Kamuzu College of Nursing

REGISTERED NURSES LIVED EXPERIENCES ON FAMILY INVOLVEMENT IN THE CARE OF HOSPITALISED CHILDREN AT QUEEN ELIZABETH CENTRAL HOSPITAL, MALAWI.

MSc. (CHILD HEALTH NURSING) THESIS

BY

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Submitted to the Faculty of Nursing in partial fulfilment of the requirements for the

Degree of Master of Science in Child Health Nursing

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DECLARATION

I the undersigned hereby declare that this dissertation titled 'Registered Nurses Lived Experiences on Family Involvement in the Care of Hospitalised Children at Queen Elizabeth Central hospital, Malawi' is my own original work which has not been submitted to any other institution for similar purposes. Where other people's work has been sued acknowledgements have been made.

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CERTIFICATE OF APPROVAL

The undersigned certify that this thesis represents the student's own work and effort and has not been presented anywhere else in or outside Africa.

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DEDICATION

I firstly dedicate this work to my son Wonderful for his endurance during my absence. I know this may have caused a lot of anxiety and psychological pain on him. Secondly, to my father Mr. Gladson Phiri, (posthumous) who passed away while I was away for studies. May his soul rest in peace, God be with him wherever he is and I will ever miss him.

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Lastly I would like to thank my wife for everything including her contribution and support during conceptualisation of the proposal and writing of this report.

May God Almighty bless you all!

ABSTRACT

Family involvement entails that care is planned around the family and the hospitalised child. Families need to be involved because they are custodians of valuable information for provision of care. QECH is the main referral hospital which provides specialised care to children across Malawi. Shortage of nurses is a chronic health problem at this hospital. The average nurse-patient ratio in paediatric unit is ratio is 1:84. This ratio is very high. However, nurses are expected to involve families in child care. Evidence shows that nurses' experiences about family involvement are key factors in the way care is delivered. Little is known about nurses' experiences on family involvement in the care of hospitalised children at QECH in Malawi.

The objective of the study was to describe registered nurses experiences when involving families in the care of hospitalised children at Queen Elizabeth Central Hospital. A descriptive qualitative design using semi structured interview guide was used. Data was collected from 14 full time registered nurses at QECH and analysed using thematic content analysis. Six themes emerged from the data: Rationale for family involvement, nurses' experiences on family involvement, power and control, factors influencing nurses' efforts on family involvement, core concepts of family centred care, factors influencing nurses' efforts on family involvement and nurses' impression with family involvement

The findings of this study are consistent with those from western countries and show that registered nurses are knowledgeable on family involvement and their experiences are mixed but are constrained by socio-cultural and institutional factors. These factors should be subjected to further research because their implications may be greater than perceived. The findings support

the notion implementation of family involvement is inconsistent. This status quo may continue unless authorities provide support in form of human and material resources and develop a policy.

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LIST OF ABBREVIATIONS

Put them in alphabetical order

IPFCC:	Institute for Patient and Family Centred Care
USA:	United States of America
UK	United Kingdom
QECH:	Queen Elizabeth Central Hospital
HMIS:	Health Management Information Systems
WHO:	World Health Organisation
WA4PS:	World Alliance For Patient Safety
HIV:	Human Immunodeficiency Virus
ART:	Antiretroviral Therapy
PMTCT:	Prevention of Mother to Child Transmission of HIV
AIDS:	Acquired Immunodeficiency Syndrome
CPD:	Continuous Professional Development
COMREC:	College of Medicine Research Committee
FI:	Family involvement
FM:	Family members

DEFINITION OF TERMS

Children

For the purposes of this study children refer to any persons from birth to 18 years

Family

A social unit where two or more individual of different ages and characteristic traits stay together under one roof in a hierarchical set up, sharing rights and responsibilities. These people may be related by birth, marriage, fostering or adoption (Shelton, 2009).

Families

In this study a families refer to core relatives, guardians or significant others who take care of the child while admitted

Family centred care

It means a combination of beliefs and practices which define particular ways of working with families which are consumer driven and competency enhancing (Espezel & Canam, 2003).

Paediatric nurses

All nurses who are working in paediatric wards not merely by their qualification as paediatric nurses

Lived experience

A personal engagement or a personal first hand encounters with, accounts of and impressions of a phenomenon over a period of time that has potential to reflect on(Thesaurus.com).

Family involvement

Participation in care envisages that patients and families are encouraged and supported in participating in care and decision-making at the level they choose (University of Iowa, 2009).

CHAPTER 1

Introduction and Background

Introduction

Family involvement is an approach which entails that care is planned around the whole family which forms part of caring team. Planning, delivery and evaluation of care is governed by mutually beneficial partnerships between providers and families (Shields, Pratt & Hunter, 2006). But it is clear that hospitalization of a child is stressful to the family members (Espezel & Canam, 2003). It is also clear that families of hospitalised children have multiple needs when in the hospital (Shields, et al., 2006; Mackay, 2009). Nurses are best placed to meet these needs in the course of care of a hospitalised child (Stayt, 2007). In Malawi, studies have mainly focused on perceptions and experiences of the parents and families during the care of the admitted children (Larwligh & Matuke, 2009). However, there is scarcity of literature on studies on how nurses involve families in child care in the country. As such, literature from elsewhere has been used to create the context of the study. It has been found that family involvement contributes to quality care. Family involvement is related to increase in participant satisfaction, parent self-efficacy, family judgments of helpfulness of caregivers and child and family well-being (Bamm & Rosenbaum, 2008; Coyne & Cowley, 2006; Harrison, 2011).

It is evident that negative or difficult situations related to the involvement of families in the care of their sick child in critical care units from the perspective of nurses exist (Chesla, Omerlly & Stannard, 2010; Bernard, 2009). This may be true for QECH paediatric section which admits children below 15years with medical and surgical conditions. Statistics for 2012 indicates

over 36,000 paediatric admissions took place in paediatric section (QECH HIMIS, 2012) averaging 3000 per month. This is against an established average of 2250 a month. In addition, the average nurse-patient ratio is 1:84 during the peak season (Personal Communication from the Section Manager). This ratio is very high. International Council of Nurses (2010) recommends a nurse-patient ratio of 1:10. This implies that the section has an increased workload. Evidence has demonstrated that increased workload is linked to disruptions and discontinuity of nursing caring care (Orril, 2009). Canadian Federation of Nurses Unions (2010) states that disruption occurs on collaboration and communication between parents and nurses. Disruption of communication and collaboration may jeopardise the process of family involvement.

Assumptions exist that most registered nurses involve families in care of their children. However, their actions are not evident (Orril, 2009; Shields et al., 2006). The extent to which registered nurses involve families depends on the nurses' experiences, time and willingness to act and the prevailing situation in the hospital (Stayt, 2007). This implies that these nurses' experiences need to be explored.

Background

Traditionally, guardians were not allowed to accompany their sick children in most hospitals around the world (Harrison, 2011). This may have negatively affected the recovery of these children. Absence of a guardian at the bedside has been linked to psychological and developmental problems in a child (Wells, 2011). Evidence has recently revealed that children's stresses and pain are aggravated by their separation from families (Paliadelis, et al., 2005; Espezel & Canam, 2003; Coyne & Cowley, 2007). As such nurses are encouraged to involve

families in child care. Families play significant role in meeting the child's emotional needs and relieving the nurses from workload (Coyne & Cowley, 2007; Shields et al., 2006).

Paediatric nursing literature has concluded that for nurses to involve families effectively, both families and nurses need to be mutual partners (Stayt, 2007; Lam, et al., 2006; Shields, et al., 2006; Soderstrom, et al., 2003; Soderback & Christenssen, 2008; Paliadelis, et al., 2005;Bernard, 2009). However, nurses are expected to play a leading role in establishing this partnership to create a conducive environment. A conducive environment enables family members of critically ill children to communicate and collaborate with nurses. This enables nurses to meet family and children's daily needs. In this partnership there is need for respect and dignity, information sharing, participation and collaboration between families and nurses which are pillars of family involvement and family centred practice (Soderstrom, et al, 2003). Families and nurses regard family involvement as important in meeting both the family and child physical and psychosocial wellbeing (Evagelou, 2003; Shields & King, 2001).

Parents appreciate being allowed to stay and be involved in the care of their child during hospitalisation (Irlam & Bruce, 2002; Ygge, 2007). However they value good relationships and communication with the staff as prerequisite to their involvement (Ygge, Lindholm & Anertz, 2004). Effective family involvement recognises parents as the experts and is keepers of vital information that health workers can learn from and use to avoid unnecessary care (Sodomka, 2010; Mackay, 2009). In family involvement nurses empower families to develop supports systems which will be continued when the child is discharged (Paliadelis, et al., 2005; Soderback & Christenssen, 2008). It is evident registered nurses are key to this because they regulate and coordinate care and stay with patients for longer (Wells, 2011; Soderstrom, et al., 2003). But this depends on the strategies nurses employ (Shields, et al., 2004). Some strategies used by nurses

for developing family relationships include showing interest and providing explanations to family members (Stayt, 2007). However, some nurses act with inhibiting behaviours such as depersonalizing family members despite family members' willingness to be involved in the care (Bernard, 2009). This implies that not all nurses show respect and dignity to family members and understand the need to collaborate with the families members in the hospital.

For family involvement to be effective, nurses and families need to share unbiased and timely information (IPFCC, 2010). However, the researcher's observations at QECH indicate the contrary. He observed that guardians of hospitalised children knew little about their childrens' conditions and treatment plans. This observation agrees with Manji & Reckon (2011) who in the study on how much information guardians of patients know about their illness in Malawi found that 77.2% of guardians did not know medication regimes their patients were getting. This may imply that information sharing challenges exist. Inadequate interpersonal and communication skills affect good collaboration and communication between nurses and families (Fults, 2011). Some nurses indicate that family members characterise nurses' as pathological and intimidating (Soderback & Christensen, 2008; de Lima, et al., 2001) while others regard nurses as understanding professionals.

Family involvement is directed by guidelines, protocols and policies. These guidelines need to be incorporated in hospital policies and legislative arms of governments (Sodomka, 2010). Clinical practice guidelines in nursing are a way of providing consistent high quality care, by adhering to recognised, evidence based standards (Paliadelis, et al., 2005; Whittenmore & Grey, 2002). In Malawi, there are guidelines on family involvement in HIV and AIDS services (Betancourt, Abrams, Mc Bain & Fawzi, 2010). Betancourt, et al., (2010) suggested that a combination of patient and family-centred approach to PMTCT has the potential to enhance

health outcomes in Malawi for the mother and child as well as other members within the household. A review of policy documents such as the health sector strategic plan at national level, directions on family involvement are not clearly evident. This is congruent with the researcher's findings at QECH. Gondwe, Bhengu & Bultemeier (2011) in their study "Challenges encountered by intensive care unit nurses in meeting patients' family needs in Malawi" found that there are no policies and guidelines to support family involvement in the care of their sick relatives in Malawi. In the paediatric department, there are no guidelines and policies on family involvement in the care of hospitalised children. This may imply that registered nurses at QECH lack a good basis for involving families in child health care.

In 2004, World Health Organization (WHO) launched the World Alliance for Patient Safety (WA4PS). WA4PS ensures that perspectives from patients and families are at the central reference point when providing and evaluating care, making protocols and guidelines and measuring progress on quality of care (Conway, Johnson, Edgman-Lentan & Schcluter, 2006). This means that universally, interventions are needed to address the stress experienced by families during hospitalisation.

In Malawi, studies have focused on patients' experiences and their perception of nurses and nursing care (Larwigh & Makupe, 2009; Brysiewicz & Bhengu, 2010). However, registered nurses play an essential part in attending to the needs of families (Soderstrom, et al., 2003). This implies that experiences of nurses which form a critical part in the family nurse partnership remain silent. Nurses also accept the notion that family involvement is crucial in paediatric care but not unproblematic. In particular, in developing countries, studies show that low staff numbers and hospital infrastructure affect both nurses and parents efforts on meaningful family

involvement (Lam, et al., 2006; Brysiewicz & Bhengu, 2010). The extent to which shortage and increased workload are linked to family involvement has not been investigated at QECH.

According to the Section Nursing Manager, Queen Elizabeth Central Hospital (QECH) paediatric department admits children nationwide. The section has 8 units namely: Accident and Emergency, (A & E), Paediatric Special Care (PSCW), Paediatric Nursery (PNW), Surgical, Oncology, Orthopedic, Moyo and Medical wards. The section has 36 nurses of which 16 are registered nurses. The admission statistics from July, 2013 to March 2014 indicate that there is a significant difference on total patient censuses between peak months and off peak months (QECH, HMIS, n.d). The average peak season admission per month was 4640 (December, 2013 to March 2014) and 3323 during off peak season (July to October, 2013). The nurse-patient ratio remained 1:78 during peak season and 1: 64 during the off peak season. On average, the patient nurse ration is 1:84 (Communication from the Section Nursing Manager). This implies that the nurse patient ration in this section is very high. It is apparent that during this time nurse patient ratio remained above recommended standard of one nurse to ten patients (International Council of Nurses, 2010). This implies that disruptions in nursing care may exist. However, despite this high nurse-patient ratio, it is professionally expected of professional child nurses to involve families of hospitalised children in child care at all cost (Soderstrom, et al., 2003; Guestello, 2009).

Given the situation at QECH paediatric section, one may assume that at QECH, family involvement in the care of their hospitalised children by nurses may be challenging. However, no studies have highlighted the nurses' experiences when involving families in child health care in Malawi. At QECH, it is not known on the experiences of registered nurses when involving

families of hospitalised children in paediatric care. This study seeks to explore and describe the registered nurses lived experiences on family involvement in the care of hospitalised children.

Statement of the problem

Family involvement in the care of hospitalised child is a requirement in paediatric nursing. Sodomka (2010) indicates that families need to be involved because they are custodians of valuable information which is important for provision of individualised paediatric nursing care. However; the researcher observed that families of hospitalised children at QECH paediatric wards knew little about their child's condition and planned care. This observation is supported by Manji and Reckon (2011) who found that 77.2% of parents and guardians do not know the medication regimens of their sick children in Malawi. This may be attributed to lack of family involvement in child care by some health workers such as nurses. Furthermore, at QECH, there are no policies and guidelines on family involvement in child care. This implies that nurses may lack reference point regarding family involvement.

The admission statistics from July, 2013 to March 2014 indicate that average admission per month was 4640 (December, 2013 to March 2014) and 3323 off peak season (July to October, 2013). On average, the nurse-patient ration is 1:84 in the paediatric section. This implies that the nurse patient ratio in this section is very high. However, nurses are still expected to involve families in child care (Soderstrom, et al., 2003; Guestello, 2009). Registered nurses take a leading role both on planning and provision of care to children and their families at QECH and their willingness, experiences and commitment when working with families is paramount. However, nurses' willingness and motivation to act influences the degree of family involvement (Shields, et al, 2006). Evidence from elsewhere in the world shows that nurses' experiences about interventions with families of sick children are key factors in the way care is delivered.

Family involvement is seen by some nurses as a demanding and difficult especially in resource stricken environments or settings (Soderstrom, et al., 2003) while other's experience depersonalisation by family members (Chesla, Omerlly & Stannard, 2010). Studies on nurses' experiences on family involvement the care of hospitalised children in Malawi are not well documented. Nonetheless, little is known about registered nurses lived experiences on family involvement in the care of their hospitalised children at QECH.

Significance of the *S*tudy

Family involvement is a cornerstone in paediatric nursing and is known to be one of the means for improving quality child care where hospital routines are governed by clear policies and guidelines (Paliadelis, et al., 2005). The study findings may influence policy makers to formulate policies and guidelines on family involvement in child health care at QECH. In Malawi little is known about registered nurses experiences in care of hospitalised children. The findings may provide knowledge and understanding that can guide the implementation of family involvement in care of hospitalised children. The findings may influence nurse educators to incorporate new skill sets and competences required by nurses to effectively respond to the needs of hospitalised children and their families when reviewing, formulating or implementing the nursing curriculum. In research the study findings may serve as a basis for future research.

Broad study objective

The broad objective of this study was to describe registered nurses experiences when involving families in the care of hospitalised children at QECH.

Specific study objectives

The specific objectives of the study were to:

1. Describe what registered nurses do to show respect and dignity of hospitalised children and their families at QECH.
2. Describe ways which registered nurses use to share information and collaborate with families when providing care to hospitalised children.
3. Describe what registered nurses do to allow families to participate in the care of hospitalised children at QECH
4. Identify factors that facilitate and hinder effective family involvement in the care of hospitalised children at QECH.

CHAPTER 2

Conceptual Framework

Introduction

This study used the Patient and Family Centred Care framework developed by the Institute of Patient and Family Centred Care (IPFCC). This framework guided approaches to the planning, delivery and evaluation of health care that is governed by collaborative partnerships among health care providers, patients and families (IPFCC, 2008). This model was viewed by the researcher as strong to guide this study because of its philosophical underpinnings which view the traditional model of care as giving blind obedience to the expertise of patients and families (Sodomka, 2010). The model calls for an equal partnership between nurses and families. This model emphasises that involving families in the care of their hospitalised family members is neither about advocacy nor a favour but patients and families should be viewed as essential allies and treated as true partners in the care of the patient (IPFCC, 2010).

Patient and Family Centred Care Framework

It envisages that the experience of care, as perceived by the patient and family, is a key factor in health care quality and safety as it is for care givers (IPFCC, 2010). Evaluation of health care is grounded in mutually beneficial partnerships among health care providers, patients and families. This is the basis of this model and family involvement. The model has four core concepts which are dignity and respect, information sharing, participation and collaboration. At the centre of this, is the patient and the family. The interactions between health care providers, the family and the patient are reciprocal. That is, this interaction is two way and balanced.

Breakdown in this two way communication causes disruption of quality of care, reduces satisfaction and increases costs (Saleeba, 2008)

According to (Sodomka, 2010) the model takes on a premise that health workers must consider the process of care as an opportunity to respect patients and offer open communication with a clear and supportive language to children, families including fellow health professionals from all disciplines. Nurses need to convey respect for the individuality, patient's existing capacities and vulnerability of each child and recognise them as members of the care team and affirm positive contributions that families can make. In return, patients may reciprocate these attitudes to health workers (Mackay, 2009; Saskatchewan Ministry of Health, 2011). This may form the basis for a trusting nurse-patient relationship and mutual partnerships. This is the starting point for quality health care (IFPCC, 2010).

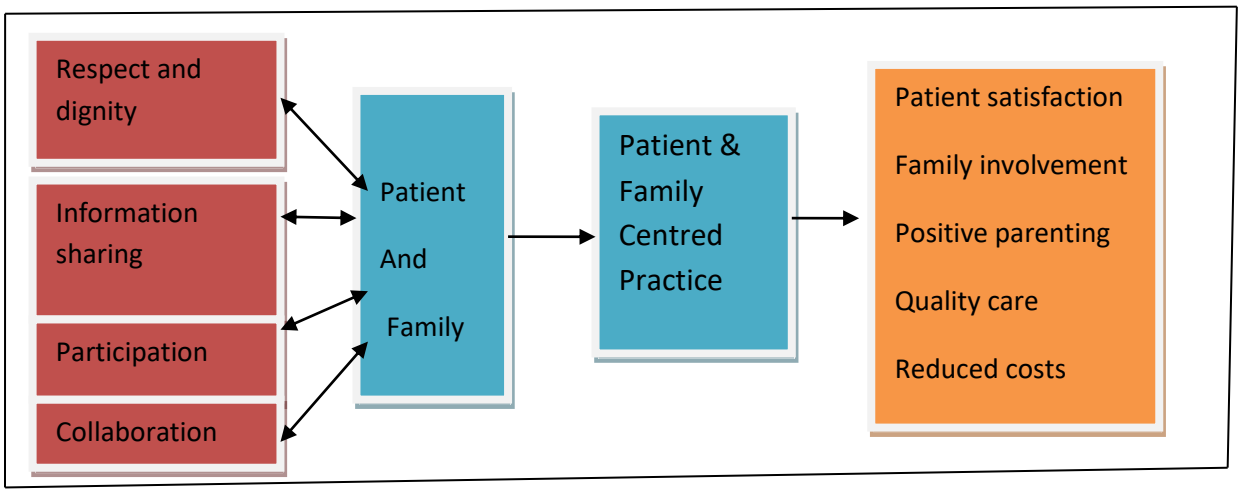


Figure 1: Patient and Family Centred Model: Adapted from: Guestello, 2009.

Description of the core concepts of the Patient and Family Centred Care Model

Dignity and Respect

Respect and dignity entails that family members are always welcome to be with their patient, in accordance with policy and patient preference and not viewed as visitors but as essential members of the health care team. Within a context of respect, dignity and support for children and their families, the health system needs to develop practices that ensure the process of care that offers respect, dignity, privacy and confidentiality to patients and families. The health workers should allow positive criticism from families and allow them to participate in rounds and nurses' handovers (IPFCC, 2008).

Information Sharing

Information sharing entails that the nurse actively supports patient and family involvement in all aspects of patient care through ongoing two-way communication and allow family members to ask questions about their care and treatment (IPFCC, 2008). The nurse should provide patients and families with information and educational materials related to their health needs and stay in the hospital in a language they understand. Nurses should be sensitive to patients' level of understanding and adequacy and appropriateness of information (Sodomka, 2010). For example, in nursing, the nurse should regularly provide feedback to patients on how planned care is unfolding and should seek feedback from patients and their families on how their health needs are being met by the caring team.

Participation

It entails determining the adequacy of family's shared decision-making, coordination and continuity of care or ease with which families access desired information and timely disclosure

of adverse events. It also entails supporting families on the nurses's delegated roles and responsibilities to the family members during the caring process based on the knowledge and information the families have. In addition, the nurse should ask the family at the beginning of a hospital stay to identify family members who should or should not be included in these discussions regarding child's illness (Mackay, 2009). Appropriately, nurses need to include the child in the discussions and his or her care plan according to age.

Collaboration

During collaboration health care professionals agree on the roles and responsibilities in the delivery and evaluation of care (IPFCC, 2010). Nurses should assess potential stressors and facilitators and discuss with family members. Mackay (2009) indicates that to facilitate collaboration health care workers must make unbiased consultations with patients and their families when implementing and evaluating care plans. For example on care planning, health workers may consult patients and families on patients and families past experiences, preferences of care and ask families if they are willing to be part of the nursing care team. However, problems exist during collaboration. Nurses and families cross the agreed upon boundaries. Nurses often relegate guardians to menial or household tasks like feeding and bathing the child rather than clinical tasks such as administration of oral medication. This is because guardians do things slowly (de Lima, et al., 2001).

Application of the Model to Family Involvement in Nursing Care

The traditional model of care places emphasis on restricting patients and families while family-centered model emphasises on strengths that patients and families can bring to the healing process (Sodomka, 2010) outlines concepts in family involvement and family centred practice

which are mutual respect for skills and knowledge between family members and nurses, honest and clear communication. A close conceptual relationship exists between components family involvement and the IPFCC Model. This IPFCC model is congruent with the family involvement objective and the directions of this study hence its choice.

It is evident that for effective family involvement, there is need for a mutual partnership between nurses and families. Nurses need to respect the patient and family members, share unbiased information and collaborate with the families in accordance with the set policies and guidelines. Family involvement is about providing respectful and dignified, compassionate, culturally sensitive care that meets the needs, values, cultural backgrounds and beliefs and preferences of patients and their families by working collaboratively with them. The possibility of achieving this relies on the nurses' knowledge, skills and experience and organisational support and guidance inform of policies and guidelines. Ward activities guided by the core concepts of family centred practice and policies on family centred care, professionals embrace family involvement as their daily and an unfavoured task for patients and families (Evagelou, Iodanou, Lemanidou, Patiraki, et al., 2007). This assertion is important to this study and will help to substantiate the findings of this study.

IPFCC model believes that health care workers should embrace family centered practice and foster collaborative partnerships with families regardless of increase in workload or shortage of materials (Guestello, 2009). This substantiates the conclusion that family centred care can be adopted by all institutions (WHO, 2004). It implies that IPFCC Framework supports studies in health systems that are understaffed and overstretched (Guestello, 2009) like Malawi. This influenced the selection of core concepts which are respect and dignity, information sharing, participation and collaboration as variables on which data will be collected.

Family involvement is a way of achieving quality health outcomes which are patient satisfaction and reduced costs (Saleeba, 2008). Quality in this model is measured by the extent to which families are involved in the care and the cultural competence applied to implement patient care by health workers (Saskatchewan Ministry of Health, 2011). In IPFCC Model, patients' beliefs, values and cultural background are embedded as core care values. This implies that the model is culturally sensitive which is congruent with values of family involvement. This study has been designed to explore nurses' application of cultural sensitivity and competence, family beliefs and values to family involvement.

In conclusion, the IPFCC Conceptual Framework will be used in this study to contextualise and guide the overall direction of investigation and to select key variables to be studied. This study is the first in Malawi. Therefore there will be a need to base its platform on internationally recognised framework to guide data collection (Mock, et al.,2007) assert that studies need explicit theoretical base to describe or control the phenomenon under study and helps researcher to be coherent.

Literature Review

A literature review is a critical summary of research on a topic of interest and is often prepared to put a research problem into context by examining what others have already done in the field concerned (Polit & Beck, 2004). An integrated review of literature was conducted based on the guiding principles of family centred care within which family or parental involvement is a core concept. This review focused on family involvement or parental participation, nurses' experiences or encounters and beliefs regarding family involvement in care of hospitalised children and challenges of involving families in the care of hospitalised children. To achieve

substantial and specific literature related to the topic, the researcher used key words which included family involvement or parental participation AND nurses experiences OR beliefs OR interactions with family members OR perceptions of family involvement in the care of the hospitalised child OR hospitalised children. The search was done using several search engines such as Google Scholar and data bases such as CINNAHL, EBSCO host, Hinari, PUBMED Central, Scirus, Cochrane Data Base and Uptodate.com. These are reliable databases because they contain peer reviewed articles. However, some articles which included nurses' experiences were included in the review. The study mostly included articles from 2000 up to 2013. However, earlier articles and studies with specific but scarce information were also included.

Overview of Patient and Family Centred Care Model

Patient and family centred care redefines relationships in the hospital and broader health care system by placing an emphasis on collaborating with patients and acknowledges that families are essential to patients' health and well-being (IPFCC, 2010; Sodomka, 2010; Mackay, 2009). A patient and family centered care approach recognises that the very young, the very old, those with chronic conditions, individuals most dependent on hospital care and the broader health care system are most dependent on their families (Sodomka, 2010). This defines the importance of involving families in the care of their loved ones through an equal partnership in the hospital.

Family Centred Care

A review of literature indicates that the concept of family centred care is important because it regards the family as central to healing of the child and brings perspectives of both the children and parents to the attention of a health care professional. Bringing the patient's and

family's perspectives in care planning, delivery and evaluation improves quality of care and safety (IPFCC, 2010). Studies increasingly show that when health care providers, patients and families work in partnership, the quality and safety of health care rise, costs decrease, and provider and patient satisfaction increases (Fults, 2011; Saleeba, 2008). This is accomplished in settings where staff members routinely follow and implement concepts of family centred care.

Core Concepts of Family Centred Care

Family centred care has four core concepts which are respect and dignity, information sharing, participation and collaboration.

Respect and dignity.

In this core concept, it is envisaged that health care practitioners listen to and honour patient and family's perspectives and choices on care. Patients' and family's knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care. Studies have shown that establishing rapport, honouring patients' choices and perspectives from clinical and cultural dimensions are key issues in this concept (Espezel & Canam, 2003; IPFCC, 2010; Sodomka, 2010; Mikkelsen & Frederiksen, 2010). Coyne, et al. (2011) examined the meaning of family centred care among nurses caring for hospitalised children in UK and Ireland. The study used both qualitative and quantitative methods in seven different children hospital units to report how nurses caring for children identified their practice and perception of family-centred care. The qualitative aspect had two open ended questions while the quantitative part used a descriptive survey on 250 nurses. The quantitative findings were not reported in this publication. The qualitative findings showed that nurses valued several core aspects of family centred care in which respect and dignity and working in partnership with families were identified as major

subthemes. This implies that nurses are aware of the need to respect patient and families' choices.

Respect and dignity also involves honouring patient and family choices even if they are contradictory to nurses' views. This is considered the best attribute because families may have good reasons for making their choices (Bernard, 2009; Fults, 2011; Mackay, 2009). In one study, Mackay (2009) used descriptive qualitative method to examine experiences of paediatric oncology nurses with family centred care in the United States of America. The study interviewed 20 registered nurses working in an oncology ward. The study found that most of the nurses conferred with parents and families of the hospitalised children. The study revealed that nurses conferred with family members because they wanted to be sure about families' decisions on the choices made. This may imply that when considering respect and dignity, nurses need to go beyond honouring choices which are deemed good to them as professionals. Studies that only focus on respect and dignity have received little attention in family centred care literature both in developed and developing countries indicating the need for more research to focus on the concept.

Information sharing.

As described by IPFCC (2010), information sharing emphasises that health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making. Literature has recognised that communication between nurses and family members is vital for a collaborative relationship and parents (Espezel & Canam, 2003; Uhl, et al., 2013; Coyne, et al.,

2011). This implies that lack of adequate information on the childrens' treatment and care may form an important gap and may contribute negatively to parents' experiences in the hospital. Coyne, et al. (2011) highlight that improved communication is a cornerstone in family centred practice.

It has become a fact that both nurses and family members values communication. In a study 'Insights into patient and family-centered care through the hospital experiences of parents' in USA, Uhl, et al. (2013) described parents' care experiences during hospitalization of their children. The study used both a descriptive qualitative study and the quantitative survey. A qualitative study involved three focus group discussions. The study demonstrated that parents valued communication between nurses and families. The study highlighted that communication between family members and nurses was instrumental in shaping their positive hospital experience because communication provided awareness during their different levels of hospital transitions. This finding is consistent with findings of Coyne, et al. (2011) in Ireland. In this study which used qualitative descriptive approach to examine perceptions and practice of family centred care among nurses in seven hospital units in Ireland, nurses reported that communication between them and family members is important. Further nurses in this study indicated that improved communication would enhance family centred care. These two findings present one thing in common although they used different participants. It shows that both nurses and parents of hospitalised children value communication.

Conversely, studies have also revealed that communication difficulties exist between nurses and family members (Lam, et al., 2006; Pongjaturawit & Harrigan, 2003; Soderback & Christenssen, 2008; Shields, et al., 2006; Shields & Nixon, 2004). Communication difficulties between nurses and parents result from nurses' lack of interpersonal communication skills

(Galvin, et al., 2000; Espezel & Canam, 2003; Ford & Turner, 2001). Coyne (2006) conducted a study entitled disruption in nursing care in England which investigated parent participation in the hospitalised child's care from the perspectives of children, nurses and parents. The study used grounded theory through in depth interviews and observation method to collected data from 12 registered nurses in four paediatric wards. The study highlighted that nurses experienced difficulties in communicating with families due to poor interpersonal skills. As a result, there was disruption in care as parents who had little information experienced anxiety, role deficit and poor role preparation. The study indicated that communication skills are essential to nurses if they are to foster a positive nurse-parent relationship. This may mean that as regulators of the hospital environment, nurses need to provide more information which in turn moderates the relationship between nurses and parents. This is important for improving children's care in the hospital.

Participation.

Participation in care envisages that patients and families are encouraged and supported in participating in care and decision-making at the level they choose (Fults, 2011; IPFCC, 2010). Family participation in care as an intervention refers to a strategy that partners family caregivers and staff to provide the best possible care for a hospitalised child. According to the University of Iowa (2009), one key aspect to the participation is for both parties to continually negotiate and clarify their expectations to establish mutually satisfactory roles and relationships. Staff members help and facilitate family members to participate in care planning, delivery and evaluation unconditionally. The hospital staff should help family members to choose the type and frequency of tasks in which they want to participate (IPFCC, 2010). An extensive review of recent

literature on parental involvement, views and perceptions about their participation in the care of hospitalised children indicate that few studies have explored parental participation in developing countries (Shields & Nixon, 2004; Shields & King 2001; Pongjaturawit & Harrigan, 2003; Soderback & Christenssen, 2008; Soderback & Christenssen, 2007). In Malawi, few studies have focused on patients' experiences and their perception of nurses and nursing care (Larwigh & Makupe, 2009; Brysiewicz & Bhengu, 2010; Gondwe, Bhengu & Bultemeier, 2011). However, nurses play an essential part in attending to the needs of families (Soderstrom, et al., 2003). This means that their experiences too need to be explored.

Soderback and Christenssen (2008) conducted a study to explore nurses' beliefs and practices regarding family involvement in Mozambique using a qualitative method. The study used a semi structured interview guide to collect data from 36 nurses with long working experience at a referral hospital in Maputo. The study concluded that employing a culturally congruent nursing care is important so that families should be accommodated. The study also concluded that although family involvement empowers family members, the Mozambican nurses themselves needed to be empowered first. This conclusion implies that nurses in this study may have experienced problems when involving families. This study does not mention the nursing cadres involved but it forms the basis on which studies from Sub Saharan Africa can be based. However, as it was done only at one site, its findings may be hard to generalise. Furthermore, education preparation for Mozambican nurses may be different from other countries including Malawi hence the findings may be hard to apply to the Malawian context.

On the contrary, studies on family participation in care have found that nurses control the amount of family involvement in care (Paliadelis, et al., 2005; de Lima et al., 2001; Soderback & Christenssen, 2007; Soderback & Christenssen, 2008). Paliadelis, et al. (2005) conducted a study

in Australia which explored nurses' beliefs and practices regarding family centred care in Australia using a qualitative descriptive study. Fifteen full time registered paediatric nurses were interviewed using a semi structured questionnaire. The study found that nurses involved parents in care but did not allow them to do more skilled tasks. Nurses in this study stated clearly that skilled tasks should be left to them because they are the ones who know nursing. It was concluded that nurses were protecting their professional boundary. This may show that some nurses regard family involvement as a threat to their nursing profession. This is consistent with the findings of de Lima et al. (2001) in Brazil who found that parents complained that nurses relegated them to doing menial and household jobs despite agreeing that they would assist in nursing jobs. These two studies agree with a growing body of literature which acknowledges that although nurses advocate for family participation in care, their actions do not reflect this notion (Shields, et al, 2006; Orril, 2009; Stayt, 2007; Pontello-Montovanni, et al., 2009).

Collaboration.

Patients, families and health care practitioners collaborate on policy and the delivery of care (Blue-Banning et al., 2004). Literature highlights that for collaborative partnerships between nurses and family members to occur, there should be trust, open communication, commitment, equality and support between them (Uhl, et al., 2013; Espe-Sherwindt, 2008; Espezel & Canam, 2003; Gallant, et al., 2002). This implies that collaboration is a product of cordial power sharing between family members and the nurses in the hospital which forms the cornerstone of their partnership.

Blue-Banning, et al. (2004) demonstrated the importance of collaborative partnerships in family centred practice through their USA study. The study explored dimensions of family and

professional partnerships. The aim of this study was to generate constructive guidelines for collaboration. The study used qualitative inquiry through 33 focus group discussions with adult family members whose child was admitted. The results identified six broad themes of collaborative indicators between family members and providers. These were communication, commitment, equality, skills, trust and respect. The strength of this study is that it identified the common gaps which lead to failures in collaborative process between families and health care workers. The key aspect of collaboration is failure of providers to understand the role trust and open communication play in collaboration. Blue-Banning and colleagues argue that failure to recognise and apply these elements makes collaboration often unsuccessful.

Espezel and Canam (2003) explored the parent-nurse interactions in the hospital environment. This study used a qualitative descriptive study to examine the experiences of parents who interacted with nurses in a hospital setting regarding the care of their children. The study identified important elements for a collaborative relationship between parents and nurses in the care of hospitalised children. These elements include establishing trust, rapport and communicating openly and clearly and that these elements are influenced by professionals' attitudes. Espezel and Canam (2003) ascertain that unless nurses understand these elements, their interaction with family members may not be construed as collaborative. Studies on collaboration are scanty in Malawi making it hard to understand how the collaborative partnership between nurses and family members is accomplished.

Family involvement in the context of the hospitalised child

Family involvement is a concept within family centred care. It is also referred to as parental involvement or participation. In this endeavour, patients and families are encouraged

and supported in participating in care and decision making at the level they choose (Saskatchewan Ministry of Health, 2011; Dunst, Trivette & Hamby, 2007a). Literature has found that family is central to child care and hospitalisation of the child is stressful to family members (Espe-Sherwindt, 2008; Sodomka, 2010; Harrison, 2011; Stayt, 2007). This implies that involving the family in the care is of paramount importance because both the child and the family need to be cared for within the health care services. Several researchers have studied the concept of family involvement in care of their hospitalised child and agree that involving families is important part of paediatric nursing (Shields & King, 2001; Irlam & Bruce, 2002; Lam, et al 2003; de Lima, et al., 2001).

Ygee (2004) conducted study to understand parental involvement in care and its implications for clinical practice in Swedish hospitals. In her study, she used qualitative approach and data was collected from 14 parents using a semi-structured questionnaire to understand factors that influence parental involvement in hospital paediatric care. The results of study showed that parents expressed concern that staff were mostly carrying out care on the children on their own and parents felt that they needed to be involved in every step of care. This view was also shared by staff members. This may imply that clear association exist between parents and staff members' views that parental involvement is important for both nurses and family members. Previous and current studies show that family involvement is essential in paediatric care (de Lima, et al., 2001; Harrison, 2011; Mackay; 2009; Coyne & Cowley, 2011).

Family involvement has been studied as an intervention as well as a concept of care. Specht, Taylor and Bossen (2009) using qualitative methods, studied the benefits and application of family involvement in the care of children and adults with dementia in Iowa in the United States of America. In their study, 30 parents of dementia children admitted to 8 paediatric units

were interviewed using a semi structured interview guide. The study concluded that family involvement was important. Family members of dementia children expressed their feelings on being involved as continually partnering with nurses, clarifying and establishing rapport with professionals. This may imply that when family members are involved in the care of their children, it helps them to be in control of the caring situations that occur during their period of stay at the hospital. However, there scarcity of literature in Malawi which entails that little is known regarding family involvement in the care of hospitalised children.

Based on the analysis of the qualitative literature, parents are willing to participate in the care of their hospitalised children (Pongjaturawit & Harrigan, 2003). Using a systematic review of literature, Pongjaturawit and Harrigan (2003) concluded that although many parents feel anxious and out of control, they wanted and are willing to participate. However, their willingness is based on culture, ability to understand and conditions of their children. In contrast, Lam, et al. (2003) found that in China, most parents were willing to participate in care but sometimes avoided communicating with nurses to avoid confrontation. In this study, it was concluded that in Chinese culture, silence is used as a tool to prevent confrontation. In conclusion, these studies show that despite cultural differences, parental participation in the care of their hospitalised children is widely valued across these countries.

In a different focus, Soderback and Christensson (2008) conducted one cross-sectional study to highlight family involvement in the care of the hospitalised children in Mozambique using a descriptive qualitative design. The aim of the study was to describe the family members' experiences, needs and expectations with family involvement in the context of Sub-Saharan Africa. The study recruited 100 parents at the Paediatric Hospital of Maputo. The findings indicated that Mozambican families needed more information before, during and after

involvement in tasks and wanted to engage with engaging nurses. Some family members were willing while some were frightened to participate. The study also revealed that unlike western and Chinese parents who had a choice, most Mozambican families were involved in care not by choice but by circumstances such as shortage of nurses and doctors.

Importance and benefits of family involvement in the context of hospitalised children

Studies demonstrate that it is beneficial to involve families in the care of hospitalised children. Majority of studies show that when parents are involved, there is improved communication, reduced costs, reduced workload on part of nurses and increased quality of care including parental satisfaction with care (Ygee, 2004; Harrison, 2011; Saleeba, 2008; Stewart, Ryan & Bodea, 2011). A study by University of Iowa (2009) studied family involvement in care for children with dementia in a nursing care home as an intervention. Using qualitative descriptive method through in depth interviews, data was collected from 28 family members of dementia patients. The study found that family involvement improves staff and family members' motivation, prevents staff and care giver tensions and negative attitudes, reduces workload for nurses and improves communication between nurses and family members. However, the study did not provide quantification for this assertion. The Saskatchewan Health Ministry in the United States assessed benefits of family participation in child care. The study used retrospective descriptive design and 250 participants were enrolled. The study found that involving patients and families in care reduces costs by 50%, medication errors reduce by 62% and satisfaction with care fell within 75^{th} to 95^{th} percentile. Saleeba (2008) also reported that besides costs and reduced hospital stay, child's emotional and physical growth improves. Saleeba concluded that without family involvement families can experience conflict with staff over competing choices

and priorities. However, Saleeba's did not quantify the changes in emotional and physical improvements. Nonetheless, it may be concluded that family involvement is beneficial.

A study to quantify monetary benefits of involving families in care through a concept of family centred care was conducted by Stewart et al. (2011) in United Kingdom and Canada. The study used a quantitative approach to compare and investigate the cost implication of family participation in care and ordinary care. 311 files were reviewed in each category. The study found that the mean cost difference was US$29.48 in favour of family centred care where families were fully involved. A meta analysis on family centred practice of 47 qualitative studies from 7 countries was done by Dunst, et al. (2007a). Results found that involving families was linked to greater family satisfaction, stronger self-efficacy and sense of control and greater family perceptions of helpfulness of support and services. However, studies on benefits of family involvement have received little attention in developing countries including Malawi hence the need for further research in this area.

Nurses' Experiences Regarding Family Involvement in the Context of Hospitalised Children

Literature indicates that nurses' experiences are mixed and depends on nursing care settings. Mackay (2009) used a qualitative descriptive study to study oncological nurses experiences regarding working with families. A total of 30 family members participated in the study. This study found that some nurses had positive experiences when working with families of hospitalised children. However, in the same study, some nurses indicated that they were challenged. The study concluded that this was because such nurses did not posses adequate interpersonal skills such as direct communication. Ford and Turner (2001) used a

phenomenological study on 4 very experienced registered nurses to explore their experiences when caring for hospitalised children in a 15 bedded hospital in Australia. The findings were mixed. The results revealed that registered nurses in that study experienced a balance between rewards and frustrations while revealing encounters with multiple realities. The study reports that nurses revealed the warmth they experienced, the frustrations and guilt feelings which come due to inadequacy when they attempt to fulfill their roles, professional goals and the uncertainty on who is the expert in care between the nurses and family members. Nurses in the study reported frictions between them and family members and difficulties in maintaining lasting relationships with family members in the wards. These assertions may indicate that not all nurses have similar experiences when working with families.

Nurses' experiences regarding involving families may be complex and country specific (Soderback & Christensson, 2007). In Mozambique, a study by Soderback and Christenssen (2007) on nurses' beliefs and practices regarding family involvement revealed cultural hierarchy and social inequalities. The study showed that nurses' experiences regarding families were based on social status, hierarchy, communism and poverty. The study found that cultural orientation and belief on communism were central to family involvement. In later study on family involvement in Mozambique, Soderback and Christensson (2008) found that Mozambican families described nurses as being of higher hierarchy than them, a thought that affected their communication and interaction with nurses. This finding is consistent with findings of Zaman (2004) in Bangladesh. In that study Zaman used a qualitative descriptive study to explore nurses' interaction with parents of hospitalised children. Zaman argues that in a society where cultural hierarchy predominates, the social interactions are also affected. Zaman further argues that such experiences are common in societies stricken by social and cultural inequality of power. It may

be concluded that some nurses' experiences are influenced by beliefs in cultural hierarchy and communism.

Factors that Facilitate and Hinder Nurses' Efforts on Family Involvement

Literature has highlighted personal and professional factors that challenge nurses when working with family members of hospitalised children. Few studies have highlighted institutional issues such as shortage of nurses and lack of policy to guide direction. Coyne, et al. (2011) used a descriptive survey design to explore ideas from 250 nurses on how family centred practice can be improved. The results indicated that in Ireland, nurses failed to implement family centred practice interventions due to lack of resources, organisational support from managers and lack of policy to guide direction in some settings. However, in this study, issues of shortages of nurses were seldom indicating the thresholds may not be critical. Paliadelis, et al. (2005) found that in Australia lack of guidelines was isolated as a drawback in furthering family centred practice. Paliadelis, et al. argue that without an evidence-based policy nurses will find it difficult to implement family centered practice. Literature has highlighted that low literacy and low self esteem affect family participation in care (Ishikawa & Yano, 2008). Soderback and Christensson (2008) found that in Mozambique, nurses highlighted poor working environment, low literacy, and poor education for nurses, low wages, long working hours and limited resources at the hospital as most important challenges. They also reported that their burden of duties and poor relationships among nurses affected their concentration at work. This may show that nurses' experiences and efforts are affected by different circumstances and contexts. These circumstances may be peculiar to each country and should be subjected to empirical inquiry.

Conclusion

The literature review has shown that it important to involve family members and significant others in caring for the hospitalised children. Health care workers need to create a deliberate opportunity so that this is achieved. It is also important to note that the experiences of nurses regarding family involvement are mixed and contextual. This may mean that no one context can completely describe the other. There is scanty literature for Africa and sub-Saharan region. Most publications done have focused on parental perception in Sub Saharan Africa (Larwigh & Makupe, 2010). Admittedly, none of the studies have explored experiences of registered nurses when working with families of hospitalised children in Malawi. This may mean that important issues concerning nurses who coordinate this care have not been elaborated. This leads to a suggestion that knowledge gaps exist on the phenomenon in a Malawian context hence the need to conduct this study to uncover such gaps.

CHAPTER 3

Methodology

The Research Design

This study used a descriptive qualitative approach to describe nurses lived experiences on family involvement in the care of hospitalised children at QECH. One assumption about descriptive qualitative studies is that for any human experience, there are essential structures that make up that phenomenon regardless of the person who experiences it. These essential structures can be discovered by studying the particulars encountered in the lived experience (Lincoln & Guba, 2004). This study was guided by naturalist philosophical paradigm. Naturalistic researchers believe in understanding the human experience as it is lived through the collection and analysis of subjective narrative data that evolve in the field (Polit & Beck, 2004) This qualitative research paradigm believes that naturalistic studies result in rich, in depth information which has the potential to bring multiple realities and dimensions of a complicated phenomenon under (Guba & Lincoln, 2004). This study used in depth interview as a means to understand the experiences that registered nurses at the QECH have regarding family involvement. This means that the researcher was intensely involved and engaged with the respondents in the data collection process. Polit and Beck (2004) asserts that this approach helps the researcher to understand the responses and their meanings better.

Setting

The study was conducted at QECH, one of the referral hospitals in Malawi situated in Blantyre. The study took place in the paediatric section of the hospital and will include Special Care Ward, Surgical Ward, Paediatric Nursery, Oncology Ward, Malaria Research Ward and the

Nutrition Rehabilitation Ward. The setting was chosen because it is the tertiary and referral hospital for critically ill children from all over Malawi where these children and their families are expected to receive family centred care. The family members are involved in the care of their sick children. Furthermore, the hospital has nursing experiences which the researcher intended to uncover.

Study Period

The study was conducted from January 2014 to July 2015. This included development of the proposal, data collection and analysis and writing of the final report.

Study Population

The study's target population included all registered nurses working in the following wards in the paediatric section: Special Care Ward, Surgical Ward, Paediatric Nursery, Oncology Ward, Malaria Research Ward and the Nutrition Rehabilitation Ward. The researcher's choice of registered nurses was based on their scope of practice which mandates them to plan, regulate, coordinate and delegate care in the wards (Nurses and Midwives Council of Malawi, 2003). This means that registered nurses take a leading role in providing care to children and their families. At the time of developing the proposal , there were 5 registered nurses in special care ward, 2 in surgical ward, 3 in Malaria Research Ward, 2 Nutrition Rehabilitation Ward, 2 in Nursery Ward and 2 in Oncology Ward making a population of 16 registered nurses.

Sampling Procedure

The study utilised a purposive sampling method to recruit participants based on the inclusion criteria. Participants were selected because they were knowledgeable and have

experience on the phenomenon under study and its social processes (Speziale and Carpenter, 2007). The researcher believed that participants with the characteristics described in the inclusion criteria will best contribute to the information needs of the study. All registered nurses who met the inclusion criteria had a chance to participate in the study.

Sample Size

Fourteen registered nurses from all paediatric wards were recruited and interviewed. Nastasi (2003) and Holloway & Wheeler (2002) stress that as a rule of the thumb, in descriptive qualitative studies, a sample of ten or fewer is adequate especially when the researcher is using participants with similar backgrounds and experiences(homogeneous participants). However, the sample may decrease or increase depending on data saturation. Data saturation is the repetition of discovered information by study participants which confirms the previously collected data (Speziale & Carpenter, 2007). In this study data saturation was reached during the interview with the 14th participant.

The inclusion criteria included the following:

- Agreeing to participate in the study after being given the information about the study
- Being a registered nurse working fulltime in the paediatric unit.
- Having one year working experience in paediatric wards at Queen Elizabeth Central Hospital

Data Collection Methods

Data Collection Tools

In-depth interviews were conducted to collect data from individual participants using interview guide (Appendix A). Section A of the interview guide contained demographic information such as the participants' age, sex and professional qualification, number of years in service, tribe and religion. The demographic data helps in informing the researcher and consumers as to whether the sample reflects the attributes of population of interest (Kaiser Permanente Nursing Research of California, 2007). Section B focused on description of the nurses' experiences and how nurses engage patients and their families based on dignity and respect, information sharing, family participation in care planning and collaboration. These are key thematic areas of family involvement and family centred practice as guided by the conceptual framework.

Qualitative variables under examination were guided by the study objectives which emanated from the theoretical framework of this study. Data was collected on description of nurse's experiences regarding family involvement. Further the interview guide sought information on four pillars of family involvement which are dignity and respect, information sharing and participation and collaboration including factors that influence family involvement. Probing, prompting and clarification will also be used to guide the respondent in answering the questions and to obtain additional information. Each interview session took 45 minutes.

Data Collection Procedure

The researcher collected data after obtaining study's ethical approval from COMREC. The researcher reported to the Chief Nursing Officer at Queen Elizabeth Central Hospital in

Blantyre to make a personal introduction and to explain the intention to commence data collection for the study. The Chief Nursing Officer referred the researcher to the Unit Nursing Manager .The researcher also introduced himself and explained the intention to seek permission to start recruiting the participants from their working wards.

From the Section Nursing Managers, the researcher approached ward in-charges. Here, the researcher also explained the study and present the intention to start collecting the data from the participants. These in-charges assisted the researcher to identify venue for interview as well as identification of eligible participants for the face to face interview. The researcher liaised with one Section Nursing Manager to arrange a room away from the wards but within the section. Before the interview, the identified participants were given full explanation of the study and information (Appendix B). Those who consented were asked to sign a consent form (Appendix C). The researcher sought permission from the participants to have the interview recorded. Data was captured using voice recorders. Data collection was expected to take one week.

Data Management

Each interview session was audio-recorded. During interview sessions data collection and analysis was done simultaneously. This assisted the researcher to identify a point of data saturation. Furthermore, data was thoroughly checked for accuracy and completeness at the end of each interview session. This ensured that all important and relevant data was collected from the respondents.

The recorded data were then transferred and stored on a computer. Later, these were transferred to compact discs which were duplicated to ensure adequate back up in case of loss or damage of the computer or voice recorders. All recorded data were secured with a password

known to the researcher only. Voice recorders were kept under lock each time they were not in use. The researcher also maintained a field diary in which field notes were documented. Audio recorded data and hard copies (transcripts) were kept for five years after which data would be erased from recording devices and hard copies incinerated.

Data Analysis

Demographic data were analysed using descriptive statistics (frequencies, percentages and means). Audio recorded data were first transcribed verbatim and categorised. The researcher utilised Thematic Content Analysis (TCA). According to Graneheim & Lundman (2004) TCA ensures that data collected through in-depth interviews method is related, appropriate and value bound and meaningful patterns emerge. TCA has five components for analysing qualitative data namely: transcription of raw data, condensation of data, grouping of data into codes, creating categories and development of meaningful themes.

Step 1: Transcription of raw data

Transcription involved identifying meaning units word by word from phrases and paragraphs containing aspects that relate to each other (Graneheim & Lundman, 2004). The words or statements that relate to the central meaning were grouped to form meaning units.

Step 2: Condensation of data

Condensation of data involved process of shortening the text while still preserving the central content (Graneheim & Lundman, 2004). The researcher did this by paraphrasing the data material to reduce the data into its basic content. At this point long sentences were turned into short forms called condensed meaning units.

Step 3: Grouping data into codes

This stage involved putting together condensed meaning units into codes based on their similarities and differences. This allowed the researcher to understand this information in a new and different way while focusing on the context.

Step 4: Creating categories

Creating categories (categorization) is the key aspect of qualitative content analysis whereby the researcher groups the content that share common similarities (Graneheim & Lundman, 2004). Data were grouped according to their similar and different units. The researcher made sure that the categories are comprehensive and have mutually exclusive meaning. At this point the researcher ensured that no data related to these meanings were omitted due to lack of a suitable category.

Step 5: Developing themes

The researcher developed main themes from the categories based on five (5) content areas as outlined by the objectives. Furthermore, sub themes were developed depending on the flow of the information from the categories. All this was guided by the four main concepts as outlined by the conceptual framework (Figure 1) which are the guiding principles of family centred practice. Finally, the researcher presented the identified themes as main findings of this study.

Trustworthiness

In this study, trustworthiness was achieved by the adhering to credibility, dependability, confirmability and transferability standards.

Credibility

Credibility includes actions that increase the probability that reliable findings will be produced (Polit & Beck, 2004). In this study, a study comprehensive methodology was laid down to indicate the researcher's strife for quality data. This methodology was followed during recruitment and data collection, analysis and presentation of findings. Information was collected from nurses who were experienced and knowledgeable about family involvement. The researcher used probing, paraphrasing and clarification techniques to elicit information from participants. The researcher ensured that the language used was simple and straight forward, data collection environment was quiet, conducive for interpersonal interaction and not intimidating to participants. The researcher also put sufficient time during data collection in order to have a deeper understanding of participants' experiences. During the analysis and presentation of finding, the researcher used peer and expert checking to ensure the credibility of findings. On expert checking, the researcher first gave the findings to the supervisor before presenting and publication. Polit & Beck (2004) indicates that experts and peers help to review and explore various aspects of the inquiry to realign the findings before publication.

Dependability

The researcher ensured dependability by being consistent and paying careful attention to the rules and conventions of the qualitative methodology (Ulin et al, 2005) as outlined in this proposal. Further the researcher stated the methodology in step by step presentation so that other researchers may repeat the process and produce similar finding in the similar contexts. For example, the researcher stated clearly inclusion criteria. According to Graneheim & Lundman (2004) the step by step presentation of the methodology prevents instability and design induced changes that may also impact consistency. The researcher ensured that research participants were

interviewed in similar conditions that is, quiet and well light environment free of intimidation and suspicion. A pilot study was done in order to pretest the data collection instrument. After piloting the results facilitated necessary changes to be made to validate the data collection instrument.

Confirmability

Confirmability refers to the objectivity or neutrality of data that is potential for congruence between two or more independent people about data accuracy, relevancy and meaning (Polit & Beck, 2004). To ensure confirmability, the researcher observed and documented own personal biases or reactions that could affect or influence data collection and interpretation. The researcher also used independent people, for instance the research supervisors, to verify participants' responses against the set questions. The researcher presented the findings in a manner that reflects the participants' feelings and thoughts not the researcher's imagination. This was substantiated by narrative data.

Transferability

To ensure transferability of the study findings, the researcher ensured correct selection of participants and adherence to the study design and data collection methods. Ulin, et al.(2004) state that careful selection and adherence to inclusion and exclusion criteria leads to transferable findings. The researcher also gave sufficient descriptive information on the participants, their experiences and the context under-which they provided care to reflect what was happening on the ground. Graneheim and Lundman (2004) state that to facilitate transferability, it is valuable to give a clear and distinct description of culture and context, selection and characteristics of

participants, data collection and analysis. The findings and recommendations were given to the head of paediatric unit and the hospital management so that they can evaluate them as well.

Ethical Considerations

The researcher got approval from COMREC and institutional clearance from the Director of QECH. This was to ensure that the study complies with ethical standards on protection of human subjects from exploitation (Appendix D). Permission was sought from Chief nursing officer and Unit Nursing Manager, in-charges and participants at QECH to start data collection. Information about the study was given to the participants (Appendix B). Participants were asked to sign a written informed consent prior to participation in agreement to their willingness to participate (Appendix C). The information letter contained information on the purpose, benefits, and risks of the study.

Participants were informed of their right to voluntary participation or withdraw and that no penalties were granted to be given on such a decision (Appendix B). Participants were duly informed that there were no monetary and other benefits for taking part in the study but that their information will contribute to quality of child health care in future. Participants were also assured that their identification was kept confidential during analysis, presentation, dissemination and publication of the findings. The researcher informed participants before signing the consent form that expected risks to be encountered during research included physical, psychological, social, and emotional due to long interview and waiting time. Long waiting time before interview could be due delays because some participants could be slow to answer questions or require a longer break during the interview or other unforeseen circumstances prior to the interview. The researcher informed and updated concerned participants regularly by telephone if a possibility

that appointments may delay became imminent. However, the researcher endeavoured to keep time during the each interview so that appointments are adhered to.

CHAPTER 4

Presentation of Findings

Introduction

This chapter is going to present the findings of this study. The first section presents the demographic characteristics of the participants using descriptive statistics while the second section presents the qualitative results which use verbatim quotes from the participants. From the analysis, seven themes emerged.

Demographic Characteristics of the Participants

Fourteen participants who were full time practicing registered nurses working in various wards in the paediatric section at QECH participated in this study. Their ages ranged from 22 years to 48 years with a mean age of 26.8 years. There were 11females and three males. Six participants were Lomwe, four were Ngoni and two were Chewa, one was Yao and one was Tumbuka. All participants were Christians of which five belonging to Church of Central Africa Presbyterian (CCAP) four were Seventh Day Adventist, two were Assemblies of God and one Roman Catholic, one Bible Believer and one Charismatic Redeemed International Church. Twelve participants had Bachelor of Science degree in nursing and two participants had a diploma in nursing. There were two participants who had specialised training in child nursing. The work experience of participants ranged from one year three months to five years ten months.

Qualitative Findings

The qualitative data was analysed using the thematic content analysis (TCA) and seven themes emerged as follows: Meaning of family involvement, rationale for family involvement, experiences with family involvement, power and control, core concepts of family centred care, factors influencing nurses on family involvement and nurses' impression of family involvement. These themes have been further described below.

Meaning of Family Involvement

Participants described family involvement as various ways of incorporating members of the family in the care of the hospitalised child from time of admission, delivery of nursing care to evaluation and discharge or death of their child. One participant narrated that involvement includes siblings and members of the extended family or significant others. "*It means whatever we do in the ward, we should involve family members at all cost" (*Participant 1*)*. Similarly, another participant described family involvement as follows:

> "*It means involving family members in the care of the child. It has different forms, It may mean the physical contact even the input on what to do on the child. The parents can be there or at home but be contacted on the decision on their child"* (Participant 9).

Rationale for Family Involvement

The reasons for involving families include sharing responsibilities with families, for social support, because the family is an expert entity in care and for partnership on decision

making. Nurses reported that they have their own clinical roles and responsibilities but they share these responsibilities with families during involvement. One participant said.

> *"It helps in care of the child because in cases where you look at the number of nurses and the amount of work that you do, you cannot commit yourself to everything so they take on other responsibilities*" (Participant 11).

Some nurses felt that family members support them mostly in making the child calm so that assessments are thoroughly done . A participant commented " *family involvement is important because it is a social support to children...it helps to share the burden of sickness and reduces workload for nurses"* (Participant 5*).* One area where responsibilities are shared is when a child dies. Participant 9 said "*When the child dies parents appreciate the work done by nurses and they share the understanding that nurse tried their best".* Furthermore, participants reported that the family members know their child better and are also experts in care and can be in a position to share their knowledge with nurses.

> "*family members know what is happening to their child and are willing to give information they have in the care of the child so that we can improve the care and nurses solicit ideas from them to provide quality care*" (Participant 8).

It was clear from participants' reports that family involvement helps in making decisions regarding care of the child. They revealed that sometimes there are difficult decisions to be made and everybody (nurses and doctors) may not be willing to risk taking that decision alone. One participant reported that "*parents and guardian are involved in care that nurses are providing so*

that they can give consent when difficult need arise in the care (Participant 8). Similar views were shared by participant 4 who said that

> "*there was a child with haemoglobin of less than one and belonged to Jehovah's Witness who refuse blood transfusion. The health care workers planned to transfuse blood. We discussed with the mother after the father and others have gone...she said we can go ahead and she will bear the consequences"* (Participant 4).

Participants also reported that family members help to offer support to their hospitalised children and nurses. The support ranges from being with the child during painful procedures to offering comfort and also helping nurses to interpret child behaviours. Participant 6 said that *"some children cooperate when their family members are around because they know them and feel secure...You can easily do procedures because guardians communicate with child".*

Experiences with Family Involvement

Subthemes that emerged from this theme include rewarding encounters, demanding encounters and encounters with multiple realities when working with family members.

Rewarding encounters.

Some participants reported that working with the family members has been a good or a fruitful experience. They said it was better to work with family members because they bring variety in care, family members cooperate with nurses and if properly utilised nurses they can benefit a lot from them.

"*To be frank with you, it has been a good experience. I have been able to do other things because mothers have assisted me on things that would have been done by me as a nurse such as feeding a child on nasogastric tube; we have given this to mothers and it has lessened my work"* (Participant 9).

Interestingly, some participants felt that family members are irresistible to work with because they deserve to take part.

"*So far so good- we work together with the families because they need to know what is going on. We cannot run away from them because treatment takes time so they need to be there, it's their right"* (Participant 7).

Other participants said that working with family members in the care of their hospitalised children has become a reality not an option. This is due to chronic shortages of staff. One participant said this:

"*you find that there are few nurses and there are many patients which is a problem here so you have no choice but to involve family members to assist you. So as a nurse can concentrate on the most other nursing care issues" (Participant 1*).

Demanding encounters.

Some participants felt that involving family members has been taxing and an obstacle to their accomplishment of daily nursing plans. They reported reluctance and negative attitudes of both nurses and the family members to each other. Some nurses reported late coming to the hospital by family members, families not following instructions and working with over demanding family members. Participant 10 said that:

"*It has been a challenging experience because the family brings the child very late when critically ill. This is a big challenge because they are bringing the child when the condition is worse. This makes sitting down with family members a challenge and you are forced to shout at them and this spoils your relationship and they don't trust you even if they are wrong".*

One participant said the following with regard to health education of the family members:

"It takes time for family members to accept and gain the skill because some skills need time for them to learn such as feeding through nasogastric tube...As we nurses work on shifts, sometimes you initiate the process of imparting the skill some nurses are not aware of what you have started to the guardian...We do hand over but you can see that your friends have done nothing the next day. So the challenge is that the break affects the guardian to understand the skill, it's a challenge" (Participant 11).

They also narrated taxing encounters. Participant 12 said; "*The attitudes of the parents...some expect a lot from us so this makes us not to involve them fully in the care of their children so you think the next one will also be too demanding".*

Encounters with multiple realities.

Some participants indicated that their experiences have been both demanding and not good among other factors.

"*It has been fair-not all of the nurses do that...it depends on the attitude of the nurse or the guardians. Some even don't want some want so it's fair- its fifty-fifty. Some involve families because they know them or understand the issues...its fifty-fifty" (*Participant 3).

Some participants felt that they may not comfortably say their experiences have been good or demanding. Participant 1 said; *"To be frank, of course here and there, there has been some problems and good things....so you can't say it has been good or bad...it's good to say it's fair".* Other participants reported that they experience professional conflicts between family involvement and ethics hence cannot describe it as good or bad. Participant 5 said;

> *"You see due to our ethics ...it is wrong to give your responsibility to family members as a nurse...but you do that instead...you feel you are guilty when you delegate tasks that are nursing in nature to parents or guardians so you may not be comfortable at times when that feeling comes".*

Nurses Power and Control

Subthemes that emerged under this theme include regulation of amount of involvement and coercion on the perspectives.

Regulation of amount of family involvement.

Participants reported that they don't involve family members in care planning but in delivery or implementation of care as most of them do not understand the planning process.

> "*To say the truth we don't plan the care with families in this ward... we just come and deliver the care especially when the child is very serious... we just tell them that we are doing this and this but do not incorporate them to make decisions on the care that we want to give to the child... Mostly we just impose on them what they should do...We don't involve them in planning... we tell them we are going to do this and this"* (Participant 6).

Some participants reported that they involve family members only in delivery of care because it is easier to involve them at this stage. Participant 8 said:

> *"It is easier to incorporate family members in delivery than planning...I feel in planning we don't involve them...we don't even ask them we tell them. Mostly we nurses plan ourselves...they just accept what we have planned for them...We just tell them this is what we are going to treat your child and you are going to assist by doing this and this".*

Participants also indicated that their involvement of family members depends on the seriousness of the condition, level of literacy and understanding of family members and time available. Participant 7 said;

> "*It depends...when the condition is serious, we mostly attend to the child...the number of patients at a time also determines how you go about involving family members to assist in caring...When busy we concentrate on sorting out the work*".

Coercion.

Participants reported that sometimes family members make difficult decisions which the participants felt that they are detrimental to the health and functioning of the child. So they use their medical knowledge to impose a choice or a decision on family members and the children. One participant said:

> "*It depends...there is some choice that I can let go but there are those that leave me with no choice but to force on them. When the child comes in and is blue, failing to breathe even if the parent may refuse Oxygen, I sometimes use my knowledge and authority just to put the child on Oxygen so that she can get well...it goes beyond my imagination if*

parents refuse...it's okay if they remove after I have commenced after all I have done my part (Participant 12).

However, not all coercive situations occurred without exhaustive discussions with family members. The participants explained that some family members are very emotional but they [participants] do things in the interest of the child. One participant said;

"*Here they have the right to choose because it's their right. But sometimes they make difficult choices...e.g. the family wants to go home while the child is seriously sick in order to go to home remedies or prayers. We inform them that we have not given up...We explain to them the good and the bad of their decision...at this point if the family still insist we just say no and they remain in the hospital until the child gets better"* (Participant 3).

Participants reported that they consult members of the multidisciplinary team before making their coercive decisions on family members. Participant 11 narrated*:*

"When they refuse treatment when the child is very ill we sometimes involve other stake holders like doctors and palliative care and nutritionists...if they still refuse we go ahead with the treatment because our motto is to save life and we don't want to be blamed...e.g. there was one who refused blood transfusion but the child was very pale and breathless, we consulted widely together with the mother...she refused. We 'just' commenced treatment".

Core Concepts of Family Centre Care

There were four subthemes which emerged under this core theme. These are respect and dignity, information sharing, family participation and collaboration.

Respect and dignity.

Participants viewed respect and dignity as an important aspect in their experiences on family involvement in the care of the hospitalised children. They described respect and dignity as an obligation for nurses to respect family members and hospitalised children's perspectives, human rights and their right to health, honouring their choices, cultural and religious beliefs and offering them privacy and confidentiality. In addition, one participant described respect and dignity as observing the code of ethics for nursing when rendering care. Major categories under this subtheme include establishing rapport, honouring family and children's choices and conferring and letting go.

Establishing rapport.

Participants reported that they assumed the role of creating a therapeutic ground from which family members and their children can be involved in care. A key aspect of establishing rapport from the participants was their demonstration of interest in the family members and the children, respecting their presence, views and valuing and accepting them in participants' life while assuming the role of an educator and a guide. Participant 2 said:

> "*Respect starts when the patient and family member come in and you establish rapport, that means good rapport and the patient becomes free. Then you teach, explain and discuss...When you explain to the family, patient and they understand and the other thing*

you just treat the family, patient not looking at race, wealthy or poor just treating them as they are then they become free to interact with you".

Establishing rapport also occurred when the participants spent longer time with the family members.

"*When you also spend time with them because of their child's condition as it is here and you speak to them in a polite and calm way, they know you are there for them and your relationship grows and you find that they ask questions and open up"* (Participant 12).

Some participants reported other avenues where rapport was being established. Participants reported that the respect and amount of information you give and changing condition of the child helped to establish rapport with family members. Participant 3 summed it as follows:

"*When you are explaining everything to them...procedures of the ward and whatever is taking place in the ward and also you respect their views on the care you give to the child...and you ask them to ask question and clarification on whatever you are doing on the child and the child's condition improves then they think you value them and become a friend".*

Honouring family and children perspectives.

Participants reported that they respect the family and children choices regarding care. The choices that are honoured by nurses to family members and children are cross-cutting and range from clinical to socio-cultural in nature. In addition, the participants indicated that they honour family choices unconditionally. Participant 5 said:

"To demonstrate respect, first we try develop an understanding between us and them whereby we tell them what is going to happen in the hospital, our roles and responsibilities and our expectation from them, our limits and we also inform them that they have the right to choose, refuse or accept health care which they feel does not meet their choices and also the effects and in such circumstances, if this situation arises we counsel them and provide adequate information so they can make the right choices or consent to go ahead with their choice just to show that we don't work on our own in the hospital e.g. if the family wants a discharge but the child is not well we allow them and tell them they are free to come back without any condition if they feel like that and we just make sure to follow a proper discharge procedure by signing a consent".

Participants reported that they consider family members' choices as the right to health and in some instances they do not regret if the family makes a choice of who to handle them but they encourage family members to look at everybody as important. Participant 1 said:

"We normally discuss issues. For example, if the patient or family doesn't want you, it's a thing that you discuss. You can't just say okay because you have chosen X and not me then go ahead; You need to discuss why you have chosen that particular person not me, what is the problem, what can I do for you. What is it that the other person can do to you so that I can also do the same to you...If there is another and they still insist to see the other person then it's their choice it has to be done like that".

Some participants reported that privacy and confidentiality is part of the respect and dignity for children and family members. Participant 2 said;

"It means giving privacy and ensuring confidentiality e.g. taking the family and discussing their issues away from others and when I give IM injections I take the child to the treatment room to ensure privacy".

Conferring and letting go.

Participants reported that sometimes they knew that the family choices were detrimental, however, they discussed and consulted with members of the multidisciplinary team and family members but family members insisted to hold their choices. The participants still honoured such choices to show respect to the families. Participant 11 said:

"I would give an example of religious beliefs when one client and other people refuse blood transfusion, I first explained to them to make them understand why it is important for the patient to get that particular medical care before I start arguing with them but they insisted I respected their belief whilst letting them know that I have done my part on why it was important to provide that kind of care...so if the child dies it's up to them".

Participant 14 corroborated the views of participant 11 by saying:

"There was a client from Mangochi, they came as referral and belonged to Jehovah's Witness...you know they don't allow blood but the child was gasping, cyanosed and pale...they refused oxygen and blood transfusion...we called the palliative care team and the social worker for counseling...everybody came to assist and the blood was there, they refused and child died two days later...we have to let their choice hold".

Information sharing.

This subtheme had two major categories which emerged and these are communication and feedback.

Communication.

All the participants reported that they communicate verbally. The most used languages is Chichewa**.** Communications is done on one to one basis as in counseling or on group basis during health education. The participants indicated that key messages communicated to family members include the diagnosis, treatment and its side effects, or care plans and prognosis of the condition including the results of laboratory investigations. Some participants reported that sometimes communication is adhoc where they just place family members according to bays regarding their diseases. Participant 2 said:

> *"We tell them about their condition. We basically explain to them verbally as said earlier. Upon arrival we tell them about their condition...we orient hem to the ward and the environment...so they can know where some things are like the chambers...of course there also posters on the wall for those who can read...they are in English and Chichewa. For patients we communicate in Chichewa when they come. We do both group and individual communication...When they come from Accident and Emergency nurse tells them and it is written on their files. Ward is demarcated depending on the condition...so this also serves as communication. So we can just say SM (name withheld) go to Malaria Bay, Diarrhoea or Cardiac bay...so those who read know what their conditions are. We also inform them on procedure say blood sample collection, transfusion etc...We don't*

have disease specific leaflets which we give to patients because we cannot manage-stationary problems in the hospital"

Other participants reported that communication is written on posters. They indicated that most of written communication found in the wards is in the form of posters which do not depict disease conditions but contain statutory messages such as hand washing, nutrition and personal hygiene and diarrhea. Participants verbally agreed that posters are mostly used in surgical and oncology wards where drawings may be used to explain surgery of a certain condition. Half of the participants reported that communication with family members depends on the sensitivity, age and the relationship of the child to the family member. If the child is older and can comprehend, they communicate directly. They reported that information is treated with confidentiality and is given anytime if needed by family members.

"*Before sharing information, we establish what kind of a relationship is the child with them and we start telling them what we have concerning their information...that is when they are being admitted, during handover or rounds. There are other family members who come at their time and ask for more information on their patients condition, when the child is bigger we tell the child also on what is happening to him or his condition...We communicate any time the information is needed to them or to us. For the families, they do tell us anything about their child or problem and we answer them accordingly. We usually talk to significant relations to the family or child because it confidential information"* (Participant 5).

Feedback.

All the participants mentioned that feedback is given verbally. They reported that feedback is a two way communication, a continuous process and is important to both the nurses and family members. Participants also reported that feedback is given any time and serves to share ideas between nurses and family members. Participant 6 said:

> "*The feedback goes in two ways; feedback from us nurses and feedback from them as parents or children. Sometimes assess and we do ask them how the child is faring. They answer my child is doing well or they are some problems with this...this...or .my child is losing weight or not losing weight. In some cases they may say the child used to have high values of fever but now it is subsiding. So feedback goes in two ways. There are things which they tell you like they may think their child is improving yet he is not improving and you exchange ideas and come up with a conclusion on the matter...We do not have specific times, sometimes we do meet them during ward round and sometime during medications or they can come any time in short".*

Participants reported that feedback is given anytime but depends on staff shortages, seriousness of the child's condition, sensitivity of information maturity of the child and understanding of the family members. Participant 1 said; "f*eedback also depends on the seriousness of the condition, we don't give feedback to every patient or family but focus on those that are very sick. It also depends on whether they understand the condition or not".*

Participation of families in care.

Three major categories emerged from this subtheme include (1) care planning and delivery,

(2) role preparation and negotiation and (3) tasks and roles.

Care planning and delivery.

Some participants indicated that they involve families from planning, delivery and evaluation of care and discharge. They said involving family members in care assists in reducing workload as shortage is real and also improves understanding between family members and nurses. Participant 12 said:

> "*I first explain to them, teach them and give a try. Considering the state of our hospitals, there are shortages...that is real. So I teach so that they can help me...e.g. I talked about emptying of urine bags, tepid sponging and feeding...they help me and that is one way of incorporating them in the care. I just tell them to inform me when there is a problem or there is need to record urine. Yes. I do involve them in both planning and delivery of care and even evaluation".*

Participants reported that they involve family members in evaluation. They indicated that they involve family members in evaluation of the general condition of the child, status of fever, progress of pain, respiratory distress, diarrhea and identification and prevention of pressure sores. Participants indicated that in evaluation, they teach family members how to look for and recognise dangers signs and signs of improvement. Participant 1 said:

> "*What we want them to do in evaluation is to know the good signs and bad signs in their child and what to do when they come out or see them on the child...we teach them now and then so that they know what to do to identify danger signs or signs that care is not*

effective...Our criteria for involvement in evaluation and care is usually the first guardian or if the child is an adult".

Participants also reported that they conduct a quick assessment before they ask the family member to give his or her opinions so that the two notes are shared and evaluation depends on the seriousness of the child's condition. Some participants reported that evaluating with members of the family is important because it helps the nurse to differentiate between the usual behaviours of the child from those resulting from the underlying condition. Participant 9 said:

...before objectively evaluating the care, I ask the mother...How do you look at the child...So my final evaluation will depend on taking what the mum has said and with my own assessment...For example I had a child who had a renal problem and his mum and they stayed in the hospital for six weeks...the child was operated on and the mum was insisting that they go home. The child always looked quiet and weak , not interested and other signs but the child looked stable, I asked the mum to say ...What is the condition of the child and what does she think we can do? The mum told me that you know the nature of my child is that he is usually quiet even at home...I feel my child is improving because he is able to do A,B,C and D now...This was an eye opener to me because I thought this child was very sick but actually was okay...so I shared this with members of my team (Participant 9).

Participants also said that they involve family members any time and depending on the condition. Some participants indicated that in their experience family members are not involved at all.

"*In my experiences families are not involved it has been a bit challenging- we are supposed to include the family but we don't. It depends on nurses' personality... Some time nurses do not explain...some do...Oh! We don't involve them, it has been a challenge due workload"* (Participant 3).

Ironically, participants who said they don't involve family members in care also reported that it is good to involve them "*No we don't usually involve them in evaluation as well....it's really important because if you involve them during planning it helps them to cooperate during evaluation and care delivery...It would help us to work better with them "*(Participant 8).

Role negotiation and preparation.

Participants identified their core function in family involvement as role preparation and negotiation with the families. Role preparation, involved establishing rapport with the family members, assessment of the capability and understanding of the family member and teaching family members the tasks followed by a demonstration and return demonstration. Teaching involved nurses or bringing in a neighbour with similar condition to teach a fellow guardian. On negotiation, majority of the participants reported that they first discussed with the family members on the need and importance for them to take part on the specified tasks and getting consent from them. Participant 14 said:

"I have to plan what care to give to each child and then isolate those that the family member can assist me during that time...so then I come to discuss with them that this is what we are going to do and this is what I feel you can do such as bathing, NGT feeding turning or positioning the child. So we discuss and ask them if they are comfortable to go ahead with the care or not...so it's like you need to ask them for their consent before they

can go ahead. Then you start preparing them for that task when they agree through teaching and demonstrating and what they are going to do...so it's important that they say they can participate before going into delegation or giving them what to do".

Interestingly, some participants reported that in their experience they have not mostly come across family members who refuse to assist. However, for those that did not consent, the participants said they would carry on the task as their own because it their duty as nurses or force on a family member if seemed not ready to take on the said tasks because of the shortage. Participant 9 said; "*We also tell them that there are tasks that they need to take part so that we achieve good results on a patient because we are in few numbers and they need to participate in the care*"

Tasks and roles.

Participants described common tasks and roles they give to unwilling and consenting family members to assist in the care of their children. The tasks and roles were given or delegated depending on the nurses' perceived ability of the family member to perform that task competently. All the participants reported that family members assisted in the following tasks:

- Providing safety and security by staying with the child at all times for comfort
- Changing nappies, emptying urine bottles and recording fluids
- Accompanying the child to the anaesthetic bay, X-Ray, theatre and laboratory and assisting nurses or doctors during procedures and helping in ambulation
- Wound dressings, Stoma care
- Acting as a communication bridge between the child and medical teams that is being a source of information, liaison person or being an interpreter and reminding nurses

- Turning and positioning of patients

However, tepid sponging, bed making and bed bathing, giving oral medications, oral or NGT feeding were commonly reported by all participants. Only a few participants said they allow some parents to do these tasks but retained their opinion that these should be done by nurses for ethical and professional reasons. One participant said; "*Due to ethics it is us nurse who should perform these. When you delegate they feel you are lazy...that may not be a professional thing for us nurses*" (Participant 4).

Collaboration.

This subtheme was characterised by the participants' view that family members were important in the delivery of care. Participants reported that the nurses' role is to encourage and support family members to take part so that the goals of care are accomplished. Partnership in care and nursing support are the two major categories which emerged from this subtheme

Partnership in care.

Participants reported that collaboration involves working with families. They said that they provided respect, consulted the family members continuously, shared their experience with the family members, and empowered family members through continuous teaching and giving a lot of information. Participants also reported doing a joint observation on the child and monitoring and supportive supervision on the quality of tasks and care family members gave to their children. Some participants also reported that they allowed family members to remind them of their tasks that they promised would perform on the child when they [nurses] have forgotten and allowed family members to ask questions. Participant 1said:

"*In collaboration with the patients, its communication between you two people. You need to be respectful, be free with them. In that way you will be able to collaborate and partner with each other but if you bring in the negative attitudes and the like, it means it won't work...you want see them work with you. So here to collaborate with them you have to smile at them...let them feel at home...We basically check on them on what they can or have managed to do...those that have difficulties we come in and teach them. We also do assessment to see what they have done and then we ask has the patient bathed, taken medication or fed. How many times has he taken food...any difficulties or problems they tell us...that how we do it. To our side they also come and ask if we have forgotten, they are free to come and ask, say you said he will go for x-ray, theatre etc and we tell them accordingly".*

Nurses Support.

All the participants reported that they provide support to family members. Some participants indicated that some family members were frustrated or unwilling. The support provided was psychological and emotional support, material and professional depending on the identified needs of the family members.

Psychological and emotional support

Participants reported that psychological support was given to family members by nurses being there for them. Some participants also reported that they provided counseling and guidance, they informed the family members that they should not worry things will work and they will accomplish the task and giving consistent messages to prevent confusion, praising them and giving positive recommendations to family members. Participant 2 said:

"After counseling and telling them what we have done to the patient together encouraged them to go ahead doing what we taught them and to keep caring for the child. There was a child with nephritic syndrome and the parents were so worried, the condition was deteriorating and the parents almost just gave up but after counseling them and after telling them that we are still caring for the patient and that they need to continue, we also told them that we are there for them...they continued doing the tasks as we agreed...they developed courage to care for the patient".

Material support.

Some participants reported that they give support by providing materials so that family members should be able to accomplish the tasks. They said that without this support, some tasks would be very challenging to family members "*We support them with materials for their tasks like syringes, gauze and bandages and gloves and warm water"* (Participant 4).

Professional support.

Participants reported that they give professional support to family members that are not willing or have problems with understanding or have fears because the child is very sick. The professional support mainly involves transfer of skills to family members so that they are competent and independent. This support ranged from working with the patient for a longer time, teaching and doing demonstrations. Participants further reported that they used fellow guardians to support transfer of skills to an underperforming family member. Participant 13 said:

"The process of feeding through NGT is so scaring so I show them this is the syringe, feeding cup and everything and demonstrate continuously how this is done...but if they are still reluctant you carry on demonstrating and teaching the task yourself. e.g. A patient from Chipini health centre she was very anaemic and it was difficult to get the vein, .the last I got was the jugular vein. He had an NGT for feeding as well, she accepted in the first place to feed the baby...but now seeing the NGT and the jugular line was reluctant to continue feeding. But I had to sit down with her explained that the two are meant for the child's treatment and should continue feeding...The mother asked me can we delay the feeds so that the blood should finish first...I demonstrated to her, we feed the baby together for some time and later she started feeding on her own".

Factors Influencing Nurses on Family Involvement

Two subthemes emerged which include factors that facilitate and factors that challenge nurses efforts on family involvement.

Factors that facilitate family involvement.

Two major categories emerged which include personal factors and institutional factors that facilitate nurses' efforts to involve family members in the care of their hospitalised children.

Personal factors.

Participants mentioned level of education and understanding of the family members. Some participants also mentioned nurses' positive attitude to their work, good rapport and trust, positive attitudes of both nurses and family members to each other. Participant 8 said:

"If you have a positive attitude towards your work and family involvement you really involve the guardians and also if you have created a good atmosphere ... you have created some good rapport and trust relationship is good...You see that the families will accept some kind of involvement in the care" (Participant 8).

Some participants mentioned family and child's right to information and choice as a motivating factor for involving families while one participant reported that ownership of the child is another personal motivating factor. "*The child is theirs so they need to be there and take part in the care of the child or help us to provide care*" (Participant 2).

Institutional factors.

Participants reported that hospital setting as a facilitating factor because it allows for members of the family to be present all the time. Some participants reported that shortage of nurses and workload as factors that influence them to involve family members.

"Inadequacy of nurses....because we are few in number we see involving families as an option so that they can assist us in doing other works on the child...I see that as the only way out" (Participant 9*).*

Another participant corroborated: "*I don't think shortage is an issue for me not to involve the family because if number of patients to nurse increases...you involve family members a great deal*" (Participant 1).

Factors that challenge nurses on family involvement.

These factors have been grouped into personal, institutional and socio-cultural factors.

Personal factors.

Participants reported that low level of education and literacy of the family members is the most important factor affecting their efforts to involve families. Participants also mentioned negative attitudes of both nurses and family members, condition of the child and time when parents bring their child to hospital.

> "*Parents preconceived negative attitudes towards health workers, may be they stay quiet, not asking questions, you see they have questions but they can't ask. May be because of their past experience...Most of them hear that nurses are bad so they come here afraid...it's real"* (Participant 4).

Participants also reported that some family members are very demanding so nurses shun them. Majority of participants cited communication as a major challenge. They reported that language problems for both locals and those from Mozambique who do not understand Chichewa or English. Participants also reported that they experience communication problems with children who are deaf or dumb or their guardians. Participant 3 said; "*Communication breakdown...there are people who do not understand English or Chichewa...especially from Mozambique...so it is difficult to involve such people...Also there are others who cannot hear or talk so it is a challenge to involve them in the care".* Some participants also reported that the harshness by most nurses makes family members shun interacting and opening up to nurses.

Institutional factors.

In contrast, some participants mentioned shortage of nurses, increased workloads and lack of adequate material resources as other principal institutional factors.

"*Resources is a big issue here...sometimes you find that you need to supply resources for the care to guardians but they are not available. You feel not doing enough...You find that you don't have the resources to give them...e.g. colostomy bags, bandages and plasters...it means care will be compromised"* (Participant 4).

Some participants mentioned lack of policy to guide direction on family involvement. Participants felt that if there was a policy it would empower both nurses and family members on family involvement. *"There is no policy. I think policy has an impact because if you have directions on human or material resources and how to involve families in the care you can do that because everyone will take that as a requirement"* (Participant 8).

Socio-cultural factors.

Participants reported that religious beliefs such as refusal to be transfused, refusing treatment and cultural factors such as belief in traditional medicine affect their efforts to involve families. Some participants said cultural factors affect decision making of family members while in the hospital as the family members wait for significant others to make a decision in line with traditional demands. Participant 1 said:

"*Religious and cultural factors all come in to hinder family involvement especially here in paediatrics...you find that a mother with child of six months...they can't make their own decision...it's a its a family which has to make a decision based on their religion or culture...that affects the child, his speed healing...also your attitude to them".*

Participants said family members with political connections want to be treated with respect, as if the hospital is rich and demand a lot and want nurses to be with them always.

Participants reported that nurses become afraid to involve some family members with political connections because they may report them as doing nothing or as leaving nursing tasks to the family members instead of nurses carrying out such tasks. Participant 8 said: "*You find they say I am sent by politician so and so... they want you to give everything to them yet the hospital does not have enough materials and there are others too to be served*". Participant 10 said: *"Sometimes you are afraid to give them tasks because they may report to politicians that you do nothing here in the hospital...it happens you know politics*".

Nurses' Impressions of Family Involvement

Participants reported that family involvement is a good idea. Participant11 said; "*Family involvement is a good idea and practice that contributes to high quality care outcomes".* Participants reported that family involvement should be well regulated so that each nurse or family members know it as a prerequisite when in the hospital. Participant 4 commented: "*Family involvement is really important if it is done rightly or properly it can promote quality care...that is what I think*". These views were corroborated by participant 11 who said:

> "*Of course family involvement is not a bad idea...I like it when I have a guardian who is understanding...If we are working together and you see that everybody including the parents are involved even if there is loss of life the guardians understand it and there are no issues like they have killed my child. They understand we tried...it is not a bad idea*".

Some participants reported family involvement is not a good idea because all the work in the hospital should be done by nurses. One said; "*Family involvement is good but sometimes I feel bad that the work that I could do is done by the family member*" (Participant 2).

CHAPTER 5

Discussion

Introduction

This chapter will discuss the study findings based on the study objectives and the themes that emerged. These themes are meaning of family involvement, rationale for family involvement, nurses experiences, power and control, core concepts of family centred care, factors influencing nurses' efforts on family involvement and nurses' impression with family involvement. This is followed by study implications, recommendations and conclusion.

Characteristics of the Participants

The study recruited 14 full time registered nurses working in the paediatric section at QECH. Data saturation was achieved during the interview with the14th participant.

Age of the participants.

The findings revealed that age ranged from 22 years to 48 years. The mean age was 26.8 years. It is evident that most of the nurses who participated in this study were relatively young.

Sex and tribe of the participants.

The study revealed that the majority of the participants 78.1% (n=11) were females. This imbalance may be due female domination in the nursing profession. The study has also revealed that majority of participants 42.6% (n=6) were Lomwe. This may be due to the fact that Lomwe is one of the dominant tribes in areas surrounding the study setting.

Religion and level of education of the participants.

The findings revealed that all the participants were believers of which 35.5% (n=5) belonged to Church of Central Africa Presbyterian (CCAP. All the participants were registered nurses of which 85.2% (n=12) had a Bachelors degree in nursing. Of these 14.2% (n=2) had a specialised training in child nursing. This implies that the majority of the registered nurses used their generic paediatric nursing knowledge which may have formed their foundation for acquisition of skills and experience in child nursing. According to McHugh and Lake (2006) without background knowledge professionals may risk using poor judgment and may lack the tools necessary to learn from and build on experience.

Working experience of participants.

The working experience of participants ranged from one year three months to five years ten months. 56.8% (n=8) were between one year three months and three years. This implies that participants had some working experience in caring for sick children.

Registered nurses' knowledge on family involvement.

The study has revealed that nurses are knowledgeable on family involvement. The findings of this study are consistent with a growing state of knowledge that most nurses are knowledgeable on family involvement in care, its benefits to the nurses, family and the child (Orill, 2009; Paliadelis, et al., 2005; Soderstrom, et al., 2003; Coyne et al., 2011; Uhl, et al., 2013). In this study nurses were able to describe family involvement as incorporating family members and significant others including members of the extended family. According to Espe-Sherwindt (2008) among other things, the nurse should recognise that the family is the

constant in the child's life should and should facilitate parent–professional collaboration at all levels of care including the socioeconomic diversity of families.

Registered nurses demonstrate knowledge and understanding of family involvement by allowing family members to be treated as partners, respect both child and family choices, social and cultural perspectives and recognise that families and children have the right to choice. This implies that these nurses are able to use their knowledge to provide paediatric care within the context of their situations. Mc Hugh and Lake (2010) indicate that knowledge of a phenomenon is very important because it enhances acquisition of nursing expertise which is fundamental to quality nursing care. This also implies that participants' educational preparation as registered nurses, their experiences and the setting or the context may have contributed to their knowledge and understanding of family involvement.

Conversely, despite the nurses demonstrating knowledge and understanding on family involvement, they are constrained in many ways which make implementation of family involvement inconsistent and problematic. This is discussed further under factors that influence nurses efforts on family involvement.

Rationale for family involvement

There are many reasons which influence nurses to involve family members in the care of sick children. They involve families as a way of sharing their responsibilities with families, fostering social support, utilizing the family expertise in care and for partnership on decision making. The study revealed that families assist registered nurses in performing nursing tasks which relieves burden from nurses. This shows that nurses share their own clinical roles and responsibilities with families during involvement. These findings are consistent with Coyne

(2006) who found that nurses relied on parents and guardians to provide care because of the shortages. It is evident that nurses involve family members to lessen workload, save time and share responsibilities (Zaman, 2004; Soderback & Christenssen, 2008). This may be the case at QECH where there is also a chronic shortage of nurses. This may adversely affect the quality of care provided to the children because family members may deliver substandard care to their children. As such nurses should assess capabilities of family members before allocating tasks so that children can receive quality care. However, literature also suggests that nurses sometimes involve parents in the care of hospitalised children for administrative efficiency and not empowerment of the family members (Coyne, 2006).

It is clear from this study that families provide social support to both nurses and children. This is consistent with a growing body of knowledge which indicates that the family is central to social and psychological well being of the child (Harrison, 2011; Lam, et al., 2006; Shields, et al., 2006). This is necessary because hospitalised children experienced fears, anxiety and concerns including separation from family and friends (Coyne, et al., 2011). The study has also revealed that registered nurses regard families as experts in care and partners in decision making. Nurses consulted family members for information regarding the child's illness, on what the family members normally do at home when the child is sick and also when making difficult decisions. This consultation by nurses is important to family members because it makes them to be part of the caring team and participate fully in decision making. Fegran and Helseth (2009) concluded that parent–nurse consultation regarding information and decision in care unit is desirable because it helps to strike a balance between nurses and parents emotions which can positively influence parents' independence and nurses' ability to maintain professional relationships with the family. This is consistent with values and beliefs of family centred care

practice which entail that parents are experts, whose ideas, choices and recommendations have to be taken seriously (IPFCC, 2010). The recognition of parents as experts may help to improve childrens' care because they may receive individualised and holistic care.

Nurses' Experiences on Family Involvement

Rewarding encounters.

The findings revealed that some registered nurses' experiences have been rewarding. This is because they show a positive attitude when working with families of the hospitalised children. In this study registered nurses were able to work well with families and got important information regarding the child's illness. Some participants indicated that family members assisted nurses with giving medications, feeding and bathing and this reduced workload. Other participants indicated that they used guardians to escort their children to radiology and laboratory departments instead of them doing this work. It was often mentioned that registered nurses' involvement of family members was an option because of the shortages and that registered nurses benefited a lot if family members were properly used. The major benefit is reducing their workload so that nurses can concentrate on important nursing roles like carrying out orders on ward rounds, drug administration and wound dressings. Shortages of nurses exist at QECH and participants in this study found these family contributions as rewarding. This finding is consistent with Zaman (2004) who found that in Bangladesh, shortages adversely affected the quality of care nurses provided to children and families and this made nurses over rely on parents to deliver care as a consequence.

Demanding encounters.

This study has revealed that some registered nurses experienced frustration and failed to cope with demands of involving families in the care because of shortage of nurses and inconsistent availability of the resources. It may now be suggested that the demanding experiences registered nurses reported are directly linked to these factors. Participants reported that shortages and workload disrupted continuity of tasks and roles of family members as given by and agreed with nurses. Increased workload is linked to disruptions and discontinuity of nursing care (Orill, 2009). It is evident that disruptions in nursing care occur on collaboration and communication between parents and nurses (Canadian Federation of Nurses Unions, 2010). This may jeopardise the process of family involvement in the care of sick children.

It is clear that findings of this study show that some registered nurses shunned family members because they were deemed demanding while others were politically motivated to demand more from nurses. Shunning demanding parents is widely recognised as a sign of inadequate coping and communication skills on the part of nurses (Espezel & Canam, 2003; Coyne, 2006; Galvin et al., 2000). This is also seen as an exclusionary tactic by nurses (Coyne, 2006). However, the findings of this study are consistent with findings of Soderback and Christensson (2008) who found that nurses in Mozambique shunned difficult and demanding parents and experienced problems to maintain communication with the family members. This may be true for nurses at QECH.

Encounters with multiple realities.

Nurses' experiences are not absolutely good, fair or demanding but are mixed. Some nurses indicated that their experiences have been affected by several factors making it difficult to

point out one issue among many. Some felt guilty when involving families while for others it was the nurse's duty to nurse the child completely. Some indicated that the nurses' code of ethics does not allow nurses to leave tasks to families. This may mean that participants faced dilemma in describing their exact experiences because of multiple factors that they experienced. Ford and Turner (2001) found that in Australia registered nurses experienced frictions between their present role on family involvement and their expected professional role. This led to disturbances with handovers from fellow nurses due to mixed professional feelings and made it difficult for others to describe their real experiences. This may make nurses and environment not conducive to family participation in child care. This could be true for registered nurses in this current study. Despite the dilemmas faced, it is clear that while nursing code of ethics is very important in their argument, absence of policy on family involvement at QECH may have contributed to the nurses' uncertainty when describing their experiences. In addition, multiple dimensions of nurses' experiences and role of nursing ethics on family involvement have received little attention in family centred care literature. Thus further research is needed in this area.

Power and control.

Regulation of family involvement in care.

This study has revealed that some registered nurses control the amount of family involvement in the care of hospitalised children. Some participants indicated that they control amount of family involvement to avoid blame, for accountability, family members' lack of knowledge on nursing issues and nurses' responsibility to save life of the sick child. Nurses control family involvement in care because they believed they are experts in care while some feel that parents should not take on 'nursing' responsibilities or tasks (de Lima, et al., 2001;

Paliadelis, et al., 2005). These preconceptions may make nurses to sideline and relegate family members to do menial or domestic tasks on their sick children instead of taking part in performance of some nursing roles. However, literature indicates that some nurses control the amount of family involvement because they want to control their identity while others would not like to be held responsible for errors or omissions in care made by family members (Lam, et al., 2006; Soderback & Christenssen, 2008; Ygge, 2004). Power and control over family involvement may make family members powerlessness to contribute effectively to the care of their child in the hospital.

Core Concepts of Family Centred Care

Respect and dignity for hospitalised children and their families.

Participants viewed respect and dignity as an important aspect in their experiences on family involvement in the care of the hospitalised children. Some participants described respect and dignity as an obligation for nurses to respect family members and hospitalised children's perspectives, human rights and their right to health, honouring their choices, cultural and religious beliefs and offering them privacy and confidentiality. This implies that some nurses give space for children and families at QECH exercise control over their choices. This could be one of the reasons that made participants to report that some family members were willing and had positive attitudes towards family participation. Willingness of parents to participate depends on whether the parents' views, opinions and choices are respected by nurses (Uhl et al., 2013).

Establishing rapport.

It is evident that patient-nurse rapport is the genesis for a collaborative relationship (Espezel & Canam, 2003; Uhl, et al., 2013). The findings of this study show that participants created rapport with families from which family members and their children can be involved in care. A key aspect of establishing rapport from the participants was their demonstration of interest in the family members and their children, respecting their presence, views and accepting them. Other aspects of establishing rapport were that of nurses assuming the role of an educator, a middleperson and a guide. Nurses' demonstration of interest in the family members implies that they were willing to work with family members in the care of the sick children. This may have acted as an invitation to family members. Soderstrom, et al. (2003) found that nurses' willingness was an inviting signal to parents and this influenced their rapport. Literature also indicates that nurse-parent rapport is sometimes largely influenced by nurses' need to interchange knowledge with families so that in turn families assist nurses better (Uhl, et al., 2013; de Lima, et al., 2001; Lam, et al., 2006; Soderback & Christenssen, 2008). This scenario may be true for registered nurses at QECH. However, irrespective of who activates establishment of rapport, both nurses and parents need it for a collaborative relationship.

Honouring family and children's choices.

The choices that are honoured by nurses to family members and children are cross-cutting and range from clinical to socio-cultural in nature. Interestingly, some of these choices are honoured unconditionally. Some nurses honour choices because they regard them as parents' and childrens' right to health. It is believed that nurses who believe that family members are

influential and pivotal to the child's care honour and respect family members' perspectives (Stayt, 2007; Kuhlthau, et al., 2010; Espezel & Canam, 2003). This may explain why participants in this study consulted family members on decisions that they regarded as difficult. This implies that in some instances, children and families' opinions, needs and choices are respected and that families take part in decision making at QECH. Literature ascertains that when family members take part in decision making they have influence and control on what is happening to their child (Stayt, 2007; Kuhlthau, Bloom, Van Cleave, Knapp, et al., 2010).

Conferring and letting go.

The study found that participants conferred with family members by discussing and consulting with members of the multidisciplinary team and family members. However, when family members insisted to hold their choices, nurses had to let families hold on to their choices to show respect to the families' choices and perspectives. In family centred care, honouring parents and children's perspectives is considered the best attribute. Mackay (2009) found that most of the nurses in USA conferred with parents and families of the hospitalised children because they wanted to be sure about families' decisions on the choices made. This could be true for registered nurses at QECH. However, in this current study, family members' choices may be compounded by past experiences, the new environment, culture and religion. Conferring with members of the multidisciplinary team such as palliative care team and medical consultants means that nurses value suggestions from both the family and multidisciplinary team members. However, in this study, there was an indication that nurses conferred with others to counter the blame against errors that may result from families risky choices. Nonetheless, it implies that the nurses are open to accommodate difficult choices.

Coercion.

The study has revealed that some registered nurses sometimes use force on children and family members especially when family members make difficult decisions which the participants think are detrimental to the health and functioning of the child. Nurses use medical knowledge to impose a choice or a decision on family members and their children. Participants indicated that coercion occurred after exhaustive discussions with family members. This implies that some registered nurses at QECH still decide what is best for children and their families. These findings are consistent with the notion that despite nurses advocating for family involvement, in reality some nurses disempower families by deciding what is best for them and their sick children (Coyne, 2006; Orril, 2009; Bernard, 2009). Bernard (2009) found that nurses acted with inhibiting and imposing behaviours such as depersonalizing family members despite family members' wish to be involved in the care in the United States of America. Despite their best intentions, it implies that nurses' power and coercion may limit the autonomy of the family members and children in the hospital. According to Fults (2011) coercion may push family members to conclude that the decision to participate rests entirely with the nurses.

Information sharing and collaboration with families of hospitalised children

Communication and feedback.

This study has revealed that nurses in the paediatric section value communication and feedback when working with family members. Participants mentioned need to give and share information including getting feedback from families in order to effectively support and involve family members in the care of their hospitalised children. This is consistent with Shields & Nixon (2004) who found that in both western and eastern countries cultures both nurses and

family members value communication. Soderback and Christensson (2008) found that found communication between nurses and parents was a consistent theme in Mozambique. This implies that the value of parent-nurse relationship and collaboration depends highly on the degree of communication between nurses and family members. However, participants indicated that communication between nurses and families is largely verbal, with few posters and leaflets. Leaflets and posters would help nurses save time. Instead nurses would be more concerned with answering questions than spending time explaining each and every condition. According to Just (2005) in routine nursing practices where parents are given leaflets and posters on common diseases and procedures, parents find their own time to read the leaflets with concentration while nurses do other things including having time to answer questions. This decreases tension on both nurses and family members. However, at QECH, chronic lack of resources such as stationery may have made nurses to use verbal communication for information sharing.

Family participation in care of their hospitalised children

Care planning, delivery and evaluation.

The findings of this study indicate that some registered nurses involve family members in care. This involvement takes place during planning, delivery and evaluation of care. Involvement in care depends on the condition of the child, understanding of the family members and the number of nurses and patients on that day. This may imply that some nurses recognise the role family members play when caring for their hospitalised children. A growing body of literature states that nurses involve family members based seriousness of the condition, overcrowding of the wards and resources available (Soderback & Christenssen, 2008; Soderback & Christenssen, 2007; Zaman, 2004; Coyne, 2006; Shields, et al., 2006). These findings may imply that some

nurses at QECH have positive perceptions towards family involvement. However, it is important to note that some nurses set conditions under which family members are involved. This implies that some nurses underrate the fact that hospitalisation regardless of the state of the child's condition is a stressful experience (Uhl, et al., 2013). This behaviour and perception of nurses is not consistent with values and beliefs of family centred care. This may lead to a conclusion that some families are subjected to trauma due to hospitalisation at QECH.

Role negotiation and preparation.

The results of this study show that some nurses negotiate with family members and prepare them before they agree and share tasks. Role negotiation and preparation involves establishing rapport and discussing with the family members, assessing the family's capability and teaching family members the tasks followed by a demonstration and return demonstration. Negotiation is the main interaction strategy in a partnership between nurses and families in the hospital and is a means by which power is shared (Gallant, Beaulieu & Carnevale, 2002; Fegran & Helseth, 2009). Mackay (2009) found that nurses negotiated and prepared family members to familiarise and prepare them for their new role in the hospital. This means that nurses in this study are aware that families have some control over what they can or cannot do. This may also imply that some nurses are aware that families have a choice of tasks that they can manage because some tasks can be overwhelming. It may also be concluded that some nurses at QECH are aware that despite benefits of family involvement, not all parents want to be involved in caring activities in the hospital. Consideration of parents' wishes and abilities while in the hospital is consistent with values of family centred care and this makes their hospital experience meaningful (Fegran & Helseth, 2009).

Tasks and roles.

The findings have revealed tasks and roles which nurses allow family members to participate and perform. Family members are involved in giving oral medications, doing tepid sponging, bed making, bed bathing and giving feeds through NGT, escorting children to X-ray or laboratory as advised by nurses. This indicates that nurses in this study give family members tasks that are mostly domestic and non skilled in nature. Paliadelis, et al. (2005) found that in Australia registered nurses indicated those skilled tasks should be left to them because they are the ones who know nursing. Similarly, Ford and Turner (2001) highlight that nurses wonder that if parents took on some of the nursing tasks then who would be an expert in care. This is consistent with findings of this study which show that nurses allow family members to take on some domestic tasks but control the extent to which families can take on nursing activities. This is consistent with studies in western and developed countries which indicate that although nurses advocate for parental participation their actions in practice are not clearly evident (de Lima et al., 2001; Paliadelis, et al., 2005; Orril, 2009; Shields, et al., 2006). The implication is that family members may see their involvement in child care as lip service. According to Pilliteri (2010) meaningful involvement requires that nurses teach family members some nursing tasks which may help family members to care for the child when at home.

Collaboration.

The results of this aspect of the study show that registered nurses regard family members as important in care. The nurses role were to encourage families to participate in caring for the sick child, coordinate and support family members so that they work as a team. Working with family members as caring team is important because it encourages development of trust

between families and nurse which is vital for accomplishment of care goals. This in turn improves the quality of care that the children receive. According to Mackay (2009) when nurses work with parents it is not only important for decision and support but it helps both nurses and family members to cope with stressful situations.

Partnership in care.

The registered nurses' collaborative partnership involved working with families, consulting the family members continuously, and sharing their experience with the family members, continuous teaching and giving information. The findings also indicate that some registered nurses and family members both monitored and supported each other to ensure that quality care is given to children. This implies that both nurses and family members were committed to this partnership and were eager to cooperate with each other. This embraces equality which is important for effective communication and is the basis for partnership. Gallant, et al. (2002) asserts that partners must subscribe to the value that each individual, regardless of social class, is a worthwhile human being with unique needs and must value co-operation, shared responsibility and accountability. A growing number of literature also concludes that the most important thing in partnership for care is leveling the ground through equal sharing of power, responsibility and accountability on the part of partners (Uhl, et al., 2013; Soderstrom, et al., 2003; Harrison, 2011; Mackay, 2009). This may explain why some registered nurses in this study indicated that they have positive attitudes towards clients and were always willing to work with families. Parent-professional collaborative partnerships are often successful when professionals show trust and transfer skills to family members through open communication (Blue-Banning, et al., 2004; Coyne,

2006; Espe-Sherwindt, 2008). Transferring of nursing skills to family members may ensure that they possess necessary tools to act with self control and improve their personal esteem and confidence which are important in child care. However, the results also show that some nurses involved families depending on the condition of the child and understanding of the parents. This implies that not all family members whose children are hospitalised benefited from this partnership.

Nurses' support.

The results indicate that some family members were frustrated or unwilling to continue with their participation especially when the condition of the child deteriorated, was taking long to change or new procedures were prescribed for their children. This implies that support was needed. The support provided by registered nurses was according to the family needs and ranged from psychological, material and professional.

Psychological and emotional support from nurses was provided by nurses' being there for patient and family members, counseling and giving consistent messages to prevent confusion including praising family members. The parents and children need psychological support because hospitalisation of the child is stressful to both parents and the child (Paliadelis, et al., 2005; Harrison, 2011; Shields, et al., 2006; Stayt, 2007). While children are stressed in many ways, parents' stresses come from the condition of the child and its unknown prognosis, the strange hospital environment and loss of power and control (Fults, 2011; Gallant, et al., 2002; Uhl, et al., 2013). Mackay (2009) asserts that presence of nurses, counseling and giving comfort restore family members' ability to stay calm and continue with tasks. Literature concludes that providing psychological support to family members prevents anxiety and exhaustion and makes

family members to care for their children in ways that are satisfying, valuable and competent (Sodomka, 2010; Harrison, 2011; Orril, 2009). This implies that the support that nurses provided helped families to cope with hospitalisation.

Nurses also provide material support to family members to prevent compromising care provided by family members to their children. Material support which is provided to family members include bandages, syringes and pails or buckets and towels for tepid sponging. Studies show that material resources are important and enhance family participation in care (Coyne et al., 2006; Soderback & Christensson, 2008; Mackay, 2009; Fults, 2011). At QECH, shortage of resources has existed as a chronic institutional problem. This implies that material support to family members is crucial. Leaving families without this support may greatly jeopardise the quality of care provided to children.

Nurses also provide professional support to family members that are not willing, have problems with understanding and have fears because the child is very sick. The professional support involves transfer of skills to family members so that they are competent and independent while remaining co-dependent with the nurses. Soderback and Christensson (2008) found that in Mozambique, nurses showed professional support through teaching, demonstrating skills and moral support to family members. Literature has described this professional nursing support as support that recognises that building caring capacity of the parents is critical (Espe-Sherwindt, 2008; Markowitz, 2001). This may imply that registered nurses support the family members to ensure that optimal care is provided to the hospitalised children and errors are prevented.

Factors that Facilitate and Hinder Family Involvement

Factors that facilitate family involvement.

Personal factors.

The study has revealed that there are personal factors which facilitate registered nurses efforts to involve families in the care of hospitalised children. These factors include nurses' positive attitude to their work which makes them able to establish rapport and work with families and family members' positive attitude to nurses. According to Espezel and Canam (2003) the attitudes of health professionals create a climate that can support rapport and collaboration. Fegran and Helseth (2009) found that nurses had more positive attitudes toward family participation than other staff members because nurses stay with the families and children longer in the hospital. Some registered nurses in this current study indicated that they involve family members because some family members are willing, knowledgeable and understand the need to be involved. Willingness of parents has been linked to success in family involvement (Espezel & Canam, 2003). It may imply that the positive attitudes and willingness of both nurses and families form the basis for rapport and collaboration. This may also suggest that family members and nurses both value each others' important role towards child's care. This mutual understanding is important because it helps nurses to provide quality and satisfactory care to the family and the child.

Institutional factors.

The study findings on this aspect show that nurses involve families because the institution allows family members to be on the bedside. The hospital allows at least a guardian to be with the patient. According to participants, this is already a positive factor.

According to Soderstrom et al. (2003) presence of family members is seen as naturally inviting nurses to an interaction.

The findings also indicate that shortage of nurses at this institution facilitates nurses' efforts to involve families in care. This is because nurses depend on family members to take on some tasks which nurses themselves could have been doing. This may increase workload on the nurses. It is also known that nurses' dependence on parents due to their shortage is meant for nurses to save time and concentrate on technical care issues (Zaman, 2004; Coyne, 2006). Furthermore, where they are shortages, nurses have used this to necessitate involvement of family members (Coyne et al., 2011; Soderback & Christensson, 2008). This could be true for QECH because the nurse patient ratio is very low.

Factors that hinder family involvement.

Personal factors.

The results reveal that low level of education among family members, negative attitudes of both nurses and family members and communication difficulties challenge the nurses' efforts to meaningfully involve families in the care of hospitalised children. Participants highlighted low level of education among family members as an important factor affecting their efforts to involve family members. This is because illiterate family members have difficulties to understand nursing issues than educated ones. Ishikawa and Yano (2000) found that low literacy was associated with negative communication and interaction between patient and physician, negative patient behaviours and affected information seeking and participation in health care in Japan. Participants reported that when working with illiterate families they avoided giving them too

much information and tasks for fear of errors. According to Ishikawa and Yano (2000) too much information may make illiterate families get confused and powerless instead of being empowered as the result health workers may not make such families participate in care routines. This could be true for nurses in this study.

Negative attitudes from nurses include labeling of family members as not knowledgeable and exercising control over family members, being harsh and shouting at parents. Evidence suggests that these emanate from negative perceptions nurses have against family members from their past experiences and the nurse willingness to exercise control (Ford &Turner, 2001). According to Bernard (2009) negative nurses attitudes also include acting with inhibiting behaviours and depersonalising patients and charecterising them as lacking knowledge.

The results show that family members are demanding, some have political connections which intimidate nurses while others stay quiet and distance themselves from nurses. Evidence suggests that family members also intimidate nurses which creates tense environment. Coyne (2006) found that family members in United Kingdom (UK) were behaving aggressively towards nurses and asking many questions resulting in being labeled as nightmare and demanding families. Some studies suggest that when families ask many questions and are demanding explanations they are seen as being in possession of more information or overqualified than nurses (Stayt, 2007; Orril, 2009;Coyne, 2006). Nurses may view this behaviour as disruptive because it challenges nurses' authority and control. Nurses may feel that their actions are being checked and this may disrupt their relationship with family members. Disruption caused by nurses and families' negative attitudes towards each other may make hospital experiences a nightmare for both nurses and family members leading to poor family involvement.

Institutional factors.

The study has also revealed that there are no clear policies and guidelines to direct implementation of family involvement by health care workers at QECH. This leads confusion because there is lack of direction. This finding agrees with that of Betancourt et al. (2010) who found that in Malawi, a policy on family involvement exists only in areas of HIV and AIDS especially ART and PMTCT where the family is considered central to adherence to treatment. Paliadelis et al. (2005) indicates that clinical practice guidelines in nursing are a way of providing consistently high quality care, by adhering to recognised, evidence based standards. Policies may also help in advocating for provision of adequate resources, providing guidance and support from managers and support from other healthcare disciplines. The absence of a policy on family involvement at QECH may explain why family involvement occurs on adhoc basis.

Socio-cultural factors.

The findings highlight that family involvement is negatively affected by socio-cultural factors such as family, cultural and religious beliefs. These impede nurses' efforts to engage families in the care of the hospitalised child because they mostly affect decision of the family members. Some indicated that family members sometimes consulted family members at home before making a decision, or sought religious or traditional leaders to make a decision for them. Literature indicates that some family members may not open up in a new environment as a way of avoiding confrontation especially in hospital settings (Lam et al., 2003). Pongjaturawit and Harrigan (2003) assert that some family members may remain quiet because they have preconception that the nurses efforts are intirely

focused on the child. Soderback and Christensson (2008) found that most family members had deep rooted family beliefs and traditions in Mozambique. As a result their stay in the hospital depended on consultation with family members at home. It is reported that families in Africa are deeply rooted in communism of living together and communism of thought (Kaphagawani, 1998) hence consultation with family members may reflect compliance with this view. This could be true for some families admitted at QECH.

The results have shown that some families rely on political links to get attention from nurses. This in turn made nurses regard such families as difficult and demanding. Contributions of political factors to family involvement within family centred care literature are not well elaborated. However, it is acknowledged that parents who rely on external factors of influence do so because they are powerless, feel intimidated and perceive the new environment or people as difficult to work with (Williams & Collins, 2001). Williams maintains that the socio-political dimensions of care relate to different community perceptions and experiences of those who live through care as a process. He further argues that communities may have a political influence on care whether is it considered satisfactory or not. However, Zgambo (2009) reported that most communities in Malawi view nurses as rude and harsh. Thus families may use political or other channels of influence to get the most of the health care services of which family involvement is an integral part. This in turn may constrain nurses. As a result registered nurses may shun those with political connections.

Nurses' Impression with Family Involvement

The findings of this study have revealed that registered nurses value family involvement in the care of the hospitalised children. Registered nurses understand the benefits of family involvement which include improving quality of care, sharing responsibilities with family members and shared decision making. This finding is consistent with western studies which have concluded that although nurses are constrained in many ways, they are proponents of family participation in child care (Shields, et al., 2006; Stayt, 2007; Sodomka, 2010; IPFCC, 2010). This may explain why participants in this study reported that nurses have a positive attitude towards family involvement in the care of hospitalised children. However, the study findings indicate that although family involvement is a good idea, it could better serve its purpose if it is regulated. Participants mentioned the need to regulate family involvement through policy or guidelines. Coyne, et al. (2011) found that nurses in Ireland felt they provided substandard care because there was no policy to guide family participation in care. This implies that nurses understand that current practice has no standard on which to base performance regarding family involvement.

Study implications

Implications for nursing practice

The study has revealed that registered nurses are knowledgeable about family involvement in the care of their hospitalised children. This implies that strides can be made to improve on family involvement in child care. However, nurses are constrained due to shortage of nurses and inadequate material resources. Thus adequate staffing is required. Optimal staffing in nursing is essential and has been linked to both optimal care and improvement in nursing

practice (American Nurses Association, 2014).This may mean that nurse leaders need to deploy optimal numbers of nurses to this section to improve family involvement in nursing care.

Implications for nursing management

The study has also revealed that there is lack of direction on policy. Policies and guidelines act as standards against which current performance is based (Paliadelis et al., 2005). In addition, the organisational policy may eliminate many challenges such as shortage of material resources. It may also help to create a safe environment for nurses and families by providing guidance on the same. This provides health care managers with an opportunity to come up with innovative strategies through a collaborative effort to develop a policy upon which nurses and families can base their practice and decisions.

Implications for nursing education

This research has revealed that nurses are knowledgeable on the concept of family involvement and its importance. However, family involvement is selective and conditional. This implies that they face difficulties in implementing the concept and may lack adequate understanding on the application of this knowledge to practice. Family members may feel that involving them in care is a lip service as authority still remains with the nurses. Nursing educators may review their existing curriculum and incorporate family centred care to produce nursing cadres that are intellectually and emotionally prepared to deal with families' issues and handle them in a manner that is conducive not only for involvement but also in decision making.

Implications for research

The findings centred more on the experiences of registered nurses and have presented opportunities and difficulties that registered nurses encounter during family involvement. Future

research should focus on hospital experiences of parents and children regarding family involvement by nurses, doctors and other members of the multidisciplinary team.

Study limitations

The limitation of this study was that the study was done at one site among many hospitals in Malawi with paediatric sections. Multi-settings would have enriched the findings and generalisation of these findings. This limitation resulted from time and financial constraints of the researcher. In addition, patients or guardians were not interviewed to get an idea of their experiences versus experiences of the nurses as the study only targeted nurses. Furthermore, participants may have felt their own practice or professionalism was being questioned and may not have given honest answers on what happens in real practice.

Conclusion

The findings of this study are consistent with those from western countries and show that registered nurses are knowledgeable on family involvement and have a positive attitude towards family involvement in care. Registered nurses experiences are mixed but are constrained by personal factors such as negative attitudes from nurses and family members, socio-cultural factors and inadequate institutional support. These factors are subject to future research because implications of inadequate institutional support may be greater than currently perceived. The findings support the notion that although nurses are proponents of family participation, it's implementation and practice is problematic and inconsistent. This status quo may continue unless authorities provide support in form of human, material resources and develop a policy.

Recommendations

The following proposed recommendations are made to QECH management and nurse leaders because they form the basis on which they can base future directions on family involvement:

- To make the implementation of family centred care and family involvement in the care of hospitalised children a reality, the QECH hospital management should develop a comprehensive policy to guide nurses and other health care workers. Paliadelis et al. (2005) indicates that clinical practice guidelines and policy in nursing are a way of providing consistently high quality care, by adhering to recognised, evidence based standards.
- To reduce burden of workload and give nurses enough time on family involvement the hospital should improve staffing and resource levels in the paediatric section. The section mangers should guide hospital management by stating appropriated staffing ratios in accordance with average patient census. The hospital may do this by deliberately increasing allocation of part time funds to this department. In the mean time, the hospital management may also conduct needs assessment to determine daily allocations. Evidence shows that low staffing contributes to disruption in family involvement in child care (American Nurses Association, 2014).
- To enhance communication and reduce time for information sharing, the section managers and nurses should develop leaflets on common disease conditions in the wards in Chichewa. These leaflets should contain information on the definition of the disease, causes signs and symptoms, treatment including complications, prognosis and home care. Just (2005) concludes that in routine nursing practices where parents are given leaflets

and posters on common diseases and procedures, parents find their own time to read the leaflets with concentration while nurses may have time to answer questions.

- The Unit Nursing Managers should develop CPD sessions on family involvement in order to update all nurses on the changing trends in family involvement so that nurses have same understanding on the implementation and application of the concept.

REFERENCES

American Nurses' Association. (2014). Safe Staffing: *The Registered Nurse Safe Staffing Act.* HR 876/S. 58.

Bamm, E. L. & Rosenbaum, P. (2008). Family-centered theory: origins, barriers and supports to implementation in rehabilitation. *Arch Phys Med Rehabil. 89*(8), 1618-24.

Bernard, F.I. (2009). Telling their story: experiences and reflections of nurses working with families of hospitalised children. *Practice Web Journals, 12,* 234-241.

Betancourt**,** S., Abrams, J. E., Mc Bain, R. & Fawzi, C.S. (2010). Review: family centred facilities approaches to the prevention of mother to child transmission of HIV**.** *Journal of the International AIDS Society, 13*(Suppl. 2), pages???.

Blue-Banning, M., Summers, J.A., Frankland, C.H., Nelson, L. L. & Beegle, G. (2004). Dimensions of family and professional partnerships: Constructive guidelines for collaboration. *Exceptional Children*, *70*(2), 167-184.

Brysiewicz, P. & Bhengu, B.R. (2010). The experiences of nurses in providing psychosocial-support to families of critically ill trauma patients in intensive care units. *South African Journal of Critical care, 26*(2), 44-49.

Burns, N & Groove, S. (2009). The practice of nursing research: appraisal, synthesis and generating evidence (6th ed.). St Louis: Saunders-Elsevier.

Canadian Federation of Nurses' Unions. (2010).*The Nursing Workforce: Regulated Nurses*. Retrieved on 14/10/2013 from: www.nursesunions.ca/workforce/env/12341/3f/d2.

Chesla, C.A., Omerlly, F. & Stannard, D. (2010). Nurses Experiences with families of traumatized hospitalized family members, *Crit. Med Arch, 112,* 1177-1187.

Coyne I., O'Neill C. , Murphy M. , Costello T. & O'Shea R. (2011). What does family centred care mean to nurses and how do they think it could be enhanced in practice. *Journal of Advanced Nursing, 67*(12), 2561–2573.

Coyne, I. & Cowley, S. (2007). Challenging the philosophy of partnership with parents: a grounded theory study. *International Journal of Nursing Studies. 44,* 893–904.

Coyne, I. (2006). Disruption of parent participation: nurses' strategies to manage parents on children's wards. *Journal of Clinical Nursing, 17,* 3150–3158.

Davies, R. (2010). Marking the 50th anniversary of the Platt Report: from exclusion to toleration and parental participation in the care of the hospitalized child. *Journal of child health care, 14*(1), 6-23.

de Lima, R. A. G., Rocha, S. M. M., Scochi, C. G. S., & Callery, P. (2001). Involvement and fragmentation: A study of parental care of hospitalized children in Brazil. *Paediatric Nursing, 27*(6), 559–564.

Dunst, C. J., Trivette, C. M. and Hamby, D. W. (2007a) Meta analysis of family-centered help living practices research. *Mental retardation and developmental disabilities Research Reviews*, *13*, 370–378.

Espe-Sherwindt, M. (2008). Family-centred practice: collaboration, competency and evidence. *Support Learning*, *23* (3), 137-144.

Espezel, H. & Canam, C.(2003). Parent-nurse interactions: care of hospitalised children. *Journal of Advanced Nursing*, *44*(1), 34-41.

Evaglou, H., Iodanou, P., Lemanidou, C.H., Patiraki, E., Kyristsi, E. & Bellou, P.(2003). Parental participation in their hospitalised child's physical and psychological care: nurses perceptions. *ICUs and Nursing Web Journal, 13*, 1-13.

Fegran, L. & Helseth, S. (2009). The parent–nurse relationship in the neonatal intensive care unit context– closeness and emotional involvement .*Scandinavian Journal of Caring Sciences, 23*, 667–673.

Ford, K. & Turner, de S. (2001). Stories seldom told: paediatric nurses' experiences of caring for hospitalized children with special needs and their families. *Journal of Advanced Nursing, 33*(3), 288-295.

Fults, R. M. (2011). *A Qualitative examination of the barriers and facilitators of family centered care and service provision in the natural environment*, Retrieved 20/9/2013 from :http:// scholarlyrepository.miami.edu/oadissertations/569.

Gallant, M. H., Beaulieu, M. C., & Carnevale, F. A. *(*2002*).* Partnership: an analysis of the concept within the nurse-client relationship. *Journal of Advanced Nursing*, 40, 149–157.

Galvin, E., Boyers, L., Schwartz, P.K., Jones, M.W., Mooney, P., Warwick, J., Davis, J., Ahmann, E., 2000. Challenging the precepts of family centered care: testing a philosophy. *Pediatric Nursing,* 26 (6): 625–633.

Gondwe, W.T., Bhengu, B.R. & Bultemeier, K. (2011). Challenges encountered by intensive care unit nurses in meeting patients and family needs in Malawi. *Africa Journal of Nursing and Midwifery*, 13(2), 92-102.

Guestello, G.J. (2009). *Application of the Institute of Family Centred Care Model to clinical epidemiology: a model for family centred public health practice*. New York: Plane Tree Publications.

Harrison, T. (2011). Family centered pediatric nursing care: State of the science. *Journal of Paediatric Nursing*. *25*(5), 335–343.

Holloway, I. & Wheeler, S. (2002). *Qualitative Research in Nursing* (2nd ed.) Oxford: Blackwell.

Institute for Family-Centered Care. (2010). *Advancing practice of patient and family centered care: how to Get Started.* Retrieved on 14/01/2014 from: www.family centered care.org /ipfcc/getting started/2010/ambulatorycare/html.

Institute for Family-Centered Care. (2008). *Partnering with patients and families to design a patient- and family-centered health care system: recommendations and promising practices.* Retrieved on 21/01/2014 from: http://www.familycenteredcare.org/pdf/.

International Council of Nurses. (2010). *Nursing standards for effective practice.* London: College of Nursing Publications.

Irlam, L. K. & Bruce, J. C. (2002). Family-centred care in paediatric and neonatal nursing: a literature review, *Curationis, August*, 28-34.

Ishikawa, H. &Yano, E. (2008). Patient health literacy and participation in the health-care process. *Health Expectations, 11*:113–122.

Just, A. M. (2005). Parental participation bridging the gap. *Newborn and Infant Nursing Reviews,5*(4) 179–187.

Kaiser Permanente Southern California Nursing Research. (2012). *The nursing research series. Essentials of science: methods, appraisal and utilisation.* Retrieved on 8/03/2014 from: http://kpscnursingresearch.org/part-07-20-what are- you-measuring.

Kaphagawani, D.N. (1998). What is African philosophy? In: Cetzee, P.H., Roux, A.P.J. (Eds.), *Philosophy from Africa: a Text with Readings.* Durban : International Thomson Publishing Southern Africa (Pty) Ltd, pp. 86–133.

Kuhlthau, K.A., Bloom, S., Van Cleave, J., Knapp, A.A., Romm, D., Klatka, K., Homer, C.J. Newacheck, P.W., et al., 2011.Evidence for family-centered care for children with special health care needs: a systematic review. *Academic Paediatrics*, 11(2), 136-143.

Lincoln, Y. S. & Guba, E. G. (2005). Paradigms and perspectives in contention. In N.Denzin &Y. Lincoln (eds.) *Handbook of Qualitative Research* (3rd ed.). Place of publication: Publisher, pp. 183-190. Oaks????.

Mackay, L.(2009). *Exploring family centred care among pediatric oncology nurses*. Lethridge: University of Alberta.

Manji, B. & Reckin, F. (2011). *How much do they know? Patient's Perspectives on health care information giving for the sick in Malawi*. Retrieved on 12/12/13from: http//:www.healthinformationmatters.org.gov/infor-article-pdf23-109.

Markowitz, A. J.(2001). Making health care safer: evidence report and technology assessment No. 43. Retrived on 23/02/2015 from: www.ahrq.gov/guide.net/ptsafety.pdf.

Mc Hugh, D.M. & Lake, T.L. (2010). Understanding clinical expertise: nurse education, experience, and the hospital context, *Research in Nursing and Health, 33*(4), 276–287.

Mikkelsen, G., & Frederiksen, K. (2011). Family-centred care of children in hospital: a concept analysis. *Journal of Advanced Nursing, 67*(5), 1152-1162.

Mock, V., Ours, C., Hall, S., Bostis, A., Tillery, M., Belcher, A., Krumm, S. & Mc Morkle, R (2007). Using conceptual models in nursing research- mitigating fatigue in cancer patients. *Journal of Advanced Nursing, 58*(5), 503-512.

Nastasi, B. (2003). *Qualitative research sampling and sample size considerations*. Retrieved on 15/02/2014 from**: http//.mylaureate.net/sample+size+for+qual+study.html.**

Nurses and Midwives Council of Malawi (2003). *The Nurses and midwives scope of practice for Malawi.* Lilongwe, Nurses and Midwives Council of Malawi.

Orril, T.D. (2009). Nurse excerpts from family involvement for families children needing speacilaised services in South Africa, *Nursing Practice Web Journals, 29*(4), 231-238.

Paliadelis, P., Cruickshank, M., Wainohu, D., Winskill, R & Stevens, S. 2005. Implementing family-centred care: an exploration of the beliefs and practices of paediatric nurses. *Australian Journal of Advanced Nursing*. *23*(1), 31-37.

Pettoello-Mantovani, M., Campanozzi, A., Maiuri, L. & Giardino, I. (2009). Family-oriented and family-centered care in pediatrics. *Italian Journal of Pediatrics, 35*, 1-12.

Pillitteri, A. (2010). *Maternal and child health nursing: care of the childbearing and child rearing family*. Philadelphia: Lippincott Williams & Wilkins.

Polit, D. & Beck, C.T. (2010). *Essentials of nursing research: appraisal evidence for nursing practice* (7th ed.). Philadelphia: Lippincott Williams & Wilkins.

Polit, D. F., & Beck, C. T. (2004). *Nursing research: principles and methods* (7th ed.). Philadelphia: Lippincott Williams & Wilkins.

Pongjaturawit, Y. & Harrigan, R.C. (2003). Parent participation in the care of hospitalized children in Thai and Western cultures. *Issues in Comprehensive Pediatric Nursing 26*, 183–199.

Robinson, J.P. (2000). Phases of qualitative research interview with institutionalized elderly individuals, *Journal of Gerontologcal Nursing* , *26*(11), 17-23.

Saleeba, A. (2008). *Importance of family centred care*. Retrieved on 28/03/2014 from: Digital commons.uconn.edu /son_articles/48/.

Saskatchewan Ministry of Health. (2011). *Patient- and Family-centred Care in Saskatchewan: a framework for putting patients and families first*. Retrieved on 28/03/2014 from: http:// wwwhealth.gov.sk.ca/primary-health).

Shelton ,T. (2009). The 4 essential types of family structures and definitions. Retrieved on 20/06/13from:www.http://ezinearticles.com/expert/toby+shelton/home+family.html

Shields L, Pratt J, Hunter J. (2006). Family centred care: a review of qualitative studies. *Journal of Clinical Nursing*, *15,* 1317-1323.

Shields, L. & King, S. (2001a). Qualitative analysis of the care of children in hospital in four countries Part 1. *Journal of Pediatric Nursing, 16*, 137–145.

Soderback, M. & Christensson, K. (2008).Care of hospitalized children in Mozambique: nurses' beliefs and practice regarding family involvement. *Journal of Child Health Care, 11*(1) 53–69.

Soderback, M. & Christenssen, M. (2008). Family involvement in the care of a hospitalized child: A questionnaire survey for Mozambican family care givers. *International Journal of Nursing Studies, 45*, 1778-1788.

Soderstrom, I., Benzein, E. & Saveman, B. (2003). Nurses' experiences of interactions with family members in the intensive care units. *Journal of Caring Sciences, 7*, 185-192.

Specht, J., Taylor, R., & Bossen, A. (2009). Partnering for care: The evidence and the expert. *Journal of Gerontological Nursing, 35*(3),16-22.

Speziale, H.S. & Carpenter, D.R. (2007). *Quantitative research in nursing: advancing humanistic imperative,* (4th ed.). Philadelphia: Lippincott , Williams and Wilkins.

Stayt, L.C. (2007). Nurses experiences of caring for families with relatives in the intensive care units. *Journal of Advanced Nursing, 57*(6), 623-30.

Stewart, M., Ryan, B.L. & Bodea, C.B. (2011). Is Family Centred care associated with low cost? *Health Care Policy, 6*(4), 27-31.

Thesaurus.com. (2013). *Lived experience meaning and definition*. Retrieved 02/01/2014 from www.thesaurus.com/definition/lived/experience/rt.e900/html.

Uhl, T., Fisher, K., Docherty, S. L. & Brandon, D. H. (2013). Insights into Patient and Family Centered Care Through the Hospital Experiences of Parents. *Journal of Obstetric and Neonatal Nursing, 42,* 121-131.

Ulin, P. R., Robinson, E.T. and Tolley E. E. (2004). *Qualitative Methods in Public Health: a field guide for applied research.* San Fransisco: Jossey-Bass.

University of Iowa. (2009). *Family involvement in care for persons with dementia in long term facilities*. Iowa City, Iowa Geriatric Research Centre. Retrived on 13/1/2015 from: http://www.medicine.uiowa.edu/igec.

Wells, N. (2011). Historic perspectives on family centred care. *Academic Paediatrics, 11*,100-102.

Williams, D.R. & Collins, C. (2001). Racial residential segregation: a fundamental cause of racial disparities in health. *Public Health Reports, 116*(5), 404–416.

Whittenmore, R. & Grey, M.(2002). The systematic development of nursing interventions, *Journal of Nursing Scholarship,* Second Quarter, 115-120.

Ygge, B.M. (2007). Nurses perception of parental involvement in hospital care. *Paediatric Nursing, 19*(5), 38-40.

Ygee, B.M., Lindhon, G. & Arnetz, E, J. (2004). A study on parental involvement in pediatric hospital care: Implication for practice. *Journal of Paediatric Nursing*, 19(3), 217-223.

Zaman, S. (2004). Poverty and Violence, Frustration and Inventiveness: Hospital Ward Life in Bangladesh. *Social Science and Medicine,* 59(10), 2025–36.

Zgambo, P. (2010). Malawi Scores High at Maternal Indaba. *Nation on Sunday,* 5(9), 28th February.

APPENDICES

Appendix A: Interview Guide

Section A: Participants demographic information

Serial Number……..……..…….....

A1. How old are you?.....

A2. What is your gender?

1. Male
2. Female

A3. Which tribe do you belong to?.....

A4. What is your religion ?.....

A5 What is your professional education level…….....…….……..

A6 Do you have a speacilaised paediatric nursing qualification?

1. Yes. 2. No

If yes specify……..…….....……

A6. How many years have you worked in this Paediatric Ward?.....

Section B.

B1. Experiences on family involvement

i. What does family involvement mean to you?

ii. What are your experiences about involving families in the care of hospitalised children?

B2. Respect and dignity for hospitalised children and their families

i. What does respect and dignity for hospitalised children and their families mean to you?

ii. What do you do to demonstrate respect to patients' and their family perspectives or choices?

iii. What do you do to incorporate patients and families in planning and delivery of care?

B3. Information sharing and collaboration with families of hospitalised children

B3. (A): Information sharing

i. How do you communicate and share information with families?

ii. How do you provide feedback and information to patients so that they can effectively participate in care and decision making?

B3. (B): Collaboration

i. How do you collaborate with families in the delivery of care to hospitalised children?

ii. How do you include patients and families in the evaluation of care?

- Can you give me an example on how this was accomplished?

B4. Participation of families in the care of their hospitalised children

i. What do you do to allow families to participate in the care of the hospitalised children

ii. What tasks or roles do you give family members when caring for hospitalised children

iii. How do you support and encourage patients to participate in care and decision making? Can you give me an example when this worked well and Why?

B5. Factors that facilitate and hinder nurses' efforts on effective family involvement

i. What factors affect and hinder your' efforts to effectively involve families in the care of the hospitalised child?

Appendix B: Nurses Information Letter

Dear participants

I am **Patrick Phiri,** a student at University of Malawi, Kamuzu College of Nursing doing Master of Science degree in Child Health Nursing. I wish to invite you to participate in my research titled *"Registered nurses lived experiences on family involvement in the care of hospitalized children at Queen Elizabeth Central Hospital"*. The aim of the study is to gain adequate understanding on registered nurses experiences including factors that affect family involvement in the care of hospitalized children. Your participation in the study is voluntary and you may agree or disagree to participate or withdraw at any point from the study. Your refusal to participate or withdraw from the study will not attract any penalties. You are free to ask questions and also you are free to refuse to answer any question that you are not comfortable with. Should you accept to participate, you will be provided with consent form which you will be asked to sign. The interview will take approximately 45minutes.

You are also informed that that your confidentiality and privacy will be maintained throughout data collection and analysis as well as publication of findings. No names or any identifiable information will be used instead only serial numbers will be used. This implies that no one will be able to identify or relate you to your responses. The study will be done in private room within to ensure your privacy and also to ensure that you return to your work easily after the interview session. After the study is completed and report has been submitted all written documents will be destroyed by incineration while recorded information will be destroyed by erasing so that no one will be able to access and use the information again.

You will be requested to answer questions related to your own experience regarding family involvement in the care of your child. 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 lockable cupboard only accessible to the researcher. You are informed that there are no direct benefits from participating in the study however it is hoped that the findings may bring awareness and clarify nurses' experiences and understanding of the concept of family involvement and identify factors that facilitators and hinder family involvement by nurses at QECH. Thus this may influence policy in nursing education and curriculum, nursing practice, management and research. Furthermore you are informed that the study does not have any foreseen physical harm. However you may experience psychological discomfort due to longer waiting time before the interview and longer time during the interview. Long waiting time before interview may be due delays because some participants may be slow to answer questions or require a longer break during the interview or other unforeseen circumstances prior to the interview. This may have negative physical and psychological bearing on you such as anxiety. The researcher will inform and update you regularly by telephone if a possibility that appointments may delay or if the interview may be longer than expected becomes imminent. However, the researcher will endeavour to keep time during each interview so that appointments are adhered to.

Be informed that no one will know about what you have to say and you will not be forced to answer any question you are not comfortable with. The interview will take approximately 45 minutes which may make you get tired**.** You will therefore be allowed to take break and rest in between if you so wish. Should you have any questions or concerns at any point about the study do not hesitate to contact me or the following people:

Patrick G.M. C. Phiri
Kamuzu College of Nursing
P.O Box 415, Blantyre
Phone: 0999493842

The Chairperson COMREC
P/Bag 360,
Chichiri, Blantyre 3
Phone: 01989766

The Principal

Kamuzu College of Nursing.

P.O. Box 415, Blantyre

Phone: 01873623

Appendix C: Participant's Consent Form

I have understood the information that you have explained to me about the study and my role in this 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 registered nurses describe their experiences regarding family involvement in care of hospitalised children at Queen Elizabeth Hospital.

I understand that my participation is voluntary and that am free to withdraw at any point and this will not attract any penalty. 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 I will be asked questions related to my experience in on family involvement in the care of hospitalised children and it will take approximately 45 minutes and I will be allowed period of rest if I wish so. I also understand that there is no direct benefit in participating. I also understand that the only risk associated is the psychological discomfort due to long waiting and interview time. I understand that I am free to refuse to answer questions am 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 therefore voluntarily agree to participate in this study.

…… …….

Participants' Signature Date

....

Researchers' Signature Date

Appendix D: Kalata Yofotokoza Za Kafukufuku

Wokondedwa,

Ndine **Patrick Phiri,** wophunzira zaunamwino kusukulu ya ukachenjede ya Malawi, ku Kamuzu Koleji amene ndi kuphunzira zokhuza umoyo wa ana ndipo ndikupanga kafukufuku wotchedwa "*Kuunikira momwe anamwino akhala akuchitira kuti achibale a ana wogonegenekedwa mchipatatala azitengapo mbali pachisamaliro cha ana awo pa chipatala cha Queen Elizabeth Central Hospital"* .Ndiye ndikukupemphani kuti mutengepo nawo mbali polowa nawo mukafukufukuyu. Cholinga cha kafukufukuyu ndi choti tiunikire zomwe anamwino akuchita komanso zomwe amakumana nazo pofuna kuti anthu wodikirira ana azitengapo mbali posamalira ana ogonekenekedwa mchipatala. Kafukufukuyu aunikiranso zomwe zimapangitsa kuti chidwi cha anamwino polimbikitsa kuti abale a ana wogonekedwa mchipatala chipite patsogolo kapene chibwerere m'mbuyo.

Dziwani kuti simukukakamizidwa kutengapo mbali komanso muli ndi ufulu ngati mukufuna kusiya nthawi imene mungafune popanda vuto lina lililonse. Kukana kusiya kapena kutuluka mukafukufukuyu sizidzasokonenza ntchito yanu komanso simuzalandira chibalo tsopano ngakhalenso mtsogolomo. Muli omasuka kufunsa mafunso alionse okhudza kafukufukuyu komanso kukana kuyakha funso lomwe simukufuna mutayakha chifukwa simukugwirizana nalo.

Mukudziwitsidwa kuti mayankho anu adzasungidwa mwachinsisi ndipo sizizadziwika kuti anayankha mafunsowa ndindani chifukwa mayina anu sazayikidwa pamapepala a mafunso mmalo mwake tizagwiritsa ntchito manambala. Mukudziwitsidwanso kuti palibe cholowa chilichonse kwa inu potenganawo mbali koma pali chiyembekezo kuti zidzathandiza kudziwitsa anthu komanso oyendetsa ntchito za muchipatala, oyanganira ndi ophunzitsa anawino ndi ena za

zomwe anawino amakumana nazo panchito yawo yofuna kuti makolo adzitengapo mbali pa ntchitoyosamalira ana omwe agonekedwa muchipatala. Kafukufukuyu akuyembekezereka kuthandizanso kuyika maziko kwa iwo ofuna kufufuza zambiri za nkhani zokhuzana ndikuti anamwino aziwalora makola kutengapo mbali pachisamaliro cha ana muchipatala.

Dziwaninso kuti palibe chiopsezo china chili chonse pakafukufukuyi. Vuto lomwe lingakhalepo ndilakuti mukhoza kukhala ndi okhuzidwa poti mukhala nthawi yayitali podikira chifukwa chakuchedwa kuyankha mafunso kwa omwe ali patsogolo panu komanso nthawi yomwe tikhale tikufunsana mafunso koma mudzaloledwa kupuma pamene mwatopa mkatikati mwa kuyankha mafunso. Muli kudziwitsidwa kuti anzanu ena ogwira ntchito mchipatala amene sakukhudzidwa ndi kafukufukuyu sadzadziwa konse zokhudza mayakho anu.

Ngati mwa vomereza kutengapo mbali pakafukufukuyi muzapemphedwa kusayina chikalata kuti ukhale wumboni oti mwavomela kutenga nawo mbali. Mudzafunsidwa kuyankhapo mafunsowa kwa nthawi pafupifupi mphindi makumi anayi ndi zisanu (45).

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

Patrick GMC Phiri, Kamuzu College of Nursing

P.O Box 415, Blantyre, Nambala ya phoni: **0999493842**

The Principal, Kamuzu College of Nursing

P.O Box 415, Blantyre, Telefoni: 01873623.

Wapampando, College of Medicine Research and Ethics Committee (COMREC), P/Bag 360, Chichiri, Blantyre 3. Telefoni: **01989766**

Appendix E: 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 ntchito yanga kapena kulandira chibalo chilichonse pakali pano kapena mtsogolo.

Ndamvetsetsa kuti ndidzapephedwa kuyakha mafunso okhudza kutengapo mbali kwanga pa chisamaliro cha mwana wanga ndipo izi zitenga pafupifupi ola limodzi.

Ndamvesetsanso kuti zonse zomwe ndiyankhule kapena kupereka mukafukufukuyu zidzasungidwa 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 Tsiku

..... …….....

Mwini kafukufuku Tsiku

Appendix F: Letter of Permission to Queen Elizabeth Hospital

Kamuzu College of Nursing

P.O. Box 415,

Blantyre.

6th April, 2014

The Director

Queen Elizabeth Central Hospital

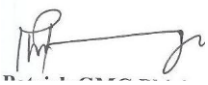
P.O. Box 295, Blantyre

Dear Sir/ Madam,

PERMISSION TO CONDUCT A STUDY

I am a registered nurse currently enrolled at University of Malawi Kamuzu College of Nursing pursuing the Master of Science in Child Health Nursing. This letter seeks to ask your office for permission to conduct a study as part of the requirement for this programme. The study is entitled "**Registered nurses lived experiences on family involvement in the care of the hospitalised children at Queen Elizabeth Central Hospital, Malawi.** After the study, a copy of the findings will be given to your office. Further information regarding this study may be obtained by calling me on the following numbers: 0999493842 or my Supervisor on 0888878290. Accompanying this is the study proposal.

Yours faithfully,



Patrick GMC Phiri

Appendix G: Letter of Approval from 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

Ref No. QE/10

9th April, 2014

Patrick GMC Phiri
Kamuzu College of Nursing
Blantyre Campus
P.O. BOX 415
BLANTYRE 3

Dear Patrick

PERMISSION TO CONDUCT A RESEARCH STUDY AT QUEEN ELIZABETH CENTRAL HOSPITAL

This is to inform you that permission has been granted to conduct a research study entitled **"Registered nurses lived experiences on family involvement in the care of the hospitalized children "** at Queens Elizabeth Central Hospital.

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

All the best in your studies.

Yours faithfully,

T.N. Soko (Mrs.)
DEPUTY HOSPITAL DIRECTOR - NURSING

Appendix H: Letter from Head of Department QECH Paediatrics

Principal
Prof. K Maleta, PhD

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

College of Medicine
Private Bag 360
Chichiri
Blanytre 3
Malawi

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

14th April 2014

Chair COMREC
College of Medicine

Dear Dr Mwaphasa,

RE: 'Registered nurses lived experiences on family involvement in the care of the hospitalised children at QECH, Malawi'

I am writing in approval of this low-risk study which will be conducted in the paediatric wards in Queen Elizabeth Central Hospital. I hope that the results will help us to improve communication to parents and children during their admission.

Yours sincerely

Dr Neil Kennedy
Associate Professor /Consultant Paediatrician

Appendix I: Letter from Head of Department-KCN

KAMUZU COLLEGE OF NURSING

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

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

7th April 2014

The Chairperson
COMREC
P/Bag 360
Chichiri
BLANTYRE 3

Dear Sir/Madam

INTRODUCTION OF MR PATRICK PHIRI

I write to introduce to you Patrick Phiri who is a student pursuing Master of Science Degree in Child Health at Kamuzu College of Nursing. He is currently working on his research proposal and the title is **"Registered Nurses Lived Experiences On Family Involvement In The Care of Hospitalised Children at Queen Elizabeth Central Hospital Malawi".**

The study that he will conduct is very important and relevant to the Malawi situation. The findings of the study may influence policy makers to formulate policies and guidelines on family involvement in child health care at QECH.

Thank you for your usual assistance.

Yours faithfully

Angela Chimwaza PhD
COORDINATOR – CHILD HEALTH PROGRAMME

Appendix J: Letter of Permission to COMREC

Kamuzu College of Nursing,

P.O. Box 415,

Blantyre.

6th April, 2014.

The Secretariat,

College of Medicine Research and Ethical Committee (COMREC),

Private Bag 360,

Chichiri,

Blantyre 3

Dear Sir/ Madam,

PERMISSION TO CONDUCT A STUDY

I am a student currently enrolled at University of Malawi Kamuzu College of Nursing pursuing the Master of Science in Child Health Nursing. This letter seeks to ask for a review of the proposal so that I can conduct this study. Approval of this study and its subsequent execution will assist me to fulfil the requirement for the award of degree of Master of Science in Child Health Nursing. The study is entitled "**Registered nurses lived experiences on family involvement in the care of the hospitalised children at Queen Elizabeth Central Hospital.** The study will be conducted in May and June 2014.

After the study, copies of the findings will be given to your office. Further information regarding this study may be obtained by calling my supervisor on 0888878290. Accompanying this are copies of introduction and the study proposal.

Yours faithfully,

Patrick GMC Phiri

Appendix K: Letter of Approval from COMREC

CERTIFICATE OF ETHICS APPROVAL

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

P.04/14/1562 – Registered nurses lived experiences on family involvement in the care of the hospitalized children at QECH by Mr. P. Phiri

On 26 June 2014

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

Dr. V. Mwapasa- Chairperson (COMREC)

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

26/06/14
Date

Appendix L: Time Frame (Not necessary. Only applicable for a proposal)

Activity	**Time frame (Months)**											
	Dec	Jan	Feb	Mar	April	May	June	July	Aug	Sept	Oct	Nov
Proposal development												
Submission of proposal to KCN and COMREC												
Data collection												
Data analysis												
Report writing												
Submission of report												

The proposed study period was from December 2013 to November 2014. This included research proposal development, consultations with supervisors, data collection and analysis and writing and submission of the report.

Study Budget (Not necessary. Only applicable for a proposal)

Items	**Quantity**	**Cost per item(MK)**	**Total cost (MK)**
Stationery			
Reams	3	2500.00	7,500.00
Pens	5	100	500.00
Pencils	10	50	500.00
Rubbers	3	500	1,500.00

Large envelopes	5	200	1,000.00
Medium envelopes	10	100	1,000.00
Sub Total			**12,000.00**
Secretarial work			
Proposal printing and binding	5	1500	7,500.00
Thesis Printing and binding	5	3000	15,000.00
Photocopying research tool	30	100	3,000.00
Subtotal			**25,500.00**
Proposal review			
Payment for approval	1	35000	35000.00
Sub total			**35,000.00**
Allowances			
Voice recorders	1	8000	8,000.00
Refreshments for participants	12	300	3600.00
Transport for researcher	5	500	2,500.00
Subtotal			**34,600.00**
Total			106,600.00
10% contingency			10,66.00
Grand total			**116,666.00**

Justification of the budget (Not necessary. Only applicable for a proposal)

Qualitative studies require more writing such taking notes, refining the proposal and data collection tools, printing and photocopying of the proposal and dissertation. This budget was planned to cover stationery items such as pens, pencils, envelopes and reams for secretarial work. This forms the bulk of any study. Envelopes number was bigger because some envelopes were used for sending letters while others will be used to keep data and notes It is a requirement that an applicant pay for an administrative fee to COMREC for proposal

review hence its reflection on the budget. The other allowances were used to buy refreshments for participants as token for taking their time to provide this needed data and transport for the researcher. Extra data collectors were not recruited for this study. Contingency of 10% was to cover unforeseeable price hike by the time the research was being executed. This money was kept aside to cater for items that may be under budgeted and also as a cushion to depreciation of the Kwacha against the US Dollar. The sponsors gave the researcher K85,000.00 for execution of this study. However, this was lower than the actual budget. The budget had gone up by K31,666.00. The researcher made a top up of this money so that the study was carried out successfully.