. It was also reported that others were told by HCWs to observe what their fellow mothers were doing to their children. These findings are similar to the findings of many studies which found that staff took it for granted that parents should participate in the care because they are there with the child (Aein, et al., 2009; Corlett & Twycross, 2006; Coyne & Cowley, 2007; Lam, et al., 2008; Pongjaturawit & Harrigan, 2003; Reeves et al., 2006; Ygee & Anertz, 2004). This is contrary to the concept of family-centred care practice of which parental participation is an integral part. Family-centred care practice requires HCWs to negotiate caring roles with caregivers. To begin with, role negotiation is a caring process not an event of care. Reeves, et al. (2006) defined role negotiation as the process in which HCWs discuss with the caregivers the level of care that they wish to be responsible for

while in the hospital. It also includes discussing the individualised plans for child care (Power & Frank, 2008). Negotiation is the main interaction strategy in a partnership between HCWs and family caregivers in the hospital and the vehicle by which power is shared (Fegran & Helseth, 2009). As documented by Corlett and Twycross (2006) HCWs need to be aware of how they interact with caregivers, how parental participation can be controlled or manipulated and need to appreciate that caregivers differ in terms of the amount of participation they want to have. It is documented that parental participation can be controlled by adequate role negotiation and preparation (Fegran & Helseth, 2009; Hopia, 2009; Roden, 2005).

However, as reported by participants, it is clear that HCWs in this study did not fully negotiate with caregivers regarding the level and type of care they need to participate in. Reeves, et al. (2006) found that lack of role negotiation between HCWs and caregivers results in HCWs placing increasing responsibility on the caregivers without the support that they needed. Similarly, Aein, et al. (2009) found that parents felt that much pressure was placed on them to do what they saw as HCWs work. Literature has documented factors that hinder negotiation between HCWs and caregivers (Aein, et al., 2009; Ames, et al., 2011; Reeves, et al., 2006; Soderback & Christensson, 2007). Reeves, et al. (2006) found that HCWs do not negotiate with caregivers because they are busy, lack time, fear increased technical care, inadequate staffing and lack negotiation and communication skills. This may be true for the HCWs at QECH because the shortage of staff has existed as a chronic health problem. The implication for not negotiating the care is that caregivers feel less empowered and powerless to contribute effectively to the

care of their child whilst in the hospital. This may compromise the quality of care that the child may receive in the hospital.

Inadequate Role Preparation of Caregivers by Health Care Workers

The study findings showed that there was inadequate role preparation of caregivers by HCWs. It was reported that most caregivers were not taught how to carry out various tasks. Interestingly, it was reported that they wished they were prepared for their role from admission because they were in a strange environment. Role preparation involves establishing rapport, discussing with family members, assessing their level of capability, teaching family members the tasks followed by demonstration followed by return demonstration (Fegran & Helseth, 2009; Mackay, 2009). Caregivers in this study realised that being prepared is a pre-requisite for effective parental participation. Mackay (2009) found that HCWs prepared the caregivers to familiarise and prepare them for their new role as partners in the hospital. This means that caregivers were given control over the task that they needed to perform on their children which is contrary to the findings of this study.

Some HCWs in this study delegated the tasks to caregivers without teaching them how to do it. A few caregivers said that they were taught only when the HCWs wanted to give caregivers tasks to do. This is consistent with the findings of a study by Aein, et al. (2009) who found that in Iran, nurses delegated the care to caregivers without sufficient preparation and training. In that study, parents did not receive any planned training on how to carry out a nursing task such as collecting urine, turning the patient, feeding, giving oral medication and wound dressing. The parents were not always provided with

sufficient information so they always had to learn that needed information from other parents. In that study, HCWs left the parents to learn about the expectations overtime by learning it partly by observing what happened to other parents, partly by asking other parents and partly by experience. The literature concludes that if caregivers do not have the knowledge and skills to perform their work they may unintentionally harm their loved ones (Aein et al., 2009; Espezel & Canam, 2003; Reinhard, et al., 2008). This could be true for caregivers in this study. It is therefore imperative that caregivers be given require knowledge and skills for them to judge and carry the task of care for their patients effectively.

Description of the Care Caregivers Provide to Their Hospitalised Children

Care that Caregivers Provided to their Children

Basic care

The findings of this study showed that caregiver's provided basic care to their hospitalised children. The basic care that they performed included staying with the child, bathing, feeding, changing, cheering the child, taking the child to the see-saw, calming and comforting their children during painful procedures. Earlier studies have demonstrated similar findings (Abdulbaki, et al., 2004; Coyne & Cowley, 2007; Espezel & Canam, 2003; Paliadelis, et al 2005; Power & Franck, 2006; Roden, 2005; Soderback & Christenssen, 2008; Tourigny, et al., 2005). This may mean that provision of basic care to hospitalised children is a universal phenomenon undertaken by caregivers. Roden (2006) asserts that there are a general agreement and an expectation from most caregivers that as parents, they need to continue with their mothering role when in the hospital by

providing basic and maiden care to their children. This mothering role may encompass doing tasks that they would normally do at home such as feeding, bathing, being with the child and changing nappies to fulfil their parenting role (Coyne & Cowley, 2007; Corlett & Twycross, 2006; Roden, 2005).

Paliadelis, et al. (2005) found that in Australia registered nurses allowed parents of hospitalised children to do basic care while the nurses retained control over technical tasks. This is also consistent with the findings of de Lima, et al. (2001) in Brazil. In that study, nurses allowed parental involvement in basic care. Given that parents are willing to participate and take up more tasks and care when caring for their children, it shows that HCWs also feel that caregivers should be involved in the care they can provide. This behaviour of HCWs may make parents feel empowered and willing to work with HCWs. This is positive and should be encouraged at QECH.

Technical care

The findings showed that caregivers provided technical care to their children. The technical care tasks included administering oral medication, collecting urine specimen, feeding through the nasogastric tube, wound dressing and escorting children to an x-ray. This is consistent with the growing body of literature which shows that caregivers are involved in the provision of technical care although levels differ (Abdulbaki, et al., 2011; Aein, et al., 2009; Coyne & Cowley, 2006; O'Haire & Blackford, 2005; Roden, 2005). HCWs depend on caregivers when providing care to children in the hospital because of staff shortages (Coyne, 2006; Shields & Nixon, 2004; Zaman, 2004). This concurs with the findings of Espezel and Canam (2003) who found that in Canada caregivers felt that they assumed nursing roles and provided technical care to their children. In that study

HCWs expected the caregivers to provide some of the technical care for their children such as giving oral medications, simple wound dressings and collecting urine specimens. This may demonstrate that some HCWs regard parents as partners in care. However, as most of these studies were done in western and developed countries where staff shortages may not be as alarming as in Malawi, HCWs' partnership with parents in providing some technical care at QECH may be seen as a way of relieving them of the workload. As documented by Aein, et al. (2009), HCWs involve and delegate some of the tasks to caregivers to diminish their workload.

The findings of this study also showed that some caregivers were not comfortable with the performance of some technical care which they said was the HCWs responsibility. This is reported in other earlier studies (Coyne & Cowley, 2007; Espezel & Canam, 2003; Tourigny, et al., 2005). Coyne and Cowley (2007) found that in England, parents were willing to provide basic care but were reluctant to provide technical care. In that study, parents reported that they were anxious about performing the technical tasks due to inadequate knowledge about medical and nursing matters. To these parents, technical care was viewed as HCWs responsibility because of their training and expertise. However, parents participated in technical care because they would not have neglected their children and wanted to comply with the HCWs expectations to establish a good relationship. This relationship was seen as increasing the likelihood of quality care for their children. According to Coyne, O'Neill, Murphy, Costello and O'Shea (2011), some parents comply with difficult and uncomfortable tasks to avoid reprisals from staff. This could also be true for the caregivers in this study who despite being not comfortable

with the care they still went ahead providing it to their children. However, one may argue about the quality of care these parents provided amidst their uncomfortable situation.

Reasons for participating in the care

The findings of this study showed that caregivers participated in care for various reasons. It was reported that they felt compelled to be there for their children and be responsible for their childrens' care. It was also reported that every caregiver in the department provided care to his or her child. It was clear from caregivers' reports that children relied on them for most of the care. Equally, reports indicated that HCWs were not always available for the children to meet their individual needs. It was evident from reports that the caregivers were uncertain about such availability. Literature reports that parents believe that it is their top priority to be with their child while in the hospital because children need their parents to be close to them, care for them and meet their basic needs (Ames, et al., 2011; Corlett & Twycross, 2006; Power & Franck, 2008; Roden, 2005; Ygee & Anertz, 2004). This is consistent with the findings of Aein, et al. (2009) who found that in Iran parents wanted to be close to their children in the hospital because this helped to meet the physical and psychological needs of their children. The parents in that study said that they were not feeling confident that nurses would be available for their child constantly due to the increased workload. This could be true for HCWs at QECH where poor staffing has existed for some time and shortages are the talk of the day. This uncertainty experienced by caregivers may reduce their trust and confidence in the HCWs. This being the case, caregivers may want to take control of the care and the child's situation.

How Information was Shared Between Health Care Workers and Caregivers

Poor HCWs-Caregivers Communication

Mode of communication

The results showed that communication was largely verbal and to some extent written. Verbal communication was in form of HCWs telling caregivers about the diagnosis, treatment plan and in other cases and sometimes prognosis of the condition. Some participants reported that HCWs wrote a child's information in the case note. The caregivers had to ask for it for the HCWs explain to them. Literature elsewhere indicates that most communication between health care workers and parents in the hospital is verbal (Espezel & Canam, 2003; Lam et al., 2006; Pongjaturawit & Harrigan, 2003). The findings of this study are consistent with these earlier assertions. Furthermore, Lam, et al. (2006) state that verbal communication is the easiest way to pass information between parents and HCWs in caring settings. This could be one of the reasons why verbal communication is commonly used at QECH.

On the contrary, none of the participants reported that they were given pamphlets, brochures or leaflets where various diseases conditions are described in simple terms so that caregivers can read at their own time. This implies that this type of written communication may not exist at QECH. Nonetheless, it is another good and factual way of communicating to caregivers in staff stricken settings as QECH. Pamphlets and posters on common diseases provide time for HCWs to do other things while caregivers read for themselves and health workers may be concerned with answering questions from the caregivers (Just, 2005). This may save time on part of HCWs. At QECH, a shortage of

resources such as stationery may be a barrier to the use of this type of communication between caregivers and HCWs.

Inadequate information from HCWs

The study findings showed that caregivers were given inadequate information regarding their children's condition and the treatment. For instance, on the child condition, the HCWs could tell them what the child was suffering from without explaining to them what the condition is, causes and possible complications. In the case of treatment, it was reported that HCWs could tell the caregivers the medication the child was on without explaining to them the name of the medication, frequency, duration, mode of action and side effects. Makaryus and Friedman (2005) indicate that during hospitalisation, patients and caregivers need more information especially on the diagnosis, the condition, treatment plan, side effects of medications and the duration such medications must be taken. Makaryus and Friedman further state that a lack of awareness of these factors affects caregivers' ability to comply with a treatment plan. This implies that the information given by HCWs to caregivers in this study was incomplete. Soderback and Christenson (2008) found that in Mozambique, caregivers lacked information before and during admission as well as during the caring process. In that study, the caregivers experienced difficulties in understanding and engagement in what was going on regarding the care of their children and felt abandoned. This feeling could be true for the caregivers in this study. Thus complete information is paramount to effective parental participation in the care of the hospitalised children (Paliadelis, et al., 2005). This implies that there is a need for HCWs at QECH to provide clear

communication and adequate information regarding the child's condition and plan of care. Clear communication is viewed as a precursor to collaboration between HCWs and caregivers and it expedites accurate determination of care needs and development of goals (Espezel & Canam, 2003). According to Roden (2005) parents also believe that communication is the most important link to having a positive and successful hospital experience.

Interestingly, the caregivers in this study acknowledged that the lack of adequate information from HCWs was because the HCWs were busy and always in a hurry. This is consistent with the earlier studies which show that caregivers lack information right from their first contact with HCWs to the time they are discharged. Literature attributes this lack of adequate information to health care workers' heavy workloads and hurriedness when working with parents (Hoffman, et al., 2012; Pongjaturawit & Harrigan 2003; Soderback & Christenson, 2008). As a result, this disrupts the continuity of care. However, this shows that the caregivers are aware of setbacks experienced by their providers. The study findings also showed that caregivers needed comprehensive information about the sickness of their children in general and how they can participate effectively in the care of their children. This has been further elaborated under the theme needs of caregivers caring for hospitalised children.

Manner of communication by HCWs

Appropriate communication

The study findings showed that some HCWs were talking to them nicely and calmly. Participants reported that HCWs did not shout at the caregivers when they made a mistake instead they corrected them and advised them. It was also reported that HCWs

greeted the caregivers every morning when they arrive and asked them how the child was. This was viewed as appropriate communication by caregivers. The greeting is an invitation signal that shows that one is willing to talk to them in appropriate manner. Literature shows that the key aspect of appropriate communication is when HCWs demonstrate interest and willingness to talk to family caregivers (Soderstrom, Benzein & Saveman, 2003). This willingness of HCWs may have enabled them to establish rapport with caregivers. When rapport has been established between HCWs and caregivers, they can work more easily with each other and share child care (Espezel & Canam, 2003). Through this rapport, parents feel that they are being respected by HCWs which caregivers may reciprocate to HCWs. This could be true for caregivers and HCWs at QECH. This appropriate communication at this institution must continue.

Inappropriate communication

On the contrary, the results of the study showed that other HCWs used inappropriate way of communication. The caregivers characterised these caregivers as communicating rudely because they shouted at them when they made mistakes and looked down at them. It was reported that these HCWs gave the caregivers names regardless of the age and gender of the caregiver. This manner of communicating to caregivers by the health care workers implied that HCWs were insensitive, unsympathetic and disrespectful to caregivers. It is clear from the caregivers' reports that almost half of them experienced this manner of communication implying that there was a poor HCW-Caregiver relationship. The value of the HCW-caregiver relationship depends highly on the manner of communication between HCWs and caregivers (Soderstrom, et al., 2003).

A growing body of current and earlier literature indicates that communication problems between parents and health care workers continue to exist (Ames, et al., 2011; Lam, et al., 2006; Roden, 2005; Soderback & Christenssen, 2008; Soderback & Christenssen, 2007). These findings concur with those of Lam, et al. (2006) who found that the majority of the HCWs in China were perceived as rude, not sensitive and enthusiastic by the caregivers. Similarly, Roden (2005) found that in England mothers were not happy with how staff communicated with them. Roden reported that doctors talked down to the mothers, talked while not looking at them and treated them disrespectfully whereas nurses were being insensitive and rude. Given that hospitalisation is stressful to the child and caregivers, rude and insensitive communication by the HCWs in this study may have aggravated feelings of anxiety and fear in the caregivers. This may explain why most caregivers view health care workers as unapproachable and self-centred.

Views of Caregivers on their Participation in Care of their Hospitalised Children

Benefits of Caregiver's Participation in the Care of Hospitalised Children

Caregiver's knowledge of child's illness

The results of the study showed that when caregivers are given a chance by HCWs to participate in the care of their children, it made caregivers know their children illness better. It was reported that caregivers learnt a lot from their interaction with HCWs, they were able to ask questions and the answers given by HCWs enabled them to understand what was happening to their children. Some indicated that they will use this knowledge at home when caring for their sick children. This may imply that caregivers felt somewhat able to care for their children while in the hospital. Chen (2005)

documented that caregivers gain ability and skills if they had an opportunity to learn from HCWs and maintain their skills in caring for their hospitalised children. Thus caregivers' participation provides the premise for them to learn from HCWs. This in turn provides caregivers with a better transition between hospital and home care for their children when discharged (Pilliteri, 2010). Shields, Pratt and Hunter (2006) corroborate Pilliteri's assertions. According to Shields, et al. (2006), if caregivers are allowed to participate in care, they maintain or improve their skills through learning during their participation in the care of their hospitalised children. In that study, it was reported that this learning made parents feel competent that they can take care of their children at home with minimal difficulties. This could be true for the caregivers in this study. Given that the literature states that participation gives caregivers a learning opportunity, such caregivers must be given enough information regarding their children's condition and the plan of care. This may facilitate their learning and continuity of care while in the hospital and at home. However, it has been reported in this study that role preparation and negotiation for caregivers was inadequate. This means that the way caregivers learnt the tasks and skills while in the hospital was problematic. As such one may argue that the depth of competence and skills gained by these caregivers was questionable and may have affected the quality of care these caregivers provided to their children.

Meeting the medical and physical needs of the child

The study findings showed that when the caregivers were involved in the care, children received individualised care. It was reported that these caregivers provided individualised care because they felt their children were different and also, they knew

their children better than HCWs. It may imply that caregivers' knowledge of their childrens' emotional and behaviour provided the basis that they can know better how the child could be managed by HCWs especially during stressful situations. A growing body of literature documents that parents provide individualised care to their children in the hospital because they know them better (Abdelkader, et al., 2013; Ames, et al., 2011; Coyne & Cowley, 2007; Lam, et al., 2006; Shield, et al., 2008). Lam, et al. (2006) found that parents provided individualised care for their children in Chinese hospitals. After all, they believed that their children had problems to fit into the hospital routine because they were expected to comply with the standardized hospital routines. This made parents in that study to feel that their childrens' individual needs could not be met only if they participate in the care. Similary, Ames, et al. (2011) found that parents knew their children nature than HCWs, therefore, sharing that expertise with HCWs was an important parental role and this could contribute to the physical as well as emotional wellbeing of the child in the hospital. For instance, caregivers may tell the HCWs what the child likes, how the child feels when in pain, the HCWs may take this information into their care routine completing the cycle of individualised care. It is a known fact and an expectation that medical doctors and nurses in practice should provide individualised care to children. However, caregivers' contribution to this individualised care may lead to the provision of quality care to hospitalised children.

Meeting the psychosocial needs of their children

The finding of this study showed that caregivers' participation in the care of their children helped them to mitigate psychological and emotional stress for their children.

Caregivers reported that they played a major role in maintaining the psychological wellbeing of their sick children by being there for them to prevent loneliness, chatted with the children to make them happy offered comfort to their children during painful procedures. Researchers have found that caregivers participate in children to give psychological care (Ames, et al., 2011; Coyne & Cowley, 2007; Pilliteri, 2010; Shield, et al., 2008). It is also acknowledged that mothers play an important role in providing such activities as a means of entertainment and psychological support (Abdelkader, et al., 2013; Neil, 2007). Hospitalisation is the source of stress and anxiety to both the caregiver and the child (Harrison, 2010; Lam, et al., 2006). In some instances, apart from the strange environment and hospital routines, HCWs themselves are regarded as a major of stress to children. Abdelkader, et al. (2013) found that in Jordan, children regarded HCWs as a symbol of giving the injection. This could be true for children in this study. The forgoing literature suggests that the findings of this study imply that caregivers stayed with their child in the hospital as one way of alleviating stress and anxiety for the child. Therefore, the HCWs should encourage caregivers' presence and participation to mitigate the emotional stress which children experience as a result of their hospitalisation.

Relieving the HCWs of their increased workload.

The study findings showed that participating in the care of hospitalised children caregivers helped to relieve HCWs of their workload. It was reported that the caregivers appreciated that HCWs had a lot of responsibilities in taking care of their hospitalised children because there were a lot of patients against few HCWs. This, according to

caregivers, made the HCWs fail to attend to every child hence a lot of basic work was not done. This may imply that the caregivers were working as assistants to HCWs by providing some of the care that was meant for the HCWs. Literature has documented that caregivers regard the HCWs as being busy most of the time because of their workload which results from the inferior numbers on the ground (Coyne & Cowley, 2007; Fegran & Helseth, 2009). As a result, some caregivers do not expect that HCWs would provide care to each child. Furthermore, studies have shown that HCWs delegate some of the tasks to diminish their workload (Aein, et al., 2009; Lam, et al., 2006; Power & Franck, 2008; Corlett & Twycross, 2006). A study in England by Coyne (2006) found that HCWs appeared to be reliant on the caregivers' contributions in the hospital. In that study, caregivers were viewed as unofficially another pair of hands for HCWs. Zaman (2004) also found that in Bangladesh, caregivers became informally part of the caring team because of a shortage of nurses. This may imply that it is common for health care workers to rely on caregivers in settings where health personnel are in short supply. This could be true for HCWs at QECH. However, whatever the benefits maybe, this is not consistent with the values of family-centred care in which parental participation is an integral part. In PP, caregivers participate in care at their own will and level. As the situation is at QECH, the participation of caregivers is by ad-hoc means. As such, there is a need to improve on communication, role negotiation and preparation so that caregivers should participate at their own will and level at which they are comfortable. This may improve the quality of child care

Provision of information to the HCWs.

The study findings showed that caregivers benefited from their participation because they acted as providers of important information to HCWs regarding their child. Caregivers in this study explained that they were key informants to the health care workers and also they informed the HCWs about any change in child condition so that the necessary assessments had to be done. This may imply that in some cases, HCWs relied on caregivers to monitor children condition and give information to them. This is consistent with earlier studies (Lam, et al., 2006; Soderback & Christensen, 2007; Abdelkader, et al., 2013). Soderback and Christensen (2007) found that mothers in Mozambique provided the HCWs with information about the change in child condition because they were the first to notice any change in child condition. This was because the caregivers monitored their children condition closely. According to Sodomka (2010), parents should be allowed to take part in the care of their children because they are the custodians of important information which HCWs can use for diagnostic purposes as well as provision of individualised care.

Needs of Caregivers Caring for Hospitalised Children.

Need for information

Study findings showed that caregivers needed comprehensive information from HCWs for them to participate effectively. These caregivers reported that they needed information concerning child illness and their participation. Literature has shown that

parents need information about their children illness and treatment plan on an ongoing basis (Ames, et al., 2011; Tourigny, et al., 2005; Vasli & Salsali, 2014; Shurdy, 2006). Dudley and Carr (2004) report that parents need for information is universal and essential for better partnership inpatient care between caregivers and HCWs. Caregivers are knowledge seekers and they rely on HCWs to give them information at all cost and each point in the care of their children (Ames, et al., 2011). However, it is evident from the findings of this study that HCWs provided inadequate information which is contrary to the values of FCC in which PP is a core concept. This implies that this need was not met. This shows that caregivers in this study may not have been satisfied with the information they had. This may explain why some caregivers in this study were doing things haphazardly.

HCWs at QECH must take an initiative to report to caregivers about the child progress and give anticipatory guidance on the same. Literature indicates that having a hospitalised child is a great source of anxiety and stress for parent (Ygee & Anertz, 2004; Soderback & Christensen, 2008; Ames, et al., 2011; Shurdy, 2006; Vasli & Salsali, 2014). Giving caregivers' information about the possible diagnosis, preliminary prognosis and clear instruction on the treatment of their children enables caregivers to cope with the child illness and handle the situation (Hoffman, et al., 2012).

Need for supervision.

The findings of the study showed that the caregivers needed to be supervised by HCWs. Caregivers reported that most of the basic care and tasks in the hospital were done by them hence they felt it was important that HCWs supervised them. It was reported that the HCWs delegated the tasks to caregivers without the necessary role

preparation and clear instruction. Earlier studies have also reported that most parents and caregivers cite the need for supervision by HCWs as crucial to them. Lam, et al. (2006) found that parents wished that the nurses should take more initiative to check if they needed help when caring for their children. It was reported in that study parents were not aware of the appropriate time to ask for help as they perceived the nurses as being busy. Furthermore, Lam et al. stated that in their study the nurses gave caregivers the tasks and the resources without coming back to see how they were fairing. This suggests that it may be common for HCWs to give tasks to caregivers without following up especially in busy settings. This may subject caregivers to make mistakes that may jeopardize childrens' care. This may be true for caregivers at QECH where there is the inadequate staff. However, studies focusing on supervision of caregivers in the clinical area have received little attention hence there is a need for further research.

Need for material support.

The caregivers also reported that they needed the HCWs to support them in form of resources for caring for their children. It was reported that every caregiver used his or her resources such as cups, basin and soap which they used when caring for their children. Studies have shown that providing material support to caregivers is important and can enhance parental participation in care (Mackay, 2009; Fults, 2011; Coyne, et al., 2006). Fults (2011) indicates that materials that may be provided to caregivers are bandages, syringes for feeding and giving medication, pails and towels for tepid sponging. This may mean that material support to caregivers is crucial. However, at QECH, there is a chronic shortage of resources that Fults mentioned that may be

provided to caregivers. This shortage of resources may explain why HCWs may not have provided them to caregivers.

Overall Impression of Caregiver's Participation in Care of Hospitalised Children

Appropriateness of caregiver's participation.

Caregivers explained that their participation in the care of their hospitalised children was important and appropriate. The caregivers reported that leaving everything for HCWs would have increased the responsibilities on them. Besides participants reported that children were free and comfortable to express themselves to their caregivers than HCWs. Furthermore, caregivers reported that they were the most appropriate mediator to assist in the provision of care and emotional support to their sick children. This may imply that caregivers acted as a bridge between the HCWs and the children. This concurs with the findings of Shields, et al. (2008) who found that in Australia parents served as the link between the child and staff. Parents also assisted in relieving the child's anxiety and provided a sense of security. Further to this, caregivers reported that the HCWs relied on them for information, physical and psychological comfort of the child. This is what made their participation appropriate in that study. This may mean that caregivers know the importance of being present and their participation in care. As such HCWs need to put in deliberate efforts that may encourage caregivers to view their participation in care as a normal process in the hospital.

Studies have shown that caregivers view their participation as important and appropriate because accompanying their children and participating in the care to the

hospital is an unconditional aspect of being a parent and hold a strong desire to be involved in the care (Lam, et al., 2006; Abdelkader, et al., 2013; Coyne & Cowley, 2007; Ames, et al., 2011, Avis & Reardon, 2009; Aein, et al., 2009). Literature also reveals that caregiver often wishes to participate in the care of their children and perceive their participation as the positive, productive and supportive relationship with the child (Van Horn & Kautz, 2007). Most of the caregivers believe that parental participation is important and beneficial to the child, caregiver and HCWs (Hughes, 2007, Rotegard, 2007, Shields, et al., 2008). It is documented that parents believe that they make important contributions to their child's care in the hospital because they have unique knowledge and ability to reassure and provide comfort to their children (Hopia, et al., 2005). Aein, et al. (2009) also reported that caregivers thought that their presence was important because it met the needs of the child, reduced the child emotion stress and increased child cooperativeness. This may lead to a conclusion that caregivers believe that participating in their child's care is crucial in meeting the emotional and physical wellbeing of the child.

Caregiver's satisfaction with their participation in the care.

The study findings showed that the caregivers were satisfied with the way they were participating in the care of their children. Caregivers reported that they were doing what they were supposed to do with their children. It was interesting to note that the participants said that their participation was a continuation of what they were doing for their children at home. Further to this, the participants said that they were able to see and understand what was happening to their children unlike if they were not participating in the care. Earlier studies have also reported similar findings (Melo, et al., 2014, Ygee,

2004; Power & Franck, 2008; Hughes, 2007). Melo, \ et al. (2014) reported that caregivers expressed gratitude for the opportunity to remain with the hospitalized child and to take part in the care provided. Also, it was reported that parents were satisfied with the level of their participation. The findings of this present study confirm the findings of earlier research which concludes that basic care is the main area of PP and is a continuation of parenting role from home to hospital and vice versa (Power & Franck, 2008). According to Ygee (2004) caregivers who are more involved in the care feel more satisfied with the care and are more likely to comply with the treatment and as a consequence have a better outcome. Further, Ygge states that caregivers' satisfaction with their participation is an indicator of quality care. While the researcher agrees with Ygee's conclusion, the quality of care at QECH may be questionable taking into consideration that caregivers verbalised that there were inadequate role preparation and negotiation and that caregivers reported that they received inadequate information.

Conclusion

In conclusion, the findings of this study showed that caregivers view their participation in child care as appropriate, important and satisfying. However, gaps exist in the way caregivers participate in the care of their hospitalised children at QECH. This is partly because there were inadequate role negotiation and preparation for caregivers and inadequate information sharing between HCWs and caregivers. Further detailed research is needed to explore factors contributing to inadequate role negotiation and role preparation including those that contribute to inadequate information sharing between

HCWs and caregivers. This is because implications from such studies would assist in improving how parental participation is practised at QECH.

Recommendations

In light of the findings of this study, the following recommendations are made to address the issues identified in this research to promote the best practices:

There is a need for QECH management to develop protocols and guidelines on parental participation in the care of hospitalised children. These will act as a guide to the HCWs in the implementation of parental participation.

There is a need to develop leaflets on common disease conditions in Chichewa the language that most Malawian understand. These leaflets should contain information on disease condition, cause, signs and symptoms, complication and details of the treatment. This will help to reduce the time for giving information.

The QECH management should conduct continuous professional development workshops on parental participation to equip the HCWs with negotiation skills, interpersonal communication skills and knowledge on how they can take parents on board during the caring process.

Hospital management should improve the staffing levels and resource allocation to the department. This may be achieved by allocating more funds to hire part-time HCWs who can add to the ones already working in the department. Besides they should make resources available especially to those who come from far and those who cannot afford to have their resources including those who stay for long periods in the hospital.

Family-centred care should be included in the curriculum during pre-service training. According to Blower and Morgan (2000), negotiation skills should not be left to develop over time as the HCWs becomes more experienced but should be taught as a central part of medical and nursing education

Areas that Need Further Study

The study identified the gaps that need to be addressed through further studies as follows:

- Nurses experience of parental participation in the care of hospitalised children
- Intervention study on how parental participation can be implemented at QECH
- Factors that contribute to inadequate role negotiation and preparation between HCWs and caregivers
- Predictors of Caregiver-HCWs information sharing in a health care setting

Limitations of the study

The main constraint to this study was inadequate time because this study was done when the researcher was also studying other courses. The other thing is that there was financial constraint due to the rise in the cost of things. The money that was given for this project was based on previous estimates hence not enough to carry out a huge project. The other limitation was that the study used a qualitative method which made it difficult to generalise. The study used in-depth interviews. According to Boyce & Neale (2006) when in-depth interviews are conducted, generalizations about the results are usually not able to be made because small samples are chosen and random sampling methods are not

used. Furthermore, HCWs views regarding their experiences with parental participation were not sought. Seeking nurses' views would have enriched the findings and conclusion of this study.

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Appendices

Appendix A: Participant semi-structured in-depth interview guide

Title: Caregivers' perception regarding parental participation in the care of hospitalised children at Queen Elizabeth Central Hospital.

Serial number.....Date of in-depth interview.....

Starting time..... Ending time.....

Section A: Participants demographic information

1. Age of participant.....
2. Gender of participants.....
3. Education level.....
4. Relationship with the child.....
5. Ward.....
6. Duration of hospital stays up to the day of interview.....

Section B:

Role negotiation and role preparation

1. Did you HCWs negotiate with you about your caring roles?

2. Explain how it happened?

Probe: What discussion did you have with the HCWs concerning the activities you are doing?

3. How were you prepared for the care that you are giving to your child?

The care which caregivers provided to hospitalised children?

1. Tell me about your role in caring for your child?

Probe: As a caregiver what activities do you do for your child?

2. Why do you do these activities for your children?

Information sharing:

1. What method do they use to communicate information to you?
2. What type of information do you get from them?
3. How do HCWs talk to you?

Participation:

1. How important is it for you to participate in the care of your hospitalised children?
2. What else would you wish HCWs would have done for you to participate effectively in the care of your child?

Perception of caregivers on parental participation

What are your views on the following?

- Appropriateness of your participation in the care of hospitalised children
- Satisfaction with your level of participation in the care of your hospitalised child

Appendix B: Caregivers information sheet

Dear participants

I am a student at the University of Malawi, Kamuzu College of Nursing doing a Master of Science degree in Child Health Nursing. I wish to invite you to participate in my research study titled “*Caregivers’ perception regarding parental participation in the care of hospitalized children at Queen Elizabeth Central Hospital*”. The study aims to explore how caregivers perceive their participation in the care of hospitalized children.

During the study, you will be required to answer questions related to your participation in the care of your child. The interview will take approximately 45 minutes to 60 minutes and when you get tired we will take a break and offer you refreshments. The information will be tape-recorded and the researcher will also write some notes for reference during data analysis. The recorded information and written notes will be kept safely in a lockable cupboard only accessible to the researcher.

You are informed that participation in the study is voluntary and you may refuse or withdraw at any point from the study. Your refusal to participate or withdraw from the study will not have any effect on the care your child is receiving and in future. You are free to ask a question and also you are free to refuse to answer any question that you are not comfortable to answer. Should you accept to participate, you will be provided with a consent form which you will be asked to sign.

You are also informed that the researcher will ensure that your confidentiality and privacy is maintained throughout data collection and analysis as well as the publication of findings. No names or any identifiable information will be used instead will use serial numbers and no one will be able to identify or relate you with your responses. The study will be done in a private room within the ward for your privacy and also that you do not

miss some of the care. After the study is completed and the report has been submitted all written documents and recorded information will be destroyed so that no one will be able to access and use the information.

There is no direct benefit from participating in the study however it is hoped that the findings may help to improve how the caregivers participate in the care process of their hospitalized children in future patients. Furthermore, you are informed that the study does not have any foreseen physical harm. However, you may experience psychological fear about your confidentiality and you may feel uncomfortable to answer some questions. Be informed that no health care worker will know about what you have to say and you will not be forced to answer any question you are not comfortable with. If you have any questions or concerns at any point about the study do not hesitate to contact me or the following:

Lophina Phiri

Kamuzu College of Nursing

P.O Box 415

Blantyre

Cell phone: 0999339162

DR. A Chimwaza

Kamuzu College of Nursing

P.O Box 415

Blantyre

Telephone: 01873623

COMREC Secretariat,

P/Bag 360,

Chichiri,

Blantyre 3.

Telephone:01989766

Appendix C: Participant's statement of consent

I have understood the information that you have explained to me about the study and my role in the study. I have had the opportunity to ask questions and have been answered to my satisfaction.

I understand that the study involves research and the purpose is to explore how caregivers perceive their participation in the care of hospitalised children.

I understand that I will be asked questions related to my participation in the care of my hospitalized child and it will take approximately 45minutes to one hour and when I get tired we will take a break and have refreshments.

I understand that my participation is voluntary and that am free to withdraw at any point and this will not affect the care my child is receiving now and in future.

I understand the information I will 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 understand that there is no direct benefit in participating. I also understand that the only risk associated is psychological discomfort. I understand that I am free to refuse to answer the question that is not comfortable with and that information I will give will be kept confidential.

I have been given information on who to contact in case I have questions or concerns.

I voluntarily agree to participate in the study.

.....
.....

Participants' Signature

Thumb print

Date

.....

.....

Researchers' Signature

Date

Appendix D: Chikalata cha mafunso

Mutu: Maganizo a makolo pa kutenga mbali kusamalira ana awo pomwe agonekedwa kuchipatala

Nambala..... Tsiku lofunzila musonso.....

Nthawi yoyambila.....Nthawi yomalizila.....

Gawo loyamba

1. Zaka za wotenga mbali.....
2. Wamuna kapena wamkazi.....
3. Polekezela sukulu.....
4. Ubale ndi mwana.....
5. Chipinda chomwe muli.....
6. Nthawi yomwe akhala mchipatala.....

Gawo la chiwiri:

Kukozekeresedwa pa udindo wanu

1. Kodi munayamba mwakambirana za udindo wanu pakutenga nawo mbali posamala mwana wanu?
2. Munakambiranako zotani ndi ogwira tchito ya chipatala zokhudza udindo wanu posamalira mwana wanu

- Munagwirizana chiani pa ntchito zomwe mungagwire kapena mukugwira?
3. Munakozekeletsedwa bwanji pa udindo wanu wosamalira mwana wanu?

Tchito zomwe oyanganila odwala amagwira pa ana awo

4. Kodi udindo wanu ndiotani posamalira mwana wanuyu?
 - Mumagwira tchito ngati ziti pa mwana wanu?
5. Mchifukwa chani mumasamalira mwana wanu?

Kugawana uthenga

1. Ogwira ntchito ya chipatala amakupatsani bwanji kapena amagwiritsa njira yanji pokupatsana inu uthenga?
2. Ndiuthenga wanji womwe amakupatsani?
3. Kodi ogwira tchito ya chipatala amakuyakhulani bwanji?

Kutenga mbali posamalira mwana wanu

1. Kodi ubwino wotenga nawo mbali posamalira mwana wanu ndiotani?
2. China chomwe mukufuna chitachitika kapena ogwira ntchito ya chipatala akanachita kuti mutengenawo bali moyenera ndi chiyani?

Maganizo a osamalira ana potengapo mbali pakusamalira ana awo

Maganizo anu ndi otani?

1. Nkoyenera kuti mutenge nawo mbali posamalira mwana wanu?
2. kukhutitsidwa ndi momwe mukutengela mbali posamalira mwana wanu?

Appendix E: Kalata yofotokoza za kafukufuku

Wokondedwa.

Ndine wophunzira zaunamwino kusukulu ya ukachenjede ya Malawi, ku Kamuzu Koleji amene ndi kuphunzira zokhuza umoyo wa ana ndipo ndikupanga kafukufuku wokhuza *maganizo a makolo pa kutenga mbali kusamalira ana awo pomwe agonekedwa kuchipatala cha Queen Elizabeth Central Hospital*. Ndiye muli kupemphedwa kuti mutenge nawo mbali polowa nawo mukafukufukuyu. Cholinga cha kafukufukuyu ndi choti timve maganizo anu pa kutenga nawo mbali kusamalira ana omwe agonekedwa kuchipatala

Mudzafunsidwa kuyankhapo mafunso okhudza kutengapo mbali kwanu posamalira mwana wanu kwa phindi 45 kufikila ola limodzi. Dziwani kuti mudzaloredwa kupuma nkati mwa mafunso pakuti ola limodzi mukhoza kutopa ndi kuyakha mafunso ndipo mudzapatsidwa zakumwa.

Dziwani kuti simukukakamizidwa kutengapo mbali komanso muli ndi ufulu ngati mukufuna kusiya nthawi imene mungafune popanda vuto lina lililonse. Kukana kapena kutuluka mukafukufukuyu sizidzasokonenza chisamaliro chomwe mwana wanu akulandila tsopano ngakhale mtsogolo. Muli omasuka kufunsa mafunso alionse okhudza kafukufukuyu komanso kukana kuyakha funso lomwe simukufuna mutayakha. Ngati mwa vomereza kutengapo mbali pakafukufukuyi muzapemphedwa kusayina kalata kapena kutsindikiza chala chanu kuti ukhale wumboni oti mwavomela kutenga nawo mbali.

Mukudziwitsidwa kuti mayankho anu adzasungidwa mwachinsisi ndipo sizizadziwika kuti anayankha mafunsowa ndindani chifukwa mayina anu sazayikidwa

pamapepala a mafunso mmalo mwake tizagwiritsa ntchito manambala. Pa zokambilana zanthu tidzakhala mchipinda chobisika momwe palibe yemwe adzamve kapena kudziwa za zomwe mungadzayakhepo zokhudzana ndi kafukufukuyu. Zotsatila za kafukufukuyu zikadzasindikizidwa, mapepala onse adzaotchedwa ndipo mawu womwe tijambule adzafufutidwa kuti wina asazigwiritsenso ntchito.

Palibe phindu lilonse kwa inu potenganawo mbali koma pali chiyembekezo kuti zidzathandiza kusitha momwe makolo angamatengele mbali posamalira ana omwe agonekedwa kuchipatala. Dziwaninso kuti palibe chiopsezo china chili chonse pakafukufukuyi. Vuto lomwe lingakhalepo ndilakuti mukhoza kukhala ndi nkhowa kukhudzana ndi chisisi chanu komanso kuyakha mafunso ena. Muli kudziwitsidwa kuti angakhale ogwira ntchito mchipatala sadzadziwa konse zokhudza mayakho anu.

Ngati mungakhale ndi funso kapena nkhowa ina iliyonse yokhudzana ndi kafukufukuyu khalani omasuka ndikubweretsa madandaulo kapena mafunso anu kwa wopangitsa kafukufuku ndi anthu enawa:

Lophina Phiri

Kamuzu College of Nursing

P.O Box 415, Blantyre

Nambala ya phoni: 0999339162

Dr. A Chimwanza

Kamuzu College of Nursing

P.O Box 415, Blantyre

Telephoni: 0187362

COMREC Sekiliteriati,

Telefoni: 01989766

P/Bag 360,

Chichiri, Blantyre 3

Appendix F: Kalata yovomera kutengapo mbali mu kafukufuku

Ine ndamvetsetsetsa zomwe ndauzidwa zokhudzana ndi kafukufukuyi ndipo ndinapatsidwa mwayi ofunsa mafunso ndipo ndakhutitsidwa ndimayakho omwe ndapatsidwa

Ndamvesetsanso kuti ndili ndi ufulu kutenga nawo mbali kapen wosiya nthawi ina ili yonse popanda chifukwa ndipo kuti izi sizizasokoneza chithandizo chomwe mwana wanga akulandira pakali pano kapena ntsogolo.

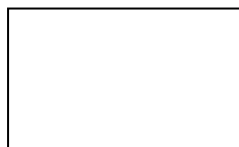
Ndamvetsetsa kuti ndidzapephedwa kuyakha mafunso okhudza kutengapo mbali kwanga pa chisamaliro cha mwana wanga kwa phindi 45 kufikila ola limodzi.

Ndamvesetsanso kuti zonse zomwe ndiyankhule kapena kupereka mukafukufukuyu zidasungidwa mwa chinsinsi.

Ndamvetsetsa kutii palibe phindu lililonse kutenga nawo mbali. Zovuta zomwe ndingakumane nazo ndi kuti ndikhoza kumakhala ndi khawa ndipo ndatsimikizilidwa kuti ndili ndi ufulu kusayakha mafunso omwe ndisakufuna kuyakha.

Ndauzidwanso momwe ndingapezere opanga kafukufukuyi kapena anthu ena ngati kuli kofunika kutero.

Ndavomera mosaumilizidwa kutengapo mbali pakafukufukuyi



.....
Kusayina kwa otengambali

.
Sindikizani chala

.....
Tsiku

.....
Mwini kafukufuku

.....
Tsiku

Appendix G: Letter of approval from Hospital Director, QECH

Telephone: (265) 01 874 333 / 677 333
Facsimile: (265) 01 876928
Email: queenshosp@globemw.net

All communications should be addressed to:
The Hospital Director



In reply please quote **No.**

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

7th April, 2014

Lophina Phiri (Mrs)
Kamuzu College of Nursing
P.O. Box 415
BLANTYRE

Dear Madam,

PERMISSION TO CONDUCT A RESEARCH STUDY AT QUEEN ELIZABETH CENTRAL HOSPITAL

This is to inform you that management has no objection for you to do your research study titled "Care givers perception regarding parental participation in care of hospitalised children" at Queen Elizabeth Central Hospital as part of your fulfillment of the award of Master's Degree.

We will appreciate if a copy of your findings is shared with the hospital.

All the best in your studies.

Yours faithfully,

A handwritten signature in dark ink, appearing to read 'L. Chewere'.

L. Chewere
CHIEF NURSING OFFICER
FOR: HOSPITAL DIRECTOR



Appendix H: Approval letter from Head of Department QECH



Principal
Prof. K Maleta, PhD

Department of Paediatrics & Child Health
Head: Dr Neil Kennedy MRCPCH MMedSci DTMH

College of Medicine
Private Bag 360
Chichiri
Blantyre 3
Malawi

Telephone: +265 1871911 ext 299
+265 995929733
Email: nkennedy@medcol.mw

2nd April 2014

Chair COMREC
College of Medicine
Blantyre

Dear Dr Mwaphasa,

RE: 'Caregiver's perception regarding parental participation in care of hospitalised children'

I am writing to support this proposal submitted by Sr L Phiri. The research is low-risk and of value to the department. I hope that it will provide valuable information regarding our communication with parents in QECH.

Yours sincerely

A handwritten signature in cursive script that reads 'Neil Kennedy'.

Dr Neil Kennedy
Associate Professor /Consultant Paediatrician

Appendix I: Approval letter from Hospital Director, KCH

Jun 20 14 11:55a KCH ADMIN 2651750994 p.1

REF. No.:
TELEPHONE No.: (265) 1 753 555/754 331
TELE FAX No.: (265) 1 756 380
PLEASE ADDRESS ALL
COMMUNICATIONS TO :
THE HOSPITAL DIRECTOR



MINISTRY OF HEALTH
KAMUZU CENTRAL HOSPITAL
P. O. BOX 149
LILONGWE
MALAWI

20th June, 2014

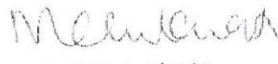
Lophina Phiri
Kamuzu College of Nursing
Post office Box 415
Blantyre

Dear Madam,

On behalf of hospital management I would like to acknowledge receipt of your request to conduct a pretest of your research tool at this hospital. Be informed that management has approved your request.

It is necessary for us to know if the research proposal has been approved by authorized bodies. If you have the approval letter save us with one before you start your pretest.

Yours faithfully.


Mabel Chinkhata
For; HOSPITAL DIRECTOR

Appendix J: Certificate of ethics approval from COMREC

