KAMUZU COLLEGE OF NURSING

EXPERIENCES OF MOTHERS SEPARATED FROM THEIR CHILDREN WITH PNEUMONIA ADMITTED IN THE PAEDIATRIC HIGH DEPENDENCY UNIT AT KAMUZU CENTRAL HOSPITAL IN LILONGWE, MALAWI.

MSC (Child Health Nursing) Thesis

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Declaration

I, Diana Chiundu, hereby declare that this thesis is my own original work which has not been submitted to any other institution for similar purposes. Where other people's work has been used, 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 been submitted with our approval.

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Dedication

I dedicate this work to my lovely husband George, my three childrenMphatso, Kingsley and Tadala who missed the motherly love and care that they were supposed to get if I were around.

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Abstract

Mothers of children admitted in the paediatric general wards at Kamuzu Central Hospital are allowed to stay with their children in the ward and take part in caring for their children. When a child is very sick and requires high level of care, is transferred to paediatric high dependency unit where the mothers are not allowed to stay with their children all the time. Studies that have explored experiences of mothers separated from their children are limited in Malawi. The aim of this study was to explore experiences of mothers separated from their children with pneumonia admitted in the paediatric high dependency unit.

The study utilized a descriptive research design using qualitative method to data collection and analysis. The study was conducted at Kamuzu Central Hospital in the paediatric high dependency unit in Lilongwe, Malawi. Twenty mothers separated from their children with pneumonia admitted in the paediatric high dependency unit were purposively sampled. Data was collected through in-depth interviews using semi structured interview guide. The data was analysed using thematic content analysis.

On experiences, fivethemes emerged: being involved in the care of their children, receiving support and guidance from nurses when providing care to their sick children,negative experience regarding attitudes of nurses and other health workers while caring for their children, feelings of lack of trust on the nurses and other health workers and feelings of anxiety.On satisfaction with care, mothers' reports were mixed. Some mothers were satisfied with care given while some were not satisfied. On parental needs, three needs were reported: the need to be with their sick child; information about condition of the child; and a good relationship with nurses and other health workers.

Taking into account the findings of the study, mothers' involvement in the care of the child should continue and be encouraged. Mothers should be given enough and continuous information, guidance and support throughout hospitalization. There should be good relationship and mutual trust between nurses and mothers to work hand in hand in caring for the sick children in order to meet their emotional needs. Health workers should avoid shouting at mothers but rather make them understand why some of the ward's regulations should be followed and for their own benefit.

The findings of the study could assist in making the nurses work in partnership with the mothers and support them during the stressful period of hospitalization in the high dependency unit. In addition, the results would also inform managers to develop policies that will address the needs of the mothers in Paediatric high dependency unit thereby improving patient care.

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ABREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ARI	Acute Respiratory Tract Infection
COM	College of Medicine
CPAP	Continuous Positive Airway Pressure
ETAT	Emergency Triaging Assessment and Treatment
HDU	High Dependency Unit
HIV	Human Immunodeficiency Virus
HMIS	Health Management Information Systems
IMCI	Integrated Management of Childhood illnesses
KCH	Kamuzu Central Hospital
MDHS	Malawi Demographic and Health Survey
MICS	Multiple Indicator Cluster Survey
NGT	Naso Gastric Tube
NICU	Neonatal Intensive Care Unit
PCV	Pneumococcal Conjugated Vaccine
PHDU	Peadiatric High Dependency Unit
QECH	Queen Elizabeth Central Hospital
UK	United Kingdom
WHO	World Health Organization

Chapter 1:

Introduction

Introduction

Pneumonia is the inflammation of the pulmonary parenchyma, which is common in childhood but occurs more frequently in infancy and early childhood (Hockenberry & Wilson, 2009). Pneumonia is the leading cause of deaths in children worldwide and the great majority of these deaths occur in resource limited settings. It kills an estimated 1.4 million children under the age of five years every year, more than AIDS, malaria and tuberculosis combined. It accounts for 18% of all deaths of children under five years old worldwide. It affects children and families everywhere but is most prevalent in South Asia and Sub Saharan Africa (WHO, 2011b). Bellos et al. (2010) in their report on the causes of under-five deaths in Africa, showed that neonatal deaths was the leading cause (26%) more than Acute Respiratory Tract Infection (ARI) (21%), diarrhoea (16%), malaria (16%), and other infection and parasitic disease. It is estimated that almost 800,000 neonatal deaths occur each year from acute respiratory tract infections and mostly pneumonia. Malawi, which is one of the Sub Saharan African countries, pneumonia is a leading cause of deaths among the under five children (WHO, 2011b). Acute Respiratory tract Infection (ARI) is the second most common cause of out-patient attendances among children under-five years and is one of the three most common causes of hospital deaths in Malawi (Ministry of Health (MOH), 1999). According to the report from WHO in the year 2000, on the causes of under-five deaths in Malawi showed that, pneumonia was the leading cause (22.6%) more than neonatal (21.7%), diarrhoea (18.1%), malaria (14.1%),

and HIV diseases 14%. In 2008, 14% of under-five child deaths in Malawi were due to pneumonia (Black, Cousens & Johnson, 2010). The Malawi Demographic and Health Survey conducted in 2010 revealed that children of ages 6-11 months are most likely to have had ARI symptoms compared with children in other age groups. Children aged 6-11 months were more likely to be taken to a health facility (84%) than other children. The ARI prevalence was estimated by asking mothers whether their children under age 5 had been ill with a cough accompanied by short, rapid breathing in the two weeks preceding survey. These symptoms are compatible with ARI (MDHS, 2010). According to the data from the Emergency Triaging Assessment and Treatment (ETAT) Coordinator at Kamuzu Central Hospital (KCH), among 31,439 total admissions for the fiscal year 2010-2011, pneumonia admissions accounted for 16.8%. Total deaths for the fiscal year were 3,707, 14% of the deaths being due to pneumonia. This shows that pneumonia is also one of the leading causes of deaths in Malawi.

World Health Organization (WHO) developed a case management strategy in the 1980s aiming to reduce pneumonia –related deaths. This was a cornerstone of the (ARI) Programme later incorporated into Integrated Management of Childhood Illnesses (IMCI) guidelines which include primary and hospital based case management. The basis for the case management strategy was that almost all ARI related deaths were in children with pneumonia. Global efforts on mortality control focus on ARI case management and improving the coverage of immunization (Rasmussen et al., 2000). In response to reduce pneumonia deaths, Pneumococcal Conjugated Vaccine (PCV) was introduced in November 2011 in Malawi to immunize children under one year old in order to protect them against pneumonia (WHO, 2011a). KCH is following ARI guidelines as a hospital

based pneumonia case management. The children with very severe pneumonia are admitted in the high dependency unit (HDU) for the provision of high level of care.

In HDU at KCH child care is almost done by nurses and the Ward Policy does not allow mothers to stay in the ward. There is no known reason given for this arrangement although some people assume that it could be due to limited space in the HDU. Shields found that in some developing countries parents were encouraged to stay with their hospitalized child only if it fitted with hospital rules (Shields, 2001c). The family is acknowledged as expert in the care of their child, and the perspectives and information provided by the family have been described as important to clinical decision making. (Irlam, 2002; Neff 2003). In the United Kingdom, the importance of promoting the role of families in the care of the hospitalized child has been acknowledged (DOH, 2003). Also reported in the literature are many factors that influence the successful implementation of family-centred care, including nurses 'perceptions of the family's role in the care of the hospitalized child, their relationships with parents, communication channels and styles, environmental constraints, and management support of staff (Bratt et al., 2000; Fenwick et al., 2001). A study done on the benefits of mother's permanence and participation in the care for their hospitalized child, the results evidenced that the mothers' presence and care increased the attachment between mother and child, increased mothers' confidence and made the child calmer. This produced positive feelings such as joy and satisfaction for being able to care for their child. Nurses should review their behaviour toward the mothers accompanying their child at the hospital, and adopt attitudes that support her participation in the care for hospitalized child (Mollina & Marcon, 2009).

In Malawi, studies about experiences ofmothers of children admitted in HDU are limited. The study therefore aimed at exploring the experiences of mothers separated from their children with pneumonia admitted in the Paediatric High Dependency Unit (PHDU) at KCH. The study focussed on the experiences of mothers of the sick children admitted in PHDU, their satisfaction with the care rendered to their sick children, and their needs during the child's hospitalization.

Background

In Malawi, Children with very severe pneumonia require admission and are given oxygen therapy 1-2 litres per minute via nasal prongs or continuous positive airway pressure (CPAP), treated with intravenous or intramuscular antibiotics, supportive care in terms of fever management, maintenance fluids intravenously or orally and oral feeds or nasogastric feeds if cannot drink (COM & QECH protocols, 2004). The use of antibiotics in under- five children with suspected pneumonia is a key intervention (MICS, 2006). Early diagnosis and treatment with antibiotics can prevent a large number of deaths caused by ARI (MDHS, 2010). Implementation of an effective oxygen therapy system in Papua New Guinea reduced severe pneumonia mortality in one hospital by 40% and when this was extended to five other hospitals there was an overall pneumonia case fatality reduction of 35% (Graham et al., 2008).

The hospitalized child may be apprehensive and the treatments and tests are frightening and stress producing. It is important to involve the entire family in the care as appropriate and to encourage questions that facilitate effective communication. Reducing anxiety and apprehension reduces psychological distress in the child, and when the child is

more relaxed, the respiratory efforts are lessened. Easing respiratory efforts makes the child less apprehensive, and encouraging the presence of the care giver provides the child with a source of comfort and support (Hockenberry & Wilson, 2009). At Kamuzu Central Hospital (KCH), children with very severe pneumonia are admitted in PHDU for high level care according to the admission criteria. Kamuzu Central Hospital (KCH) is one of the four referral hospitals in Malawi and covers the Central region. It also acts as a district hospital for Lilongwe district. According to 2011, KCH data from Health Management Information Systems (HMIS), paediatric wards are more congested than adult wards as evidenced by KCH bed occupancy of 52.5% and paediatric bed occupancy of 69.6%. The high bed occupancy could be due to high rates of admissions in the paediatric ward than in adult wards. At KCH in the paediatric unit general wards, as a general practice, children stay with their mothers all the time. During this time the mothers take part in the care of their children like bathing, feeding, tepid sponging, changing nappies and turning. However, when the children are very sick and require high level of medical or surgical care, they are admitted in the Paediatric High Dependency unit (PHDU).They are admitted to the unit from under five clinics, intensive care unit, main operating theatre, casualty, and paediatric general wards. The unit has six beds for six children ranging from infants to adolescents making a ratio of 1 nurse to 3 patients per shift. In the PHDU, the ward policy does not allowmothers to stay with their children, they just come during visiting hours or they are called when they are needed. There is no known and documented reason given for this arrangement although some people assume that it could be due to limited space in PHDU. Therefore, it is not well known how mothers regard or react to this arrangement, and how it might affect them and their sick children because experiences of mothers

separated from their children with pneumonia admitted in the PHDU have not been examined in Malawi.

Problem statement

Hospitalization involves that parents are in an unfamiliar environment and their parental role changes (Hallstrom, Runesson, & Elander, 2002). Admission in a Paediatric Intensive Care Unit is often a transitional phase in the child's recovery from a critical illness. Most parents experience a PICU admission with a certain emotional impact. Qualitative studies on parental experiences identified the role of parents, the parents-professional relationship, and emotional burden as the themes which encompass all the other themes as well as being the most important (Shudy et. al., 2006). Separation from the child had also been found to be most difficult aspect for mothers when their new-born child is hospitalized in a Neonatal Intensive Care Unit (NICU). The experience had caused them emotional strain and anxiety which were related to the staff, the child, the environment, the mother herself, the child's father and other mothers (Nystrom & Axelsson, 2002).Parents also experience grief and anxiety upon leaving the NICU for any period of time including brief departures to get something to eat or drink (Smith et al., 2012).The studies from developed countries recommended that parents should be allowed to stay in the hospital with their child and that parents' participation must be appropriate. While in developing countries, the insufficient literature suggested that the importance of parents' participation in the care of a hospitalized child is starting to become recognized. (Shields, Young & Mc Cann, 2008). To understand the extent of the effect of hospitalization, knowledge of the individual experiences of the mother is essential to providing improved service provision that is centred towards serving the client better.

Mothers of children admitted in the paediatric general wards at KCH are allowed to stay with their children in the ward and they take part in caring for their children. When a child is very sick and requires high level of care, is transferred to PHDU where the mothers are not allowed to stay with their children all the time according to the ward policy. There is no known and documented reason given for this arrangement although some people assume that it could be due to limited space in PHDU. When they are separated from their children it is not known how they feel, what they need and if they are comfortable with such an arrangement or not. However, experiences of mothers separated from their children admitted in the PHDU with pneumonia have not been examined in the context of Malawi. Therefore, it is important to conduct this study with an aim of informing the practitioners the experiences of mothers separated from their children in PHDU to help guide designing of better service provision, protocols/practices that provides for or guide positive experiences of mothers.

Significance of the Study

The study will generate knowledge necessary for rendering care in paediatric high dependency unit after knowing the mothers' experiences, satisfaction with HDU care and their needs during the child's hospitalization. These will give a clue on how they can work in partnership with the nurses and be supported during this stressful period. It will also help service providers to better understand roles that mothers can play in the care of the child during PHDU hospitalization.It will also help the managers to develop policies that will address the needs of the mothers in PHDU thereby improving patient care.

Broad Objective

The overall objective is to explore experiences of mothers separatedfrom their children with pneumonia admitted in the paediatric high dependency unit at Kamuzu Central Hospital.

Specific objectives

1. To describe the experiences of mothersof children admitted in paediatric high dependency unit.
2. To determine mothers' satisfaction with the care provided in PHDU.
3. To identify parental needs during their child's hospitalization.

Chapter 2

Literature Review

Introduction

Literature review is a critical summary of research on a topic, often prepared to put a research problem in a context or to summarize existing evidence (Polit & Beck, 2011).An electronic search was conducted using the MEDLINE, EBSCOHOST, HINARI, PubMed and CINHAL in order to find relevant articles, original reports and review what is known about findings of recent existing studies. In addition, textbooks were also read, refer to the references listed.

The literature review focussed on the experiences of mothers of children admitted in the PHDU,their satisfaction with the care provided and their needs during the child's hospitalization.

Experiences of Mothers during Child's Hospitalization

Hospitalization involves that parents are in an unfamiliar environment and their parental role changes (Hallstrom, Runesson, & Elander, 2002).Most parents experience a Paediatric Intensive Care Unit (PICU) admission with a certain emotional impact (Shudy et. al., 2006).Despite the benefits of high care provided for thecritically ill children, leaving the infant in the NICU is emotionally painful. Parents experience grief and anxiety upon leaving the NICU for any period of time including brief departures to get something to eat or drink (Smith et al., 2012). The emotional impact experienced by most parents in the PICU was revealed in the study which was donewith the aim of describing mothers' experiences in the NICU and develop guidelines for registered nurses to assist these

mothers. The mothers experienced shock, fear, anger, guilt, grief, helplessness and a desire to care for the infant. They needed support from the nurses, personal knowledge, and accurate information explained in understandable terms. Guidelines for nurses included: establishing and maintaining a therapeutic relationship (Van Rooyen et.al., 2006). Qualitative studies on parental experiences identified the role of parents, parents-profession relationship and emotion burden as the themes which encompass all the other themes as well as being the most important (Shudy et. al., 2006). A qualitative study exploring the experiences of parents of children admitted to seven Dutch Paediatric Intensive Care Units revealed six major themes which were attitude of the professionals, coordination of care, emotional intensity, information management, environmental factors and parent participation. By the association among these themes it shows that, poor information provision might raise parents' stress, particularly when parents do not acknowledge empathic staff behaviour (Latour et al., 2010). A similar association was identified from interviews with parents of children with severe antecedent disabilities in which communication and sympathy within the parent-professional relationship was frequently addressed (Graham, Pemstein, & Curley, 2009). The interaction between parents and professionals also seems to be an important factor not only for parents of children with specific health care needs, but for all parents whose children need intensive care treatment. In a study exploring psychological outcome among 20 parents of children admitted to a PICU or to a paediatric ward, interaction with the medical team was one of the three factors influencing poorer outcomes among PICU parents throughout hospitalization (Diaz-Caneja et al., 2005). Also from the interviews of the study on the experiences of parents of children admitted to seven Dutch Paediatric Intensive Care

Units, it appeared that themes like staff attitude, emotional intensity, and information management played a role from the onset of the admission till discharge (Latour et al., 2010). The attitudes of health professionals will create a climate that can either support or impede collaboration (Newton, 2000). From these studies, it appears that some major themes are similar across the studies which include parental role, emotional burden, staff attitude, and parents – professional relationship.

Parents' experiencesof a PICU admission are often related to their roles. The mothers experience parenting role during child's hospitalization.A study done in Ghana at the children's ward at AngloGold Ashanti Hospital in Obuasi, in Ashanti region on the role of mothers in the care of children under-five years on admission revealed specific roles mothers play to complement that of Health care providers. The responses included breastfeeding, bathing/grooming, feeding (oral), mouth care, assisting in medication, provision of information on the child's health status, provision of emotional support, provision of spiritual support and washing of child's clothing (Asamoah, Safro & Aw-uah-Peasah, 2013). In Brazil, a study of parental care of hospitalized children revealed that mothers actively participated in the care of their children and were taught to do advanced procedures like postural drainage and medication administration (Garcia et al., 2001). The cross-section study measuring parents' actual and desired level of participation in care of their hospitalized child and examined congruency between them, revealed care activities which parents participated in like providing comfort, assisting with activities of daily living and advocating for the child (Romaniuk et. al., 2014). A study done on the benefits of mother's permanence and participation in the care for their hospitalized child, the results evidenced that the mothers' presence and care increased the attachment between

mother and child, increased mothers' confidence and made the child calmer. This produced positive feelings such as joy and satisfaction for being able to care for their child (Mollina, & Marcon, 2009). Lack of information, non-negotiation of roles, inadequate facilities, feelings of anxiety and loneliness are the difficulties that parents experience when they participate in their hospitalized child's care (Coyne, 2007). From these studies it can be drawn that the mothers have a role in caring for the sick child.

Mothers experience separationduring hospitalizationof their critically ill child.Separation from the hospitalized child had also been found to be most difficult aspect for mothers when their new-born child is hospitalized in a Neonatal Intensive Care Unit (NICU). A study in Sweden on mothers' lived experiences of co- care and part- care after birth and their strong desire to be close to their baby revealed that mothers wanted to be close to their infants, be seen, and be part of a functional team. The organization/ staff prolonged the separation. Even after retaining home, mothers had difficulty dealing with the separation (Erlandson & Fagerberg, 2005). Nystrom andAxelsson (2002) explored the mothers' experiences of being separated from their new born when their new born was admitted to the NICU. The first theme was the mothers' experience of the situation as being an outsider, which was reflected in their feelings of despair, powerlessness, homelessness and disappointment. The second theme was the mothers' lack of control due to emotional instability, threat, guilt, and insecurity. Parents' positive experience was reflected in the theme of caring in which the mothers experienced love, relief, closeness and appropriate explanations. The experiences were related to the staff, the child, the environment, the mother herself, the child's father and other mothers. Hurst (2001b) explored mothers' description and interpretation of their experience in the NICU, which

revealed the underlying theme of mothers vigilantly watching over their infants. Mothers were alert to issues of safety that might signal danger for the infant, feared being labelled difficult, and expressed concerns over the lack of complete and accurate information provided, inadequate staffing and lack of continuity of care.Allowing the mother to stay is a strategy that makes it possible to strengthen the emotional bonds, reduce the emotional stress of both the child and the family thereby contributing to a shorter time of hospitalization. (Mollina & Marcon, 2009).

Mothers'satisfaction with the care provided in HDU

From the time of admission, mothers expect collegial relationships with health care professionals. What they need and what they need to know may be different than the health care professionals' assumptions. When difficulties arise, usually due to discrepant expectations, they may cause significant difficulties for mothers'relative to therapeutic goals, expectations about hospitalization and the child's relations, and perspectives about family involvement. There may also be misunderstandings about expectations regarding the amount of time spent with their child and the degree of participation in care (Potts & Mandleco, 2002**).** Today, patient satisfaction is considered an important indicator of quality of care. If patients are dissatisfied, health care has not achieved its goal. Satisfaction has been conceptualized to measure the degree of congruence between parents' expectations and their actual experiences of the perceived care. The key concepts, in this respect, are affective support, health information, decisional control, and professional/technical competencies (Wagner & Bear, 2009). As revealed in the study on family satisfaction with care in the ICU: Results of multiple centre studywhen examining individual item scores, satisfaction with nursing skill and competence and the compassion

and respect given to the patient scored highest, whereas satisfaction with the waiting room atmosphere and frequency of physician communication scored lowest.However, attempts to improve the atmosphere in the waiting room may not lead to an improvement in overall satisfaction. The results of the regression analysis suggested that the main determinants to overall satisfaction have more to do with how providers treat and communicate with patients and their families and the amount of care the patient receives that is a by-product of that communication, than the waiting room atmosphere (Heyland et al., 2002). In another study, one that focussed on different aspects of nursing practices that were predictive of parent satisfaction, the authors reported that overall satisfaction was strongly associated with collaboration between nurses and parents. 60% (n=42) related their care as being excellent. Satisfied parents reflected that the nursing care had been tailored to their specific needs and preferences which included information sharing, warm and caring interaction with the parents, respectful, age appropriate interaction with the child, and acknowledgement and development of competences in caring for their ill child. (Marino & Marino, 2000). A study done in the Midwestern United States on family-provider relationships and well-being in families with preterm infants in the NICU revealed that mothers had a greater family satisfaction, and were more satisfied with their care and reported greater psychological well-being when they viewed their provider relationship as positive (Van Riper, 2001). Supporting parental participation in a way that facilitates congruency between actual and desired participation may contribute to a satisfying experience for families of hospitalized children (Romaniuk et. al., 2014). Parent involvement has been identified as a large determining factor for the parent satisfaction of

child medical care (Weech-Maldonaro, 2001). Therefore, Client satisfaction reflects quality of services that meets clients' perceived needs.

Parental needs during their child's hospitalization

It is important to estimate all the needs of the family which had been categorized as needs of knowledge, emotional needs and personal needs in order to avoid a crisis during patient hospitalization due to dysfunction and instability. It has been observed that many families have inadequate knowledge concerning the provision of effective care to their patients. The major needs of knowledge essential to family are about their daily information of progress of patients condition from the doctor, the diagnostic and therapeutic program, illness prognosis, program of nursing care, familiarization with the staff caring for the patient, any changes which may occur when they are absent from the hospital, communication with the nurse who is responsible for their patient, the environment where their patient is hospitalized, assurance that the best possible care is provided to their patient, and provision of sincere answers and comprehensible explanations concerning condition of patient (Dyer, 1991)(Smitka, 1998). Emotional needs aim at the improvement of the therapeutic program, the communication with the nursing and medical staff, and the participation in patient's care. Specifically, parents and relatives wish to be near their patient during hospitalization, to receive the appropriate education in order to help their patient in the hospital, to participate in their patient's care, to express their feelings to nursing and medical staff, to feel that they are acceptable from nursing and medical staff, that there is a hope for patient's recovery and staff concerns about their patient (Dyer, 1991). Personal needs according to relative studies have the smallest interest. They are focussed on the facilities that should be disposed in a hospital.

More specifically, many members of families remaining in the hospital, considered waiting rooms, rooms for stay, and spaces for food as very essential (Dyer, 1991).

Certain needs of mothers have been identified whilst involved in the care of their children in hospital. Ward (2001) found that mothers want to be informed about the condition of their children and want honest answers to their questions. They also want nurses to listen to their fears and expectations and assist them to understand the responses of infants to hospitalization. Yui andTwinn (2001) also reported eight categories of needs that influence parental experiences during their children's hospitalization. These included the recognition of their reactions, support, financial assistance, household help, personal time and parenting skills. The needs of caregivers during the crisis of hospitalization include the need to have accurate and timely information; to trust the competence of physicians and nurses; and to know their child is comfortable and free from pain. They also need health professionals to trust them(Potts & Mandleco, 2002). A study on the relationship between maternal needs and priorities in the NICU in United Kingdomrevealed that 93% of mothers (n=209) ranked receiving accurate information as a priority. Good communication with staff was also important while self-related needs were considered less important (Bialoskurski, 2002).Self- related needs according to the relative studies have the smallest interest, and are focussed on the facilities that should be disposed in a hospital.In North California, astudy done on mothers' strategies to meet their needs in the NICU showed that the mothers had informational, interactional and emotional safety needs. They negotiated actions with health care providers, cautiously challenged authority, and gathered support from other mothers, friends and family. Fear of being labelled difficult and vigilance were key concepts underlying themes of mothersvigilantly

watching over their infants (Hurst, 2001a).A study on parents needs during their child's hospitalization describing the needs of 103 parents of the hospitalized children, 2months to 14years old, in a paediatric hospital in Athens showed that parents perceived all groups as important, but mostly emphasized information, trust, support and guidance from the nurses and doctors during their child's stay at the hospital (Kyritsi et al., 2005).

A study on the observed parental needs during the child's hospitalization whereby 35 parents of 24 children were followed by observers during their child's hospitalization at paediatric department in Sweden, nine themes were identified which included, the need for security, mediating security to the child, communication, control, pleasing staff, being a competent parent, the family, relief, and satisfying personal needs. The most prominent needs were need for security and mediating security to the child (Hallstrom, Runessol & Elander, 2002).

Summary

In summary, studies on experiences of mothers are limited. Available literature has shown that parents experiences PICU with a certain emotional impact. As revealed in the studies the mothers experience shock, fear, anger, guilt, grief, helplessness, a desire to care for the infant, lack of information, non- negotiation of roles, inadequate facilities, feelings of anxiety and loneliness. It has been shown that needs influence parental experiences during their child's hospitalization. From the studies, special needs for parents and their children have been revealed which include staying with their children, being given accurate and timely information about the condition of their children, being listened to and given honest answers to their questions, fears and expectations, trust between parents and professionals, support and guidance in care giving to the sick child, need for security and

mediating security for the child. The most frequently cited need was to be with the child followed by being able to participate in the child's care. The reason of staying with the hospitalized child is to meet emotional needs because they know best their children's needs and that the child feels safe with the presence of the parents. Mothers experience becomes positive when their needs are met and they become satisfied. From the literature, satisfaction has been conceptualized to measure the degree of congruence between parents' expectations and their actual experiences of the perceived care.Supporting parental participation that facilitates this congruency may contribute to satisfaction which is considered an important indicator of quality of care.

Chapter 3

Methodology

Introduction

This chapter narrates the procedures which were followed in exploring the experiences of mothers separated from their children with pneumonia admitted in the PHDU at KCH. It gives an overview on the study design, study setting, study population, sample size and sampling method, the inclusion criteria, data collection methods, data management, and analysis. It also covers ethical considerations and conclusion.

Research Design

In this study, the research design was descriptive using qualitative methods to explore experiences of mothers separated from their children with pneumonia admitted in the paediatric high dependency unit. Qualitative descriptive study is a method of choice when straight descriptions of phenomena are desired (Sandelowski, 2000).

Study Setting

The study was conducted at Kamuzu Central Hospital (KCH) in the paediatric high dependency unit in Lilongwe, Malawi. Kamuzu Central Hospital is one of the referral hospitals in Malawi and it covers the Central region. It also acts as a district hospital for Lilongwe District. PHDU is where very sick children who require closer observation and monitoring are being admitted.

Study Population

The population is a particular type of individual or element who is the focus of the research and the target population is the entire set of individuals or elements who meet the

sampling criteria (Burns & Grove, 2009). In this study, the study population comprised of all the mothers separated from their children with pneumonia admitted in the PHDU at KCH, during the period of study. The current average population per month in PHDU is about 200 according to 2010-2011 HMIS routine data. Among these, about 50% - 60% (100-120) are children admitted due to pneumonia.

Sample Size

The sample comprised of 20 participants. In qualitative studies sample size may vary from 10 to 30. Small sample sizes are usually used in qualitative studies due to the in-depth nature of the interviews. This is the reason why there was no generally agreed upon consensus on the number of informants required as this was determined by data saturation (Klenke, 2008). According to Speziale and Carpenter (2007), saturation refers to the repetition of discovered information and confirmation of previously collected data. Therefore, rather than sampling a specific number of individuals to gain significance based on statistical analysis, the qualitative study looks for repetition and confirmation of previously collected data. The decision to stop seeking new subjects is made when the researcher ceases learning new information (informal redundancy) (Burns & Grove, 2007). The focus is on quality of information obtained from the person, situation, events, or documents sampled versus the size of the sample (Polit & Beck, 2010).

In this study, data saturation was attained after interviewing 20 participants. There was repetition of responses which was a signal that data collection was complete.

Inclusion criteria

The inclusion criteria were:

- All the mothers of children admitted in the paediatric high dependency unit with pneumonia and have stayed for at least 3 days.
- Or, mothers of children that have been transferred to the general ward after staying in the HDU for at least 3 days.
- Mothers who can speak Chichewa or English for easy communication.

Exclusion criteria

The exclusion criteria were:

- The mothers of children admitted in the high dependency unit with pneumonia for less than 3 days.
- Mothers without children in high dependency unit.
- Mothers who have no children with pneumonia in PHDU.

Sampling Method

In this study, purposive sampling was utilized to identify mothers separated from their children with pneumonia admitted in the PHDU at KCH. Once identified and found to meet the inclusion criteria, they were requested to participate in the study. Any mother meeting the criteria and willing to participate in this study was interviewed in the order of identification. According to Polit and Hungler (1999), purposive sampling is a form of non-probability sampling. The researcher has prior knowledge about possible participants and deliberately selects them because the subjects are seen as likely to produce the most valuable data. That is, respondents are chosen because they have particular features or characteristics which will enable detailed exploration of the phenomena under study (Office for National Statistics, 2016 Online). Purposive sampling group participants according to preselected criteria relevant to a particular research question (Mark eta l.,

2005). This method was chosen because according to Schmidt and Brown (2012), it provides information which is rich where one can learn a lot about issues of central importance to the purpose of the study. The researcher deliberately selected the subjects who likely to produce the most valuable data.

Data Collection

Data collection instruments.

This study used a semi-structured interview guide to conduct in depth interviews (Appendix C and D). A semi-structured interview guide was developed by the researcher. The questions were formulated from the study objectives and literature review on relevant topics of the objectives. The instrument composed of two parts namely Part A and Part B. Part A addressed demographic data while Part B addressed mothers' experiences with paediatric HDU care. The interview guide contained open ended questions which promoted discussion to expand from the interview guide. Semi structured interviews allow informants the freedom to express their views in their own terms. The participants' interview guide was translated from English to a local language, Chichewa by two different people and the two versions were compared. The Chichewa version was back-translated to English to check that the meaning was not lost. The participants' interview guide was designed to collect data that led to better understanding on the mothers of the sick child by looking at the care being given, their feelings about not being with the child all the time in the unit, and what their suggestions were to reduce the stress during the crisis.

According to Boyce & Neale (2006), in depth interviews provide much more detailed information than what is available through other data collection methods such as

surveys. In addition, they provide a more relaxed atmosphere in which to collect information. The interview guide provides a framework for the interview and it allowed an open forum which allowed for focused conversational, and a two-way communication.

Pre-testing of the data collection instrument

A pre-test is a trial run to determine in so far as possible whether the instrument is clearly worded and free from major biases and whether it solicits the type of information envisioned (Polit &Hungler, 1989).

Before the collection of data, the participants' interview guide was pre-tested at the same centre where the research was done in the month of June, 2012. Pre-testing was done with three mothers of children admitted in the paediatric HDU with other conditions other than pneumonia. This assisted the researcher to come up with more appropriate follow up questions and probes. As a result of pretesting, the participants' interview guide was refined. Two questions were observed to have the same meaning and one was removed. Some questions were not well translated from English to Chichewa version and had to be re-translated. The pretesting also helped the researcher to understand the tools and their flow of information. The interview guide was also reviewed by experts in the field and their comments were incorporated.

Data collection process.

Before the commencement of data collection, permission was sought from the Hospital Director of KCH (Appendix F). The researcher was directed to meet the Chief Nursing Officer, Paediatric Head of Department, unit Matron and the ward sister in charge before starting the data collection for their permission which was granted. The Head of Department asked the researcher to present proposal abstract during the morning handover

so that everyone is aware of the researcher's presence in the Department. The researcher was arriving daily at the study setting at 8 a.m. to approach the ward sister in charge of PHDU and ask her to identify potential participants. With the assistance of the sister in charge and other nurses in paediatric HDU, eligible children were identified both in the HDU and those who had been transferred to the general ward. The children's mothers were identified and the details of the study were being explained to them individually and privately. The participants were asked to participate in the study after obtaining informed consent and were required to sign a consent form to participate in the study after they were well informed (Appendix A & B). The mothers were further informed that they would be free to withdraw at any time during the interview. All the participants were willing to participate in the study after the study was explained and consent sought. The interviews were conducted in Chichewa and not tape recorded as proposed because the mothers were not open enough and only interview notes were taken for each interview session. Mothers showed unwillingness to talk when asked if the interview could be tape recorded. The researcher then resolved to take notes herself.

The interview was taking place at a place within the hospital premises in the paediatric Annexe in order to offer confidentiality and privacy, and at a time that was convenient to the mothers. All the interviews were conducted by the researcher to ensure consistency of the data collection process. Field notes were taken during the interviews and non-verbal communication was also captured. Data collection took more time than anticipated because participating mothers meeting the inclusion criteria were not easily identified. Most mothers were staying in PHDU less than 3 days. This made data collection took more days to complete.

Data Management and Analysis

Data on itself does not provide answers to our research questions. In order to meaningfully answer the research questions, the data must be processed and analysed in some orderly, coherent fashion so that patterns and relationships can be discerned (Polit & Hungler, 1989**).** The purpose of data analysis is to organize, provide structure to, and elicit meaning from research data and that researchers dwell with or become immersed in the data (Speziale & Carpenter, 2007).

Data was reviewed soon after collection and where it was not clear the participant was contacted for further clarification, Data analysis was done simultaneously with data collection. This allowed the refinement of the interview guide content as new information emerged. Data was analysed manually through thematic content analysis (TCA). This is a descriptive presentation of qualitative data (Anderson, 2007). In other words, it is analysis based on the identification of themes, identified by means of a coding scheme.

Steps

1. According to Collaizi's method (Polit & Beck, 2010), field data was arranged according to the interviews
2. Data was translated from Chichewa to English
3. Data was summarized according to the theme and the themes and subthemes have been presented as results
4. Specifically, data was read several times and coded line by line and identified distinct units, grouping and re-grouping similar and dissimilar units was done, and relabelling of categories. To ensure validation of the analysis this was done with the assistance of experts
5. Finally, similar responses were grouped together into themes

Parents' comments were used to determine major themes as shown in the table as an example

Table 1: Example on determining major themes

Objective	Theme	Quotation
Describe experiences of mothers separated from their children with pneumonia admitted in HDU.	Negative Attitudes of health workers	One mother said: *"*I did not like the way the cleaner talks when am there changing nappies, she shouts and chases me out by saying that I should go out because she wants to do her work" (*Participant #* 02).
Determine mothers' satisfaction with HDU care.	Adequate and good care	One mother said: "Adequate care and treatment is being given to my child, was weak, and not recognizing me, but now has improved than before" (*Participant #06).*
Identify parental needs during child's hospitalization in HDU.	Being with the child	Another mother who was sobbing said; "Am used to stay with my child at home all the time and the child is my heart and always in my mind" *(Participant # 16).*

Responses were stored in a lockable cabinet which was accessible to the researcher. Data analysis expresses group information and there is no identification of individual responses.

Trustworthiness

Steps were taken to demonstrate trustworthiness of the data while in the field. The central feature is to confirm that the findings accurately reflect the experiences and viewpoints of participants, rather than the researcher's perceptions (Polit & Beck, 2010). According to Lincoln andGuba (1985) as cited in Speziale and Carpenter (2007), suggested four criteria for developing the trustworthiness of a qualitative inquiry which includes credibility, dependability, confirmability, and transferability.

Credibility refers to confidence in the truth of the data and interpretations of them. Lincoln and Guba (1985) as cited in Speziale and Carpenter (2007)pointed out that credibility involves two aspects which include carrying out the study in a way that enhances the believability of the findings, and taking steps to demonstrate credibility to external readers (Polit & Beck, 2010). In this study, all the mothers of children admitted in the paediatric high dependency unit with pneumonia and had stayed for at least 3 days, or they had been transferred to the general ward after staying in the PHDU for at least 3 days were selected. The sample was capable of providing rich data because they had experienced PHDU care with fresh memories. In case of inconsistencies during data collection, the participants were asked to clarify certain issues in order to develop an in depth understanding of the phenomenon under study.

Dependability refers to the stability (reliability) of data over time and over conditions. That is if similar study findings will be obtained upon replication of the inquiry with the same or similar participants in the same or similar context (Polit & Beck, 2010). In this study, dependability was achieved by ensuring that right data collection tools were used, through pre-testing, and through setting a proper and unambiguous sampling frame to sample the participants from.

Confirmability refers to objectivity that is potential for congruence between two or more independent people about the data's accuracy, relevance, or meaning. It is concerned with establishing that the data represent the information participants provided, and that the interpretations of those data are not figments of the inquirer's imagination (Polit & Beck, 2010). To achieve this criterion in this study, an interview guide was used in order to direct the interviews in form of a conversation so that the researcher should not influence the participant but be a facilitator and an active listener. Furthermore, wherever necessary the participant's expressive language is incorporated in the report as direct speech.

Transferability refers to the extent to which qualitative findings can be transferred to or have applicability in other settings or groups. As noted by Lincoln and Guba, the responsibility of the investigator is to provide sufficient descriptive data in the research report so that consumers can evaluate the applicability of the data to other contexts (Polit & Beck, 2010). In this study, transferability was achieved by terminating data collection when saturation was reached. Thus the results may be transferable to all mothers who are within or have undergone PHDU care at KCH since the study was not conducted in the whole Malawi. However, sufficient descriptive data in the report of the findings is

provided so that consumers interested to make a transfer can evaluate the applicability of the data to other contexts.

Ethical Considerations

The proposal was sent for ethical review at College of Medicine Research Ethics Committee (COMREC) through Kamuzu College of Nursing and this was done through submission of a research proposal. This was reviewed and accepted by the committee on 18 June 2012. Permission was sought from the Hospital Director of Kamuzu Central Hospital before data collection started (Appendix F). All respondents gave a written informed consent prior to participation (Appendix A, or B) with option of withdrawing from the study if they did not wish to participate. The participants were told the purpose of the study, methods of data collection and the benefits of the study. They were also reassured of confidentiality of information they gave. Code numbers were used instead of names in order to ensure respondents anonymity. No participant was forced to enter into this study. As the patients stay in the unit, their mothers were asked to join the study, with all ethical considerations observed. Those who accepted were joining the study in as first come first serve basis until all the 20 respondents had been identified.

Conclusion

This chapter has described step by step, the methodology as utilized in the study. The study design, inclusion criteria, the sampling process, the data management, data analysis and finally the ethical considerations have been clearly outlined in this chapter.

Chapter 4

Results

Introduction

This chapter presents the results of the study which was conducted to explore experiences of mothers separated from their children with pneumonia admitted in the PHDU at KCH in Lilongwe, Malawi. The results have been presented by intertwining data and interpretation, with direct quotes from participants, to illustrate important points. Anonymity and confidentiality of participant's responses were maintained throughout the study through the use of identification numbers in place of names. The results are presented according to study objectives: experiences of mothers, satisfaction of the mothers with care provided and parental needs during child's hospitalization. On experiences, five themes emerged: being involved in the care of their children, receiving support and guidance from nurses when providing care to their sick children, negative experience regarding attitudes of nurses and other health workers while caring for their children, feelings of lack of trust on the nurses and other health workers and feelings of anxiety. On satisfaction with care, mothers' reports were mixed. Some mothers were satisfied with care given while some were not satisfied. On parental needs, three needs were reported: the need to be with their sick child; information about condition of the child; and a good relationship with nurses and other health workers.

Demographic Data

The study was conducted through in-depth interviews with 20 mothers. Almost all the participants were married except one who was a widow, andall were the biological mothers for the sick children. All the mothers attended schooland most of them

(65%)were less than 25 years. Most of the participants (45%) belonged to Chewa ethnic group. The majority of the participants (95%)were Christians.Most of the mothers(55%) reported coming from the rural areas. Most of the mothers (50%) reported having one child. The majority of the participants' sick children(85%) were of the age range of 1 to 11months. The participants' demographic data has been summarized in table 1.

Table 2: Demographic characteristics of participants (n=20)

Characteristics	Number	Percent
Age group		
Less than 25	13	65
25-29	2	10
30-34	2	10
35-39	2	10
45 and above	1	5
Marital status		
Married	19	95
Widow	1	5
Ethnic group		
Chewa	9	45
Ngoni	5	25
Yao	3	15
Other (Lomwe, Sena and tumbuka)	3	15
Religion		
Christianity	19	95
Moslem	1	5
Level of education		
Standard 1-4	4	20
Standard 5-8	8	40
Form 1-2	3	15

Form 3-4	5	25
Number of children		
One child	10	50
2 children	4	20
3 or more children	6	30
Age of sick child		
1-11months	17	85
12-59months	3	15
Residence		
Rural	11	55
Urban	9	45

Experiences of mothers when caring for their sick children in PHDU

Results on the experiences of mothers are presented under fivethemes namely: being involved in the care, receiving support and guidance from nurses when providing care,negative experience regarding attitudes of nurses and other health workers, feelings of lack of trust on the nurses and other health workers and feelings of anxiety.

Theme1: Being involved in the care

The mothers reported that they were involved in the care of their children. Mothers wereinvolved in breastfeeding, changing linen and bed making, bathing child, chatting/playing with child, nappy changing and washing it, giving child feeds orally, turning child, wiping mouth secretions,cleaning feeding cups, washing beddings and child's clothes, covering the baby, calming baby when crying, applying Vaseline on the child's lips, feeling the child's body to determine temperature and observe child to check progress. One mother said: "When I go there, I play with my child, if it is feeding time I express breast milk and feed my child with acup, if is crying I make her calm" (participant

05).Another mother said; “Early in the morning they give us a basin and warm water to bath our babies. When am there I check the nappy and if it is wet or soiled I change” (Participant # 02).

Theme2: Receiving support and guidance from nurses when providing care

The mothers also experienced support and guidance from nurses regarding the following: giving medication through nasogastric tube, helping child breathe by bagging, giving child feeds through the nasogastric tube, reporting to the nurses if oxygen tubes are out so that they should be replaced, sealing nose if Continuous Positive Airway Pressure (CPAP) apparatus is not bubbling, supporting the leg where a cannula for intravenous fluids is inserted, giving Oral Rehydration Salt as advised orally or through the nasogastric tube and assisting the nurse by holding the child during cannula insertion and suctioning.One mother said: “If a nurseis doing a certain procedure like insertion of cannula, I am asked to assist by holding the child” (participant #03).Another mother said: “The nurses taught me how to help my child breathe to increase oxygenation by doing manual bagging, when am tired the nurses and doctors assist me and my mother too” (participant # 10).

Theme3: Negative experience regarding attitudes of nurses and other health workers

Although the mothers reported that they received good treatment and care, they complained about several issues which were revealed in this study like being shouted at by the nurses and cleaners, nurses not playing with the children or calming them when crying, sometimes not allowed to enter the PHDU and not allowed to stay with the child all the time. They emphasized that some nurses care for their children very well while

others do not, for instance, some nurses work hard in the presence of the white doctors, but they relax in their absence. Some mothers were being told to go out, without even sitting down upon entry into PHDU, even if child is crying or mother did not finish whatever she was doing. One mother was chased away by a cleaner and said this while crying: “Even if I did not finish my activity during that time, the cleaner chased me away” (Participant #04). Sometimes they were being chased away when they wanted to assist the child, for instance, wiping the child's secretions on the nose. Yet, other times they are not chased away. One mother responded while sobbing, narrated as follows:

> *The child is getting good treatment and care but one nurse does not listen to me when I tell her that my child has changed condition, she does not come immediately. Also cleaner shouts at us on simple issues, they forget that we have come with critically ill children*- (Participant #01).

Theme4: Feelings of lack of trust on the nurses and other health workers.

The mothers experienced feelings of lack of trust on the nurses and other health workers despite receiving good care in the PHDU. One mother said: *“I do not even understand why they decided to put the policy of not allowing the mothers to stay with their sick child all the time in HDU, because some nurses are bad they can do harm to my child*’’.Another mother said: *“I do not trust the nurses, you do not know what is going on and what type of activities are being done on your child. If they shout at us, what more our sick children”*(Participant # 04). Themothers also complained of lack of uniformity on how nurses gave instructions that is demonstration on how to give nasogastric tube feeds which made the mothers to not trust the nurses.

Theme5: Feelings of anxiety

The mothers experienced feelings of anxiety which were expressedby crying during their narratives about being separated from their sick children and the negative attitude portrayed by the health workers in PHDU.The mothers noted that the ward had very sick children and therefore needed the presence of the mothers all the time because nurses are always busy, some of the things can be taken note of by mothers. One mother narrated while crying as follows: "*Nurses give good care but I fail to sleep, am always anxious about my child because is used to stay with me and is looking miserable and unhappy for not being there"* (Participant #15). Some mothers got anxious about the child's wellbeing when they were away from the PHDU due to the attitude portrayed by the health workers in the ward, who dealt with the mothers harshly by shouting at them and chasing them away when they enter into the PHDU. The mothers said they are worried about their critically ill children and their stress worsen if shouted at and did not know how to cope with this. One mother narrated while sobbing as follows:

Some nurses shout at us if we want to go and see our children by saying that if we are not obeying, they will go out and leave the children under our care, yet it is them who told us to be going three hourly to feed the children or change nappies frequently- (Participant #13).

Satisfaction of the mothers with care provided

On satisfaction with care,the reports were mixed. Some said that they were satisfied with care because the care that their children received was adequate and good.

While some reported dissatisfaction with care.Some mothers were satisfied with the good care and treatment given to their children because most of them improved with the oxygen therapy administered. They said that children were frequently seen, nurses showed their expertise with frequent monitoring, and were friendly including the doctors who were giving immediate attention upon being called. Some mothers reported that when a child cries or if any need arises, they were being called by the nurses who would be trying to calm the crying child. One mother said: *"Adequate care and treatment is being given to my child, was weak, and not recognizing me, but now has improved than before"* (Participant #06).

The mothers reported that they were satisfied with the activities they were doing when they were with their children because they were finishing everything they wanted to do. The child was left asleep, not crying, and they saw improvement on the child.

Mothers were mostly happy with the following: Nurses were always there all the time who were intervening immediately if child's condition changed, which led to improvement in the children's condition, preparation of child's milk, mothers were not being chased away in PHDU by nurses until they finished whatever they wanted to do and go out, resuscitation of children who would have died, frequent observations and examinations done, nurses chatting with the mothers, church groups being allowed to pray for the children, nurses calling mothers when child was crying or when the nappy was wet or soiled, child being looked after by nurses day and night, cleanness of the room , friendly nurses and doctors, and nurses provided the mothers with clean basins and warm water to bath children at 4am. One mother said:"When nurses are asked to see my child when condition changes they come immediately to intervene"(Participant #07).Another

mother said*: "Some nurses chat with us to make us forget our worries. They comfort us so that we cope with stress"* (Participant #13).

The mothers seemed to be comfortable with the arrangement of not being with their children all the time. These mothers explained that mothers cannot manage to take care of the sick children as the nurses were doing, for instance, nurses do other things like suctioning and instillation of nasal drops, in the absence of the mothers. They said that children were getting good treatment and frequent care and were improving; children also were having enough time for resting, if child changes condition nurses/doctors could take note and intervene immediately.

On the other hand, some mothers reported that they were not satisfied with the care given because they were doing things against time; they felt sorry when leaving the child crying who was not even fed with enough milk. They also reported that the cleaner and nurses sometimes shouted at them to get out of the PHDU even if they wanted to stay with the child for some more time and continue breastfeeding the baby.

Some mothers felt that PHDU services did not meet their expectations because the nurses did not chat with the sick child nor calm the child when crying. The other reason given was that it took time for the nurse to intervene when an urgent problem was reported to them. Specifically, some mothers did not like the following: The nurses' delay when being called when the condition of the child changes or an urgent problem is reported. For instance, when a CPAP bottle stops bubbling and the child gets less oxygen, the nurse took long to intervene after being informed. Some nurses and cleaners shouted and chased mothers away from PHDU even if they did not finish the activity that they wanted to do.

Other reasons include being told by the nurse to wash hospital linen soiled with stools by the sick child, not allowing mothers to stay with the child all the time, being shouted by the nurses if mother reports change in the child's condition, and nurses not giving explanation of the child's progress. One mother said: *"I did not like the way the cleaner talks when am there changing nappies, she shouts and chases me out by saying that I should go out because she wants to do her work"* (*Participant* # 02).

Another mother narrated as follows:

> Some nurses shout at us if we want to go and see our children by saying that if we are not obeying they will go out and leave the children under our care, yet it is them who told us to be going three hourly to feed the children or change nappies frequently-(Participant # 13).

Parental needs during child's hospitalization

Results on the parental needs during child's hospitalization include theneed to be with their sick child, information about condition of the child, and good relationship with nurses and other health workers.

Theme1: Need to be with their sick child.

Most of the mothers reported that they wanted to stay with their children all the time without any limit because they needed to be there when their child is sick. Mothers reported that they would want to be allowed to stay in the ward full time and play with the child, and assist the nurses in taking care of the child like calming the child when crying, and turning child frequently. The mothers also noted that the ward had very sick children

and therefore needed the presence of the mothers all the time because nurses were always busy, some of the things could be taken note of by mothers.

Another mother who was sobbing said; "*Am used to stay with my child at home all the time and the child is my heart and always in my mind"*(Participant # 16). On the contrary, some mothers did not want to stay with their children all the time because some mothers felt that the 30 minutes that were given was enough to stay with the child and show motherly love, and do certain activities for the child. Others said that there was no need to stay longer because children are very sick, and it is sympathetic.

Some of them felt that time do not matter provided the child is left comfortably and not crying. One of the mothers had suggested that after feeding their children, they should be given some more time to observe the children before being sent outside. One mother said*: "Even a short time, one hour would have been enough, but I do not like to be chased away"* (Participant #0 6).

Various visiting times came out from the mothers. Most of the mothers reported spending time together with the child especially during the feeding times ranging from hourly, 2 hourly, 4 times, 5 times, 6 times and above 10 times depending on the child's feeding schedule. Others reported 3 times especially visiting hours 6am, 12noon and 4pm. Some mothers reported that they were sometimes staying with the child all the time to assist child in breathing by doing bagging or as needed if the cleaner is not around, and at times, whole day when the child was critically ill. Other responses included once a day because child was not feeding and nappies were changed by the nurse, not frequently because of being afraid of child's condition, frequently but could not remember the

frequency because the mother would go there whenever the child cried to change nappies and give nasogastric tube feeds. During the night, the mothers reported a range of 2 to 6 times or visits to the sick child per night or on average 3 times.

The women reported that when they visited their sick children, the time that they spent together with the child was dependent on the nurse on duty, could be 30 minutes or a short time like about 5 minutes, and it was also dependent on activity to be done which could be short time like when changing a nappy, long time like when expressing breast milk then feeding through the nasogastric tube. One mother, who indicated to have been taking 1 hour with the sick child in PHDU, had this to say: *"It depends on how the child responds to sleep probably one hour, because child cries when I want to go out, I try to comfort then it takes long"* (Participant #15).

One mother was not sure and declined to suggest number of times the mothers can visit their children, or how long they can stay with their children in PHDU, because she feels the decision depended on the nurses or doctors working in the unit, whereby some would allow mothers to stay for a short time and not frequently visit their children while others would give mothers more time with their children.

Some mothers did not find the time spent with their sick child to be enough and the reasons given included inability to be with the child for so long so that they take note of any problems the child is having and then report to the nurses.

Other mothers found the time they spent with their children to be adequate because they finished whatever activity they wanted to do before they went out and that they went out if they wanted to, while leaving their children comfortably, and added that it was

adequate because the ward policy did not allow them to stay long. The other reason was that it was the nurses who were taking care of their children full time. Another mother said: *"The time is enough to me because am afraid of my child's condition therefore I do not like staying for a long time"* (Participant # 08).

Theme2: Need for information about condition of the child.

The mothers reported that despite not allowing them to stay all the time, if thorough explanations or information is given to them on daily basis, about the child's condition, mothers will not have anxiety. Mothers needed to be updated on the child's condition, progress, and also to being taught where they are not doing fine in caring for the child. When the mothers ask question, the nurses need to respond in a professional manner.

Theme3: A good relationship with health workers.

The mothers reported that they wanted good relationship between them and the nurses and expected the nurses to be calling them when child changes condition, when child is crying, and when nappy is wet or soiled to avoid peeling of skin around the nappy area. They also wanted the nurses and cleaners to stop shouting at the mothers because they are already worried about their critically ill children and their stress may worsen if shouted at, and they do not know how to cope with this. They said that nurses should not be harsh but support them by listening to their concerns, and being empathetic.

Chapter 5

Discussion

Introduction.

This chapter presents a discussion of the findings of the study, which describes the experiences of mothers separated from their children with pneumonia admitted in the paediatric HDU at Kamuzu Central Hospital. The discussion is guided by the objectives of the study which include experiences of mothers of children admitted in paediatric HDU,mothers' satisfaction with the care provided in HDU and needs during their child's hospitalization. Study recommendations, implications of the findings as well as the study limitations are also presented in this chapter.

Demographic characteristics

The study sample consisted of 19 married mothers and one widow. All participants were the biological mothers for the sick children. As a tradition, in the Malawian families, the mother is the main care giver for the children.All the mothers attended school and most of them (65%) were less than 25 years. In Malawi, improved educational status of women is associated with better access to health care (Geubbels, 2006). Education empowers people. People who have some education are in a better position to seek and comply with health care provider's instructions. In this study many women went to school which meant that they were empowered to seek health care on their own. Most of the participants (45%) belonged to Chewa ethnic group. The majority of the participants (95%) were Christians. Most of the mothers (55%) reported coming from the rural areas. Most of the mothers (50%) reported having one child. The majority of the participants'

sick children (85%) were of the age range of 1 to 11months.These children were admitted due to pneumonia which is common in childhood but occurs more frequently in infancy and early childhood (Hockenberry & Wilson, 2009). Consistent to the findings, the Malawi Demographic Health survey (MDHS) found that children aged 6-11months are most likely to have had ARI symptoms and be taken to a health facility compared with children in other age groups (MDHS, 2010).

Experiences of mothers of children admitted in pediatric HDU

Being involved in the care of their children.

Findings of the study revealed thatmothers were involved in the care of their sick children on parental roles like breastfeeding, changing linen and bed making, bathing child, chatting/playing with child, nappy changing, giving child feeds orally, turning child, wiping mouth secretions, cleaning feeding cups, calming baby when crying, applying Vaseline on the child's lips, feeling the child's body if it is not hot and see how the child is doing without being taught or instructed. The findings showed that the mothers experienced a parenting role during their child's hospitalization. Consistent with the findings of this study are results of a study which was done at Kamuzu Central Hospital in Lilongwe, Malawi, of the role of the family in the care of their sick relatives in the hospital, which revealed that relatives in the hospital filled the gap in performing the tasks which nurses would not do and that nurses were relieved from the duties and do other things as well. In the same study, it was found out that activities like bathing, feeding, lifting, turning and toileting patients were perceived as the duty of carers by nurses. In this case, it is not known whether the caregivers perceived in the same way since it was revealed in the same study that carers perceive that nurses are trained personnel who have

knowledge to care for patients (Magai, 1991). Similarly, a study done in Ghana on the role of mothers in the care of children under-five years on admission revealed specific roles mothers play to complement that of Health care providers. The responses included breastfeeding, bathing/grooming, feeding (oral), mouth care, assisting in medication, provision of information on the child's health status, provision of emotional support, provision of spiritual support and washing of child's clothing (Asamoah, Safro & Aw-uah-Peasah, 2013). Also in the cross-section study measuring parents' actual and desired level of participation in care of their hospitalized child and examined congruency between them, revealed care activities which parents participated in like providing comfort, assisting with activities of daily living and advocating for the child (Romaniuk et. al, 2014).

Receiving support and guidance from nurses when providing care to their sick children.

The mothers were also involved in the care of their sick children by getting support and guidance from the nurses as follows; giving child feeds and medication through nasogastric tube, helping child breathe by manual ventilation/bagging, reporting to the nurses if oxygen tubes are out so that they should be replaced, sealing nose if Continuous Positive Airway Pressure (CPAP) apparatus is not bubbling, supporting the leg where a cannula for intravenous fluids is inserted, giving Oral Rehydration Salt as advised orally or through the nasogastric tube and assisting the nurse by holding the child during certain procedures like cannula insertion and suctioning. Similar findings were revealed in a study done by Garcia et al. (2001) in Brazil, on parental care of hospitalized children whereby the mothers actively participated in the care of their children and were taught to

do advanced procedures like postural drainage and medication administration. Nurses are in a significant position to support parents as they provide care to their sick child, as they are in regular contact with parents during the child's hospitalization (Denney, 2003).In support of these are the findings of the study done at Kamuzu Central Hospital in Lilongwe, Malawi, of the role of the family in the care of their sick relatives in the hospital, which revealed thatcarers perceive that nurses are trained personnel who have knowledge to care for patients Magai(1991). Mok and Leung (2006) also found that the highest source of satisfaction for mothers was the support they received from the health care team.

Negative experience regarding attitudes of nurses and other health workers while caring for their children.

It emerged that some mothers despite having stated that they were satisfied with the care that was provided in PHDU, they were not happy with the attitude of some nurses and ward cleaners who dealt with the mothers harshly, by shouting at them and chasing them away when they enter into the PHDU, even when the activity they had gone to do in the PHDU was not finished. They said that if they were not obeying, the nurses would go out and leave the children under their mothers' care, yet it was them who told the mothers to be going three hourly to feed the children or change nappies frequently. Some mothers got anxious about the child's well-being when they were away from the PHDU due to the attitude portrayed. They thought that their sick children may undergo same treatment since they had not seen the nurses playing with thesick children or calming them when they were crying. This seemed to affect them emotionally as evidenced by their crying during the interviews by saying that the way they are being treated by the staff is as if they have

forgotten that they have come with critically ill children. There is an outcry in Malawi from the public about the attitude of health workers in hospitals. Professional bodies like Nurses and Midwives Council of Malawi are working hard to put measures on how to improve the attitude of health workers more especially the nurses. The results are unique nobody found them.The attitudes of health professionals will create a climate that can either support or impede collaboration (Newton, 2000). Jennings et al. (2005), found that certain characteristics such as rudeness, arrogance and impatience lead to greater complaints about the care providers. A non- friendly environment with bad treatment from staff are some of the obstructing factors for parents to be present in NICU (Wigert et al., 2006).However, despite some mothers being generally satisfied with PHDUcare, bringing in other negative issues shows that there were still some gaps remaining in as much as PHDU care is concerned. Therefore, nurses should adopt attitudes that supportmothers' participation in the care of the hospitalized child.

Feelings of lack of trust on the nurses and other health workers.

The mothers experienced feelings of lack of trust on the nurses and other health workers despite receiving good care in the PHDU. The mothers felt that the nurses and the other health workers with negative attitude can do harm to their children upon leaving them in PHDU.

They narrated that they do not understand why in PHDU they decided to put the policy of not allowing the mothers to stay with their sick children all the time because some nurses were bad they could do harm to their children. If the perception of the care is negative, then the mothers will not have trust in the nurses. The mothers' perception of care was negative since they mentioned that they did not trust the nurses because they

were shouting at them. Thomson et al. (2003) in their study aiming at investigating the development of trust in parents of hospitalized children, the core variable related to the development of trust in health care providers was whether parents' expectations for care were met. Thematic areas that influenced whether expectations for care were met included pre-existing trust, evaluation of care, including evaluation of technical skills and the meeting of parental and child needs, and behaviours of nurses and other health care providers that inhibited and fostered trust. The present study shows that behaviours of nurses and other health care providers inhibited the trust even though they received good treatment and care.Meech- Maldonaro (2001) found that the trust in the health care team was strengthened when open communication existed. Parents gain knowledge and understanding of the treatment plan only when the line of communication was open and information was freely shared between the family and the health care team.

Feelings of anxiety

The findings of the study revealed that the mothers' emotional wellbeing was affected as evidenced by their narrations. The mothers experienced feelings of anxiety which were expressed through crying during their narratives about being separated from their sick children and the negative attitude portrayed by the health workers in PHDU. Separation from the child had also been found to be most difficult aspect for mothers when their new-born child is hospitalized in a NICU. The experience had caused them emotional strain and anxiety which were related to the staff, the child, the environment, the mother herself, the child's father and other mothers (Nystrom &Axelsson, 2002). Parents also experience grief and anxiety upon leaving the NICU for any period of time including brief departures to get something to eat or drink (Smith et. al., 2012). The

mothers said they are worried about their critically ill children and their stress worsen if shouted at and did not know how to cope with this. Negative attitudes of the health workers may aggravate mothers' anxieties during crisis situations. As a result, mothers in the Emergency unit were often afraid to interact, approach, or ask the nurses any questions relating to their children (Affram et. al., 2008).Therefore, the findings of the present study have shown that mothers' anxiety was aggravated by separation from their children and negative attitude of the health workers.

Mothers' satisfaction with the care provided in HDU.

Findings of the study revealed mixed reports. Some mothers were satisfied with the care given while some were not satisfied. Childrengot adequate and good care, and the mothers were satisfied with the services rendered to their children. The nurses and doctors were friendly and always ready to assist and give timely intervention in case child's condition worsens. Children were frequently seen and monitored, resuscitation of children who would have died was done, which led to improvement in the children's condition. Church groups were also being allowed to pray for the children, nurses were calling mothers to attend to their children when child was crying or when the nappy was wet or soiled, and the cleanness of the room. The mothers' statements emphasize their satisfaction with their experience with nurses and doctors relating especially to the way their children were treated in the PHDU environment. Client satisfaction reflects quality of services that meets clients' perceived needs. This is encouraging because mothers' perception of the care provided is what determines the trust in the staff working in PHDU. Similarly, in another study, one that focused on different aspects of nursing practices that were predictive of parent satisfaction, the authors reported that overall satisfaction was

strongly associated with collaboration between nurses and parents. 60% (n=42) related their care as being excellent. Satisfied parents reflected that the nursing care had been tailored to their specific needs and preferences which included information sharing, warm and caring interaction with the parents, respectful, age appropriate interaction with the child, and acknowledgement and development of competences in caring for their ill child (Marino & Marino, 2000).The present study is supported by these findings. Similarly, a study on family satisfaction with care in the ICU: Results of multiple centre study revealed that when examining individual item scores, satisfaction with nursing skill and competence and the compassion and respect given to the patient, scored highest, whereas satisfaction with the waiting room atmosphere and frequency of physician communication scored lowest. However, attempts to improve the atmosphere in the waiting room may not lead to an improvement in overall satisfaction. The results of the regression analysis suggested that the main determinants to overall satisfaction have more to do with how providers treat and communicate with patients and their families and the amount of care the patient receives that is a by-product of that communication, than the waiting room atmosphere (Heyland et al., 2002). Potter and Fogil (2013), reviewed previous studies conducted on nurses' care behaviours and explained that care behaviours, including nurses' availability, performing of examinations, follow up measures, fulfilment of human needs and providing medical care were the main care behaviours effective in the development of satisfaction. Therefore, Client satisfaction reflects quality of services that meets clients' perceived needs. Supporting parental participation in a way that facilitates congruency between actual and desired participation may contribute to a satisfying experience for families of hospitalized children (Romaniuk et. al., 2014).Parent

involvement has been identified as a large determining factor for the parent satisfaction of child medical care (Weech-Maldonaro, 2001).

On the other hand, some mothers reported that they were not satisfied with the care given because they were doing things against time; they felt sorry when leaving the child crying who was not even fed with enough milk. They also reported that the cleaner and nurses sometimes shouted at them to get out of the PHDU even if they wanted to stay with the child for some more time and continue breastfeeding the baby. They did not like the nurses' delay when being called when the condition of the child changed or an urgent problem is reported. For instance, when a CPAP bottle stops bubbling and the child gets less oxygen, the nurse took long to intervene after being informed.Tzeng and Yin states that the nurses should be prompt to respond to their patients' needs and help them with whatever they need, as the nurses' failure to meet the patients' needs in a prompt manner can reduce satisfaction with the nursing care received.

Parental Needs during Child's Hospitalization

Need to be with their sick child.

The findings of the study revealed that most mothers considered that it is important to be with their sick child all the time without any limit so that they assist the nurses in taking care of the child like calming the child when crying, turning child frequently and take note of any problems the child is having and then report to the nurses. Mostly, they went in PHDU to assist the child on regular times and did not spend much time. The regular visiting time include feeding times according to schedule given by nurses and when child needs attention like when crying or during bathing. The mothers complained that the number of times they are allowed to visit and length of time they spend with their

children in PHDU was not enough and they would prefer to stay in the PHDU by the child's bed side all the time or for longer periods. Similar findings were revealed in a study in Sweden describing how mothers experienced care and their own health which showed that the mothers wanted to be close to their infants, be seen, and be part of a functional team in the NICU(Erlandson & Fagerberg, 2005). According to Dyer (1991), need to be near the patient during hospitalization is being categorizedunder emotional needs which aim at the improvement of the therapeutic program, the communication with the nursing and medical staff, and the participation in patient's care.The mothers' emotional wellbeingwas affected as evidenced by their narration that they failed to sleep and were always anxious because they used to stay with theirchildren and that the children were looking miserable and unhappy due to the absence of the mothers. Child lacks motherly love, and a mother cannot have a peaceful mind wherever she goes because she is used to staying with the child all the time and needs to be close during this time when the child is sick.Despite the benefits of high care rendered in PHDU, leaving the child is emotionally painful. Parents experience grief and anxiety upon leaving the NICU for any period of time including brief departures to get something to eat or drink (Smith et al, 2012).According to Ygge, Lindholm and Arnetz, 2006, the presence of parents near their child in the hospital and their participation in the care given has been recognized to be important and necessary for the child and for the parents themselves. Encouraging the presence of the caregiver provides the child with a source of comfort and support. (Hockenberry & Wilson, 2009).

In the present study it shows thatthere is no specific period of time regulated for mothers to spend time with their children, as this depends on activity being done, the

nurse/cleaner on duty, child's age and needs, and condition of the child. The similar results were found by Wigert et al.(2006) on parental presence when their child is in NICU which revealed that Parental presence at NICUs varied depending on types of accommodation offered. Those who stayed in parent rooms at the units showed a significantly higher presence with their children than parents who stayed at family hotel, at home or on a maternity ward. Factors that motivated parental presence were primarily the willingness to take parental responsibility, the child's condition requiring it, and the need to have control. Good treatment by the staff, a family-friendly environment and high quality care were main facilitating factors for parents to be present at the NICU. Obstructing factors were primarily ill health by parents, a non-family-friendly environment, care of the home, and of children at home (Wigert et al., 2006).

The mothers who would not want to stay with their children all the time said short time was enough to stay with the child and show motherly love, and do certain activities for the child. They continued to say that there is no need to stay longer because children are very sick, and it is sympathetic. Some mothers said that the time spent with their children was adequate because the ward policy did not allow them to stay long and that the nurses are the ones taking care of the sick children full time, and that they were afraid of the children's condition, and therefore did not like staying for a long time.

The mothers seemed to be concerned with the emotional and physical welfare of their sick child. The findings can be supported by Coyne (2007) in the study describing parents' experiences of participation in their hospitalized child's care on a general surgical paediatric ward which indicated that parents chose to participate because of concern for the child's emotional welfare. The influencing factors included sense of parental duty, past

experiences with hospitals, and concern for consistency of care.Some studies done on experiences of parents in the PICU have shown that parents' needs were related primarily to parental role function and the alleviation of stress. The most frequently cited need was to be with the child followed by being able to participate near their child and being able to participate in the child's care (Kasper & Nyamathi, 1988).

The need for information about condition of the child.

The findings revealed that mothers needed daily information from the nurses about the child's condition, progress, and being taught where they are not doing fine in caring for the child. They also wished to be answered lovely and politely when they ask questions, given the fact that they were not allowed to stay all the time with their sick child, in order to allay anxiety. According to Smitka (1998) the findings are among the knowledge needs which are essential for the provision of effective care to the patients.Consistent to the findings are the results from a study done in UK on the relationship between maternal needs and priorities in the NICU in which revealed that 93% of mothers (n=209) ranked receiving accurate information as a priority. Good communication with staff was also important while self-related needs were considered less important (Bialoskurski, 2002). Ward (2001) also found that mothers want to be informed about the condition of their children and want honest answers to their questions. They also want nurses to listen to their fears and expectations and assist them to understand the responses of infants to hospitalization. Similarly, Yui and Twinn (2001) foundthe needs during child's hospitalization as need to have accurate and timely information; to trust the competence of physicians and nurses; and to know their child is comfortable and free from pain. Furthermore, a study on parents needs during their child's hospitalization describing

the needs of 103 parents of the hospitalized children 2months-14years old in a paediatric hospital in Athens showed that parents perceived all groups as important, but mostly emphasized information, trust, support and guidance from the nurses and doctors during their child's stay at the hospital (Kyritsi et al., 2005). All these findings show that need of accurate and timely information has been emphasized as essential during child's hospitalization.

Good relationship with nurses and other health workers.

The results of the study revealed that the mothers wantedgood relationship with health workers. They did not like being shouted at by some nurses and cleaners because they were already worried about their critically ill children and shouting at them worsened their stress, whichthey did not know how to cope with it. They wanted the nurses not to be harsh but support them by listening to their concerns and be empathetic. They expected the nurses to be calling them when child changes condition, when child is crying, and when nappy is wet or soiled to avoid peeling of skin around the nappy area. It is necessary that health workers who provide care in PHDU avoid instillation of negative attitudes and recognize that admission to the PHDU is a signal to attend not only to physical needs of the child but also to the interpersonal and communication needs of mothers. Similar findings were found in a study in Ghana describing experiences of mothers with children hospitalized in a children's Emergency Unit which revealed two sets of nursing behavioural characteristics as described by the mothers which either facilitated or inhibited an effective relationship. Those things mothers described as facilitative were few including friendliness and carrying out of expected duties on time. Those that inhibited an effective relationship with nurses were unfriendliness and limited interaction with

mothers. Negative attitudes of the health workers may aggravate mothers' anxieties during crisis situations. As a result, mothers in the Emergency Unit were often afraid to interact, approach, or ask the nurses any questions relating to their children (Affram et al., 2008). These findings support the work of Fenwick, Barclay and Schmied (2000) who found that the mother's relationship with the nurse is the single most important influence on the woman's experience of mothering in the nursery. Therefore, the mothers need to have a positive relationship with health workers in order to meet their emotional needs.

Constraints and limitations

- The study was conducted at one central hospital as such the findings cannot be generalized to other settings. The sample of this study is also limited to mothers in PHDU at KCH as such little generalization can be made across other clinical settings. Having multiple sites could have enriched the study findings.

- Data collection took long in order to get enough participants because it was not peak season for children admitted with pneumonia and also the fact that the mothers had to stay for at least 3 days and the PHDU bed capacity was 6 only and not all of thechildren were admitted due to pneumonia.

- Financial and material constraints were also experienced since the budget was higher than the assigned money for the study due to price increase of things.

- Time was also a limitation as the researcher had to comply with the school calendar since this thesis being an academic requirement for the Master of Science in Child Health Nursingit was required to be completed within a specified period of time.

Recommendations

Taking into account the findings of the study the researcher recommends that:

- The nurses should be encouraged to continue involve the mothers in the care of theirsick children. Mothers' participation in their child's care can give nurses an opportunity to observe and train themothers for providing a proper and safe child's care.
- The nurses and clinicians should givethe mothers enough and continuous information, guidance and support throughout hospitalization.
- Health workers which include nurses, cliniciansand support staff should have good relationship and mutual trust with the mothers to work hand in hand in caring for the sick children. They should avoid shouting at mothers but rather make them understand why some of the ward's regulations should be followed and for their own benefit.

Areas for further study

Further research is needed to explore nurses' perceptionof parental involvement in Paediatric High Dependency Unit care and challenges faced by nurses providing care in such a set up where mothers are separated from their hospitalized critically ill children.

Conclusion

Findings of the study revealed that mothers were involved in the care of their sick children on basic parental roles. When performing advanced roles, they were getting support and guidance from the nurses. The mothers were satisfied with the care rendered in PHDU but it emerged that some mothers despite having stated that they were getting good and adequate care, they were not happy with the attitude of the health workers who were shouting and causing anxiety on them. Most mothers considered that it is important to be with their sick children all the time without any limit so that they assist the nurses in

taking care of the children. The mothers wished to be fully involved in their children's care because they were only coming in PHDU to assist children on regular times and could not spend much time, which resulted into not fulfilling their needs. The mothers needed daily information from the nurses about the child's condition, progress, and being taught where they are not doing fine in caring for the child. They also wished to be answered nicely and politely when they ask questions in order to allay anxiety. They alsowanted good relationship with health workers and did not like being shouted at by some nurses and cleaners because they were already worried about their critically ill children. They wanted the nurses not to be harsh but support them by listening to their concerns and be empathetic.

It is believed that the findings of the studycan assist in making the nurses work in partnership with the mothers and supportthem during the stressful period of hospitalization in PHDU. It will also help managers to develop policies that will address the needs of the mothers in Paediatric HDU thereby improving patient care.

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Appendix 1: Consent Form

Information Sheet

Experiences of mothers separated from their children with pneumonia admitted in the paediatric high dependency unit at Kamuzu Central Hospital

You are being invited to take part in a research study on experiences of mothers separated from their children with pneumonia admitted in the paediatric high dependency unit at Kamuzu Central Hospital. Before you decide to participate in the study, it is important for you to understand why the research is being done and what it will involve. Please ask if there is anything that is not clear or if you would like more information. Participation is voluntary.

What is the purpose of the study?

The aim of this study is to explore experiences of mothers separated from their children with pneumonia admitted in the paediatric high dependency unit at Kamuzu Central Hospital. Therefore, it is important to explore the experiences of these mothers separated from their children with pneumonia during admission of their children in HDU and what they think of their stay there with an aim of being informed and possibly help to make improvements to services being offered in the HDU and how they can work hand in hand

with the nurses and be supported during this stressful period. The service providers will also be helped to understand roles that mothers can play in the care of the child during HDU hospitalization.

Do I have to take part?

You are free to take part or not or to withdraw at any time you desire without giving reasons. Your refusal to take part in the study will not affect the quality of health care you are going to receive in any way. If you agree to take part you will be asked to sign a consent form. Information about you will be confidential and no one will identify who answered which question as no names will be written on the interview guides. Code numbers will be used instead. In addition, no name will be mentioned during the interviews to ensure anonymity. The interview guides, field notes and the tapes will be destroyed at the end of the study.

If I take part what will happen to me?

You will be asked some questions about your experiences during separation from your child with pneumonia admitted in the paediatric high dependency unit. You will be asked to respond to the questions and give explanations and descriptions where necessary. Your responses will be tape recorded and I will also be taking some notes as you are talking. This is to ensure that no information is missed or misunderstood.

What are the possible risks for taking part?

There are no known risks associated with the study.

What are the possible benefits of taking part?

There are no immediate benefits to you. The findings of the study will assist in making improvements to services being offered in the HDU and how mothers can work hand in hand with the nurses and be supported during this stressful period. The service providers will also be helped to understand roles that mothers can play in the care of the child during HDU hospitalization.

Who do I contact you if I have questions about the study, my rights and welfare?

If you have additional questions pertaining to your participation in the study, or if you have any questions about your rights as a research participant, or concerns or complaints about this study, please do not hesitate to contact the following people.

Mrs.M. Simbota ,

Kamuzu College of Nursing,

P. O. Box 415,

Blantyre,

Cell: 0999952060

Professor. J. Mfutso-Bengo,

College of Medicine Research Ethics Committee,

Private Bag 360,

Chichiri, Blantyre 3

Tel. 01871911

Cell: 0999957805

Mrs. M. Mbeba,

Kamuzu College of Nursing,

P. O. Box 415,

Diana Chiundu,

Kamuzu College of Nursing,

P. O. Box 415,

Blantyre

Blantyre,

Cell: 0999243212

Please read and sign this form if you are taking part in this study

1. I have read and (or have had another person read to me) the attached information sheet for this study and have understood the purpose of the study and the problems involved.
2. I agree to voluntarily participate in the study, be questioned and provide answers to the best of my knowledge. I understand that I am free to withdraw any time without giving reasons and this will not influence the health care given to me.
3. I understand that my information will be kept confidentially and will only be accessed by the researcher or those people directly concerned with this study.
4. I understand that I will not benefit financially.
5. I know how to contact the researcher if I need to.

I……voluntarily agree to participate in this research.

……..	……	…….
Client's name	Signature (or thumb print)	Date
……	……	……..
Witness	Signature	Date
……	……..	…….
Researcher's Name	Signature	Date

Thank you for participating in this study.

Appendix 2: Chichewa Consent Form

Muli kuitanidwa kuti mutenge nawo mbali pakafukufuku wofuna kuona zomwe amayi amakumana nazo pa nthawi yomwe ana awo odwala zibayo agonekedwa muchipinda cha ana odwalika kwambiri pachipatala chachikulu cha Kamuzu. Musanapange chisankho ndikofunika kuti mumvetsetse chifukwa chimene kafukufukuyu akupangidwa ndipo chizafunike ndichiyani. Mukhonza kutifunsa ngati pali china chake chimene simunamvetsetse kapena ngati mukufuna kumva zambiri. Kutenga nawo mbali pa kafukufukuyu sikoumirizidwa.

Kodi cholinga cha kafukufukuyu ndi chiyani?

Cholinga cha kafukufukuyu ndikufuna kudziwa zomwe amayi amakumana nazo pa nthawi yomwe ana awo odwala zibayo agonekedwa muchipinda cha ana odwalika kwambiri pachipatala chachikulu cha Kamuzu. Kotero nkofunika kufufuza zomwe amakumana nazo akagonekedwa mchipindachi kuti timve maganizo awo zamomwe akhalira chipindachi zomwe zingathandize kusintha zinthu komanso momwe angagwilire ntchito limodzi ndi anamwino panthawi yovutayi. Ogwira ntchitonso mchipindachi zizawathandiza kumvetsetsa ntchito zimene amayi, odikilira odwala angathandizepo panthawi yomwe mwana wawo wagonekedwa ndi matenda a zibayo mchipindachi.

Kodi ndingatenge nawo mbali pa kafukufukuyu?

Ndikufuna kwanu kusankha kutenga nawo mbali mukafukufukuyu kapena ayi. Muli ndi ufulu kusiya nthawi imene mukufuna kusiya popanda kupeleka zifukwa. Ndipo izi sizingasokoneze chithandizo chimene mungalandire. Ngati mungavomereze kutenga nawo mbali mukafukufukuyu mudzafunsidwa kuti mutsindikize chizindikiro choti mwavomera. Mayankho anu azasungidwa mwachinsisi ndipo sizidzadziwika kuti anayankha mafunso awa ndi ndani

chifukwa maina anu sadzaikidwa pamapepala a mafunso m'malo mwake tidzagwiritsa ntchito manambala. Mapepala a mafunso ndimayankho onse zizawonongedwa pomaliza pakafukufukuyu.

Kodi chidzachitike ndi chiyani ngati nditenge nawo mbali?

Mukavomereza kutenga nawo mbali mukafukufukuyu mudzafunsidwa mafunso okhudzana ndi zomwe amayi amakumana nazo pa nthawi yomwe ana awo odwala zibayo agonekedwa muchipinda cha ana odwalika kwambiri pachipatala chachikulu cha Kamuzu. Mupemphedwa kuyankha mafunso mmene mukudziwira ndi moona mtima. Mudzajambulidwa mawu pamene mukuyankhula komanso wopangisa kafukufuku azizalemba mfundo zomwe mukuyankhulazo.

Kodi zovuta zimene zingaoneke potenga nawo mbali ndi ziti?

Palibe zovuta zodziwika mukatenga nawo mbali mukafukufukuyu

Kodi phindu lake nchiyani?

Sikuti pali phindu lina lake la padera mukatenga nawo mbali. Pali chikhulupiriro chakuti zotsatira za kafukufukuyi zidzathandizira achipatala kusintha zinthu makamaka pa chisamaliro chomwe chimapelekedwa komanso ndi momwe amayi a ana angagwilire ntchito limodzi ndi anamwino pa nthawi yovutayi. Komanso zizathandiza kuzindikilitsa anamwino ntchito zomwe azimayi a ana angathandize anamwino.

Ngati ndili ndi mafunso zokhuzana ndi kafukufukuyu ndingafunse yani?

Ngati mungakhale ndi mafunso owonjezera, kapena mafunso okhudzana ndi ufulu wanu monga inu wotenga nawo mbali pakafukufukuyu, khalani omasuka ndikufunsa anthu awa:

Mrs.M. Simbota ,

Kamuzu College of Nursing,

P. O. Box 415,

Blantyre,

Cell: 0999952060

Professor. J. Mfutso-Bengo,

College of Medicine Research Ethics Committee,

Private Bag 360,

Chichiri, Blantyre 3

Tel. 01871911

Cell: 0999957805

Mrs. M. Mbeba,

Kamuzu College of Nursing,

P. O. Box 415,

Blantyre

Diana Chiundu,

Kamuzu College of Nursing,

P. O. Box 415,

Blantyre,

Cell: 0999243212

WERENGANI NDIPO NGATI MWAVOMEREZA KUTENGA NAWO MBALI PA KAFUKUFUKUYU SINDIKIZANI MMUSIMO

1. Ndawerenga (kapena wina wandiwerengera) kalata yolongosola za kafukufuku ali pamwambayu ndipo ndamvetsetsa cholinga cha kafukufukuyi ndi zovuta zake.
2. Ndavomereza kutengapo mbali pa kafukufukuyu mosaumirizidwa, kufunsidwa mafunso ndikuyankha mafunso mmene ndingadziwire. Ndamvetsanso kuti ndili ndi ufulu kusiya nthawi ina ili yonse popanda chifukwa ndikuti izi sizidzasokoneza chithandizo chomwe ndingalandire.
3. Ndikumvetsa kuti zonse zomwe ndiyankhule kapena kupereka mukafukufukuyu zidzasungidwa mwachinsisi ndikugwiritsidwa ntchito ndi opanga kafukufukuyi kapena okhuzidwa mwachindunji ndi kafukufukuyi.
4. Ndamvetsetsa kuti palibepo phindu la ndalama.
5. Ndikudziwa mmene ndingampezere opanga kafukufukuyu ngati ndikofunika kutero.

Ine……. Ndavomera kutenga nawo mbali pakafukufukuyu mwakufuna kwanga ndi popanda kukakamizidwa.

……..	……	…….
Dzina la otenga mbali	Chitsindikizo	Tsiku
……	……	…….
Mboni	Chitsindikizo	Tsiku
……	……..	…….
Mwini kafukufuku	Chitsindikizo	Tsiku

Appendix 3: Interview Guide

Experiences of mothers separated from their children with pneumonia admitted in the paediatric high dependency unit at Kamuzu Central Hospital in Lilongwe district.

Date:_____

Location: _____

Interviewer(s): _____

Interviewee ID/NO. _____

INTRODUCTION:

Hello, my name is Ms. Diana Chiundu. I am from Kamuzu College of Nursing where Iam doing Masters in Child Health and am conducting a study on experiences of mothers separated from their children admitted in High Dependency Unit (HDU) with pneumonia. I would like to discuss your experiences on the admission of your child in HDU and what you think of your stay here, with an aim of being informed and possibly help to make improvements to services being offered in the HDU. Your name will not be disclosed and the information you give will be kept confidential. The information you give will only be used for the purposes of this study and to help us make improvements in our services. Would you allow me to ask you a few questions? Thank you.

PART A: DEMOGRAPHIC INFORMATION

1. Sex

Male…… 1

Female…… 2

2. How old are you?

Less than 25…… 1

25- 29…… 2

30-34…… 3

35-39…… 4

40-44…… 5

45 and above ……..…… 6

3. What is your marital status?

Married…… 1

Divorced…… 2

Widowed…… 3

Single (Never ever married)…… 4

4. What is your tribe or ethnic group?

Chewa…… 1

Yao…… 2

Lomwe…… 3

Ngoni…… 4

Tumbuka…… 5

Nkhonde…… 6

Tonga…… 7

Sena…… 8

Other (specify)_____ 9

5. What is your religion?

Christianity…… 1

(Specify)_____

Moslem…… 2

Hindu…… 3

Bahai…… 4

Traditional religions…… 5

Other (specify) _____ 9

6. What is your highest level of education?

Standard 1 - 4……...…… 1

Standard 5 – 8……...…… 2

Form 1 – 2……..…… 3

Form 3 – 4……..…… 4

7. What is your highest qualification?

Certificate..... 1

Diploma…… 2

Degree……..... 3

Masters..... 4

Others (specify) _____ 9

8. Do you live in urban or rural area?

Urban…… 1

Rural……..…… 2

9. How many live children do you have?

One…… 1

Two…… 2

Three or more……..…… 3

10. How old is the sick child?

Less than 1 month……..…… 1

1 to 11months…… 2

12 to 59 months…… 3

60+ months…….…….. 4

11. What is the sick child suffering from?

12. For how long did your child stay in HDU?

13. Have you ever been separated from your child since birth? If yes, why and for how long?

_____

PART B: EXPERIENCES OF HDU STAY

14. How can you describe your stay in HDU? ***(Probe for assistance to the sick child by health service provider, treatment given, nursing care)***

_____

_____

_____

15. How many times in a day are/were you spending together with your child?

_____

_____

_____

I. How many times during the day were you spending together with your child?

_____

_____

_____

II. How many times during the night were you spending together with your child?

_____

_____

_____

III. When you visit the child, for how long do you spend time together with the child?

_____

_____

_____

16. Is the duration of time allocated to visit your child adequate for you? Explain?

_____

_____

_____

17. When you are with the child, what activities do you do for the child?

_____

_____

_____

18. When you leave the child, are you satisfied with the care given? Explain?

_____

_____

_____

19. How would you want to be spending time with your sick child when admitted in HDU? ***(Probe for time, period etc)***

_____

_____

_____

20. Are/Were you comfortable or not with this arrangement of not being with your child all the time? Explain why?

_____

_____

_____

21. Can you tell me the kind of arrangement that would make you more comfortable?

_____

_____

_____

22. Are/Were you helping the nurses in caring for your child? Explain. ***(Probe activities done on the sick child, timing of activities, whether instructed by nurses or not, and whether activities were demonstrated by nursing staff or not)***

_____

_____

_____

23. In your view, what have been your roles in caring for the sick child while in HDU? Explain?

_____

_____

_____

24. What were your expectations in your involvement during the time you were in the HDU with your child? ***(Probe expectations from nursing services, expectations on what they can be involved)***

_____

_____

_____

25. Do you think the services in this ward (HDU) met these expectations? Why?

_____

_____

_____

26. What did you like most of the HDU services? Why? ***(Probe nursing service, mother's involvement/role)***

_____

_____

_____

27. What did you like least of the HDU services? Why? ***(Probe nursing service, mother's involvement/role)***

_____

_____

_____

28. Do you have anything else to share with me about your experience in this ward?

_____

_____

_____

_____

THANK YOU!

Appendix 4: Chichewa Interview Guide

Zomwe amayi amakumana nazo pa nthawi yomwe ana awo odwala zibayo agonekedwa muchipinda cha ana odwalika kwambiri pachipatala chachikulu cha Kamuzu.

Date: _____

Location: _____

Interviewer: _____

Interviewee ID/NO._____

Dzina langa ndine mayi Diana Chiundu. Ndine wophunzira ku sukulu yaukachenjede ya anamwino ya Kamuzu ndipo ndikupanga maphunziro a ukadaulo wa ana ndipo ndikupanga kafukufuku wa zomwe amayi amakumana nazo pa nthawi yomwe ana awo odwala zibayo agonekedwa muchipinda cha ana odwalika kwambiri pachipatala chachikulu cha Kamuzu. Ndikufuna kukambirana nanu za momwe mwakhalira ndi momwe mwaonera chisamaliro cha ana anu ndi cholinga choti tidziwe zomwe zingathandize kusintha kasamalidwe ka ana odwala mu chipindachi. Dzina lanu silidziwika ndipo mayankho anu azasungidwa mwa chinsisi. Mayankho amene mupeleke azagwiritsidwa ntchito pa kafukufukuyu yemwe azathandize kusintha mayendetsedwe antchito muchipindachi. Mungandilore kuti ndikufunseniko mafunso? Zikomo.

GAWO LOYAMBA: KUDZIWA ZA OTENGA MBALI PA KAFUKUFUKU

1. Mwamuna [1]

   Mkazi [2]

2. Kodi muli ndi zaka zingati ?

Kuchepera zaka 25 [1]

25-29 2

30-34 3

35-39 4

40-44 5

Kuposera zaka 45 6

3. Kodi muli pa banja?

Ndili pa banja 1

Banja linatha 2

Namfedwa 3

Sindinakwatiwepo 4

4. Kodi ndinu a mtundu wanji?

Chewa 1

Yao 2

Lomwe 3

Ngoni 4

Tumbuka 5

Nkhonde 6

Tonga 7

Sena 8

Zina(tchulani) 9

5. Kodi ndinu a chipembezo chanji?

Chikhristu (mtundu)	1
Chisilamu	2
Chihindu	3
Chi Bahai	4
Chamakolo (chachikhalidwe chathu)	5
Zina (tchulani)	9

6. Kodi sukulu munalekeza kalasi lanji?

Sitandade 1 mpaka 4	1
Sitandade 5 mpaka 8	2
Folomu 1 mpaka 2	3
Folomu 3 mpaka 4	4
Diploma	5
Kupitilira pa diploma	6
Zina (tchulani)	9

7. Kodi ndi maphunziro ati a pamwamba muli nawo?

Certificate	1
Diploma	2
Degree	3
Masters	4

Zina (tchulani) 9

8. Mumakhala mtawuni mom’muno kapena kumudzi?

Mtawuni 1

Kumudzi 2

9. Kodi muli ndi ana angati amoyo?

Mmodzi 1

Awiri 2

Atatu kapena ambiri 3

10. Kodi mwana wodwalayu ali ndi zaka zingati?

Ochepera mwezi umodzi 1

Mwezi umodzi mpaka miyezi 11 2

Chaka chimodzi osaposera zaka 5 3

Zaka 5 kapena kuposera apo 4

11. Kodi mwanayu akudwala matenda anji?

_____

_____

_____

12. Kodi mwakhalamo nthawi yaitali bwanji mu chipinda chimenechi?

_____

_____

_____

13. Munayamba mwakhalako motalikirana ndi mwanayu kuchokera atangobadwa? Ngati ndi choncho, ndi chifukwa ninji? Komanso kwa nthawi yaitali bwanji?

_____

_____

_____

GAWO LACHIWIRI: MOMWE MWAKHALIRA MU CHIPINDA CHA HDU

14. Kodi mungandifotokozereko momwe mwakhalira mu chipinda chimenechi?
    (Chisamaliro ndi thandizo la mankhwala kuchokera kwa anamwino ndi madotolo)

_____

_____

_____

15. Kodi mumakhala limodzi ndi mwana wanu wodwala kangati pa tsiku?

_____

_____

_____

I. Ndi kangati nthawi ya mmawa mpaka madzulo?

_____

_____

_____

II. Nanga ndi kangati usiku?

_____

_____

_____

III. Panthawi yomwe mwalowa kukaona mwana muchipindachi mumakhalamo nthawi yaitali bwanji?

_____

_____

_____

16. Mukuona kuti nthawiyi ndiyokwanira kwa inu? Fotokozani?

_____

_____

_____

17. Ndi zinthu ziti zomwe mukumapanga zothandiza mwana wanu panthawi yomwe muli naye limodzi?

_____

_____

_____

18. Mukasiyana naye mwanayu mukumakhutitsidwa ndi chisamaliro chomwe mwapeleka kwa mwanayu? Fotokozani?

_____

_____

_____

19. Kodi mukanakonda mutamakhala naye limodzi bwanji wodwalayo? (nthawi yanji/ nthawi yaitali bwanji?)

_____

_____

_____

20. Kodi mukudziona bwanji zosakhala ndi mwana wanu limodzi nthawi yonse. Ndizabwino kapena ayi? (Fotokozani zifukwa?)

_____

_____

_____

21. Kodi mungathe kundifotokozera chikonzero chomwe mungakondwere nacho?

_____

_____

_____

22. Kodi mumatengako mbali kuthandizana ndi anamwino posamala mwana wanu? (ntchito zanji, nthawi ziti, mumachita kuuzidwa ndi anamwino, kapena ayi? Nanga amachita kukuphunzitsani anamwinowo?)

_____

_____

_____

23. Kodi mukuganiza kuti ntchito zanu ndi ziti posamalira mwana wanu wodwala mu chipindachi?

_____

_____

_____

24. Kodi inuyo mumayembekezera zotani panthawi yomwe mumatenga nawo mbali pomusamalira mwana wanu odwala mchipindachi? (kuchokera kwainu komanso anamwino)

_____

_____

_____

25. Kodi mukuganiza kuti chisamalirochi chikukwaniritsa ndi zomwe mumayembekezera? Fotokozani chifukwa?

_____

_____

_____

26. Kodi chakusangalatsani koposa ndi chiyani pa chisamaliro choperekedwa kwa odwala mchipindamu? Fotokozani chifukwa? (mbali ya anamwino komanso yanu yomwe mumachita/kapena kutenga mbali)

_____

_____

_____

27. Kodi simunasangalatsidwe koposa ndi chiyani? Fotokozani chifukwa? (kumbali ya anamwino, inuyo/ kapena mbali yotenga mbali)

_____

_____

_____

28. Kodi muli ndi zina zomwe mukanakondanso kugawana nane kumbali ya momwe mwaonera muchipindachi?

    _____

    _____

    _____

ZIKOMO!

Appendix 5: Approval Letter 1

REF. No.
TELEPHONE No.: (265) 1 753 555/754 331
TELEFAX 0.: (265) 1 756 380

PLEASE ADDRESS ALL
COMMUNICATIONS TO :
THE HOSPITAL DIRECTOR
E-MAIL: kchosdir@ gmail.com

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

Friday, May 18, 2012

Diana Chiundu University of
Malawi Kamuzu College of
Nursing P.O Box415
Blantyre

Dear Madam

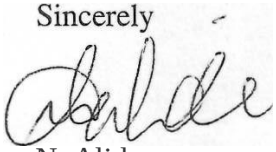
PERSMISSION TO CARRY OUT A RESEARCH STUDY

Thank you for your letter regarding the request to conduct a study on experiences of mothers separated from their children with pneumonia admitted in the paediatric high dependency unit at Kamuzu Central Hospital.

Please note that I have reviewed the proposal you presented to my office and wish to inform you that you can carry out your studies as required.

Wishing you all the best

Sincerely



N. Alide
HOSPITAL DIRECTOR