



**Experiences of Caregivers of Infants who have been on Bubble Continuous Positive  
Airway Pressure at Queen Elizabeth Central Hospital.**

**MSc. (Child Health Nursing) Thesis**

**By**

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**Submitted to the faculty of Nursing, in partial fulfilment of the requirement for the  
award of Master of Science in Child Health Nursing.**

**KAMUZU COLLEGE OF NURSING**

**MARCH 2016**

### **Declaration**

I **Mtisunge Joshua Gondwe** hereby declare that this thesis is my own original work which has not been submitted for any other awards at the University of Malawi or any other University.

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### **Certificate of Approval**

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

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## **Dedication**

I dedicate this work to my husband Baxter Gondwe, my son Gracious Gondwe and my daughter Glory Gondwe for continuous support and encouragement rendered to me during the two years of study at Kamuzu College of Nursing and University of Cape Town. You are such a blessing to me. May good Lord continue blessing you.

## **Acknowledgement**

Above all I am grateful to God, the Almighty for good health, protection, guidance and wisdom given to me during two years of study. My heartfelt gratitude should go to my supervisors Dr. Belinda Gombachika and Maureen Majamanda for their contributions, guidance, support and patience during development of this thesis.

I am very grateful to my husband Baxter Gondwe, beloved son Gracious Gondwe and daughter Glory Gondwe for love and support during my study. I am also thankful to my parents Mr and Mrs Joshua, parents in-law, Mr and Mrs Gondwe, brothers, sisters, in-laws and friends for continuous support and encouragement during my study.

I would also like to appreciate the management and staff of Queen Elizabeth Central Hospital (QECH) for allowing me to conduct this study at their institution. I am also very grateful to all the participants in this study whose cooperation made it possible for me to complete the study. I would also like to thank G.A.I.A for financial support they rendered during my study. May good Lord bless you all.

## **Abstract**

The bubble Continuous Positive Airway Pressure (bCPAP) is a form of oxygen treatment given to children with severe respiratory distress. The bCPAP treatment might be stressful to caregivers caring for their sick infants. As such, caregivers may need continuous psychological support and adequate information for them to understand treatment better. This was a descriptive study that utilized qualitative method to explore experiences of caregivers of infants who have been on bCPAP at QECH. Data was collected from a purposive sample of twelve caregivers from Chatinkha and Paediatric nursery wards through in-depth interviews using a semi- structured interview guide. Qualitative data was analyzed using Colazzi's framework which resulted in identifications of 3 themes; information about bCPAP, perception of caregivers and psychological support. The study found that information given about bCPAP was inadequate and not standardized for caregivers to understand bCPAP treatment. Most caregivers perceived bCPAP as a good treatment that saved lives of their infants. The caregivers were more stressed due to interrupted parent-infant interaction and bCPAP machine as they prevented them to be in physical contact with their infants. The family members, friends and religious beliefs were among preferred source of psychological support rather than the healthcare workers. Therefore, the results have shown that there are gaps in providing support to caregivers of infants on bCPAP at QECH in terms of giving information and psychological care. As such, it is recommended that specific interventions be developed to minimize psychological distress and promote psychological health of caregivers with sick infants on bCPAP at QECH.

*Key Words:* Infants, bubble Continuous Positive Airway Pressure (bCPAP), Information giving, perceptions about bCPAP and psychological support.

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### **List of Abbreviations**

ALRI	: Acute Lower Respiratory Infection
ARI	: Acute Respiratory Infection
bCPAP	: bubble Continuous Positive Airway Pressure
CNW	: Chatinkha Nursery Ward
COMREC	: College of Medicine Research Ethical Committee
CPAP	: Continuous Positive Airway Pressure
HDU	: High Dependency Unit
HMIS	: Health Management Information System
KCH	: Kamuzu Central Hospital
KCN	: Kamuzu College of Nursing
MDHS	: Malawi Demography Health Survey
nCPAP	: nasal Continuous Positive Airway Pressure
NICU	: Neonatal Intensive Care Unit
NMR	: Neonatal Mortality Rate
OGT	: Oral Gastric Tube
OSA	: Obstructive Sleep Apnea

PICU:	Paediatric Intensive Care Unit
PNW:	Paediatric Nursery Ward
PSCW:	Paediatric Special Care Ward
QECH:	Queen Elizabeth Central Hospital
UNICEF:	United Nation Children Fund
USA:	United States of America
WHO:	World Health Organization

### **Operational Definitions**

Caregiver:	Any person who was the guardian of the admitted child
Communication:	The giving and exchange of information, ideas or feelings.
Health information:	Involves information concerning child's medical diagnosis, treatment, any investigation/procedures, care of the child throughout the disease process and the possible outcome or complications that can arise
Health information giving:	The act of conveying health information to caregivers
Infant:	Child aged from zero to twelve months old.
Neonate:	Child aged from zero to 28 days old.

## **CHAPTER 1**

### **Introduction and Background of the Study**

#### **Introduction**

Continuous Positive Airway Pressure (CPAP) is the application of positive pressure to the airways of spontaneously breathing patients throughout the respiratory cycle to treat respiratory distress (Fuhrman & Zimmerman, 2011). Respiratory distress is a response to the clinical condition where the respiratory difficulty has become so severe that the child is likely to die unless given respiratory support (Brown et al., 2013). Bubble continuous positive airway pressure (bCPAP) is one way of delivering CPAP to patients with respiratory distress. In bCPAP, the expiratory limb is submerged in water to the depth of desired nasal CPAP with the flow set for constant bubbling (Meeks, Hallsworth, & Yeo, 2010). The bCPAP works by driving air with additional pressure on collapsed alveoli to increase the surface area for gas exchange (Walsh, Czervinske, & DiBlasi, 2010). Common causes of respiratory distress in neonates is respiratory distress syndrome while pneumonia and bronchiolitis cause respiratory distress in older children (Brown et al., 2013).

Studies have shown that use of CPAP is effective in treating severe respiratory distress due to respiratory distress syndrome in preterm, pneumonia and bronchiolitis in children (Wilson, Morris, Biagas, Otupiri, & Moresky, 2013; McCollum, Smith, & Golitko, 2011; Van Den Heuvel et al., 2011; Vamvakiti, Saha, & Linney, 2010). A study conducted in South England on use of nasal CPAP had a good survival rate (78.5%) in bronchiolitis (Vamvakiti et al., 2010). Similarly, a study conducted in Western Cape, in South Africa showed that, early use of CPAP in extremely low birth weight infants was associated with

survival rates that were similar to those seen in developed countries (Kirsten et al., 2012). In Malawi, at Queen Elizabeth Central Hospital (QECH), use of bCPAP has increased survival rate of children with respiratory distress to 64.8 % (Lang et al., 2011).

Infants with respiratory distress are kept in Paediatric Intensive Care Unit (PICU) or High Dependency Unit (HDU) for close monitoring (Khilnani, 2005). The procedures and environment are stressful to caregivers and may need continuous education for them to understand. For example, when bCPAP machine is set, hudson prongs and helmet are used to connect the infant to bCPAP system. The hudson prongs are inserted into infant's nostrils while the helmet assists in holding the hudson prongs in place. In addition, an Oral Gastric Tube (OGT) is inserted to the infant. Apart from its use in providing feeds to the infant, the OGT is also used to allow aspiration of air and stomach contents to prevent abdominal distention (Bonner & Mainous, 2008).

However, little is known about the experiences of caregivers caring for infants on bCPAP worldwide. According to studies done on children with assisted breathing devices like high flow nasal prong oxygen, intubation, bi-level positive airway pressure and CPAP showed that mothers were distressed with the oxygen delivering methods (Cervantes, Feeley, & Lariviere, 2011; Peeler, 2011). For example a study was conducted in Canada to examine the experience of mothers whose very low-birth-weight infants required the delivery of supplemental oxygen during their hospitalization in the neonatal intensive care unit (NICU). The study revealed that mothers were particularly distressed by the physical barriers created by oxygen delivery methods (Cervantes, Feeley, & Lariviere, 2011). Another study was conducted in Australia on experiences of parents and nurses of hospitalized infants requiring oxygen therapy for severe bronchiolitis. The study revealed

that mothers described various oxygen delivering methods that they found stressful since they prevented them to see or hold their child (Peeler, 2011).

In Malawi there are no published studies exploring caregiver's experiences when caring for their infants on bCPAP. Therefore, a qualitative research was conducted in exploring experiences of caregivers of hospitalized infants on bCPAP. New knowledge generated will help health care workers to assist caregivers caring for infants on bCPAP to reduce stress and anxiety, understand and comply with the treatment plan.

### **Background Information**

Acute Lower Respiratory Infections (ALRI), such as pneumonia and bronchiolitis are a common and leading cause of morbidity and mortality in young children worldwide (Nair et al., 2010). The World Health Organization (WHO) estimates that 2 million children under the age of five die of pneumonia each year (Bryce, Boschi-Pinto, Shibuya, & Black, 2005). In 2010, 1.4 million of children died because of Acute Respiratory Infections (ARI) (Nair et al., 2010). About 40% of these ARI associated deaths occurred in Africa (Bryce et al., 2005).

Although children are dying from neonatal conditions and pneumonia, the direct cause of death is respiratory failure (Brown et al., 2013). In addition, conditions associated with respiratory failure account for a large percentage of the approximately 4 million neonatal deaths annually and these deaths mainly occur in resource limited environment (WHO, 2006).

In Malawi, there is a sharp decline in infant and under-five mortality rates per 1,000 live births, from 81 and 145 deaths in 2004 to 66 and 112 in 2010 respectively (MDHS, 2010). Neonatal Mortality Rate (NMR) is at 31 per 1,000 (MDHS, 2010). Despite progress

in child mortality reduction, children are still dying, mostly of preventable causes among which neonatal conditions and pneumonia are among the leading causes of deaths (UNICEF, 2007). According to QECH Health Management Information System (HMIS), pneumonia was among the leading cause of admissions and deaths in infants admitted at Paediatric Nursery Ward (PNW) and Paediatric Special Care Ward (PSCW) in 2012/2013 fiscal year. While Chatinkha Nursery Ward (CNW) statistics reported severe prematurity, respiratory distress syndrome, meconium aspiration and birth asphyxia as common cause of severe respiratory distress and deaths in neonates.

In order to increase the survival rate of children with respiratory distress, bCPAP has been introduced in Malawi. This is in addition to use of nasal prong oxygen and antibiotics which have been the standard treatment plan for children with respiratory failure (Phillip, Kazembe, Nelson, Fisser, & Grabosch, 2008).

The first clinical use of CPAP was reported by Gregory in 1971 in United States of America (USA). Prior to the creation of this treatment, the mortality rate of neonates with respiratory distress syndrome was more than 50% (Mai, Yaster, & Firth, 2013). The innovation greatly improved the ventilation of infants with respiratory distress and led to significant improvements in survival rates (Gregory et al., 1971).

Shortly after, Kattwinkel from University of Virginia in USA reported successful use of nasal prongs to provide CPAP in infants with respiratory distress (Kattwinkel, McGowan, Zaichkin, Bloom & Cropley, 2011). Then, they reported that, it gradually fell out of favor in the 1980's because of the advent of newer modes of ventilation and perceived complication of CPAP. However, they noted that, rebirth of interest of CPAP occurred after

Columbia University unit that used more CPAP reported low incidence of chronic lung disease in infants.

In Malawi, introduction of CPAP in managing children with respiratory distress has been a slow process than in developed countries. A study by Van Den Heuvel et al. (2011) was conducted at QECH to evaluate if bCPAP can be implemented in neonatal unit. In 2008, they developed a CPAP system consisting of a compressor, oxygen concentrator, bottled water to control the pressure and binasal prongs. They found that, out of five neonates treated with this CPAP, three survived. At Kamuzu Central Hospital (KCH), a teaching and central hospital in central region of Malawi offering tertiary care, bCPAP was successful in treating a three months old infant with pneumonia (McCollum et al., 2011). However, it was still difficult to roll out the use of bCPAP in hospitals of Malawi due to high cost of CPAP machine. One standard CPAP machine can cost about \$6,000 which is very expensive for resource limited countries (Brown et al., 2013).

In 2010, a low cost bCPAP was developed which cost about (\$350) 15 times less than standard CPAP machine used in developed countries. It was effectively used in a 6-months-old baby with bronchiolitis and a full-term neonate with respiratory distress caused by congenital pneumonia at QECH (Brown et al., 2013). Then, in 2010 feasibility study was conducted at QECH (neonatal unit) to evaluate use of low cost bCPAP. The overall survival rate of 64.8% was achieved (Lang et al, 2011). As such, bCPAP has been rolled out in all central and district hospitals of Malawi to treat children with severe respiratory distress who fail to respond to nasal prong oxygen.

Communicating treatment plan and supporting caregivers are essential in managing sick children (Verhaeghe, Defloor, Van Zuuren, Duijnste, & Grypdonck, 2005). Similarly,

when planning to put infants on bCPAP, caregivers have to be informed for them to understand the treatment and this helps to reduce stress created by the whole procedure. The information may include, what bCPAP is, why an infant needs bCPAP, how bCPAP works, period the child can be on bCPAP, benefits and side effects of bCPAP. Verhaeghe, et al (2005) explains that information that is accurate, complete and comprehensive helps to relieve negative feelings and facilitates the development of realistic hope among caregivers.

A qualitative study was conducted in Australia on experiences of parents and nurses on hospitalized infants requiring oxygen therapy, CPAP inclusive. The study showed that mothers were willing to participate in the care of their children but they needed communication and emotional support from the health care workers (Peeler, 2011). Additionally, it was also observed that attention by health care providers to the caregiver's questions and comments about the child's illness, emotions and parental needs during child sickness, play a major role in the treatment process (Meshkan & Bavarian, 2005). In another study conducted in one district hospital in Western Cape in South Africa, it was found that good communication between health personnel and caregivers on CPAP assisted the caregiver in understanding the treatment better than those who did not have good communication (Hendriks, 2010).

However, in Malawian hospitals, communicating essential information and supporting caregivers was found to be a challenge. A study of 8 hospitals in six districts in Malawi, found that factors such as shortage of nurses, congestion and increased workload affect information giving and support to caregivers (Schell, Rankin, Chipungu, Rankin & Weiller, 2011). For example, an average daytime nurse-patient ratio was at 1:38 and the night time ratio was 1:77 (Schell et al., 2011).

Little is known worldwide about the experiences of caregivers who have cared for infants on bCPAP. Most studies have general information such as oxygen delivery methods not specific to bCPAP. In Malawi, there are no published studies conducted on this area. The study therefore explored the experiences of caregivers which include; type of given information about bCPAP, perceptions about bCPAP and psychological support received from health care workers.

### **Problem Statement**

Health workers have a role to communicate information and support the caregivers during bCPAP. This assists the caregivers to have reduced stress and anxiety, understand and comply with the treatment plan (Verhaeghe et al., 2005). Despite above benefits caregivers expressed lack of or inadequate health information concerning the child's illness, medical treatment, nursing care provided, purpose and side effects of drugs and outcome or prognosis (Soderback & Christenson, 2008; Wahl, Banerjee, Manikam, Parylo & Lakhanpaul, 2011).

Unfortunately in circumstances where information is given, it is often not clear, sometimes conflicting and inaccurate. As a result the caregivers are often left with a lot of unanswered questions about the child's condition (Kiguli, Mafigiri, Nakigudde, van Dalen & van der Vleuten, 2010). Levetown (2008) estimated that 35 – 70 percent of medico-legal actions result from poor delivery of information and failure to understand the child as a patient and the family. Lang et al. (2011) in their feasibility study on use of bCPAP in Malawi recommended that guardians need to be clearly informed so as to play an important role in caring for their children on bCPAP. However, there are no studies in Malawi that have been conducted to explore caregiver's perception, type of information and

psychological support caregivers receive when caring for children on bCPAP. As such, this study looked at experiences of caregivers who have cared for infants on bCPAP.

### **Justification of the study**

In this study, new knowledge of experiences of the caregivers who have cared for infants on bCPAP was generated. This knowledge will help nurses/ health care workers assist caregivers to understand and comply with the treatment plan. It will also promote acceptance of bCPAP treatment by parents for their infants who are in severe respiratory distress. In the long run, this will improve survival rate of infants with severe respiratory distress hence reducing infant mortality rate in Malawi.

### **Study Objectives**

#### **Broad objective.**

To explore experiences of caregivers of infants who have been on bubble Continuous Positive Airway Pressure at Queen Elizabeth Central Hospital.

#### **Specific objectives.**

- To describe type of information caregivers receive from health care workers when caring for infants on bCPAP.
- To determine the perceptions of caregivers on use of bCPAP in infants
- To identify the psychological support offered by health care workers to caregivers when caring for infants on bCPAP.

## **CHAPTER 2**

### **Literature Review**

#### **Introduction**

This chapter presents a review of studies done on bCPAP from Malawi and other countries. The review of literature has been organized in accordance with the study objectives. Therefore, studies on experiences of caregivers on information giving by healthcare workers during care of their infants on bCPAP, perceptions and feelings of caregivers about bCPAP and issues of psychological support given to caregivers with infants on bCPAP were reviewed. The review included peer reviewed articles that were published in English from a period of 2003 to 2014. This was done because the researcher could only understand articles in English. Literature search was done through various academic data bases (MEDLINE, CINAHL, PUBMED, HINARI and Google scholar) in order to review what is known about experiences of caregivers of infants who have been on bCPAP. The search terms that were used for the literature search were infants OR children OR neonates AND bCPAP OR CPAP, information given to caregivers AND bCPAP OR CPAP, Perceptions AND bCPAP, Psychological support of caregivers AND bCPAP OR CPAP. In addition, the researcher reviewed grey literature from the internet such as national and international reports that were related to the topic. The researcher also did a hand search of literature related to the topic from research books.

## **Experiences of caregivers on information giving by health care workers during care of their infants on bCPAP**

Communication is defined as giving of information, ideas or feelings (Trigg & Muhammad, 2010). Communication is essential to all aspects of health care, from history taking to providing information to the patient. According to Soderback and Christenson (2008), communicating health information between children, caregivers and health care providers should be considered as an aspect of paramount importance irrespective of the cultural circumstances. Information that is accurate, complete and comprehensive helps to relieve negative feelings and facilitates the understanding and development of realistic hope among family members (Verhaeghe, et al., 2005). Similarly, studies have reported that nurses who communicated with mothers by providing constant information and updates on the baby's health condition, helped mothers to understand their health needs which eased anxiety (Orapiriyakul et al., 2007; Mok & Leung 2006). In addition, communication provided to caregivers of hospitalized children after diagnosis of an illness may reduce anxiety or sadness and potentially increases compliance with treatment (Huang, Kenzik ,Sanjeev, Revicki, & Nackashi, 2010).

Caregivers need adequate information to reduce stress created by oxygen delivering methods when caring for their sick infants (Cervantes et al., 2011; Peeler, 2011; Hendriks, 2010).The information to be communicated to caregivers caring for sick children may include: the child's illness, medical treatment, nursing care provided, purpose and side effects of drugs, outcome and/or prognosis (Strohbuecker, Gaertnerb, & Stocka, 2011). On the contrary, poor quality of communicating health information can seriously affect compliance to treatment and disease outcome (Huang et al., 2010).

The way in which a health care provider communicates information to a patient can be equally as important as the information being conveyed. Nurses and other health care workers need to communicate effectively with clients and caregivers to develop cost-effective plans of care and achieve positive client outcomes (Dalton, 2005). Use of verbal and non verbal skills is important when communicating with caregivers to promote understanding. Kiguli et al. (2011) found that caregivers of sick children would like doctors to build a relationship with them, by demonstrating the verbal and nonverbal skills such as, maintaining eye contact, using appropriate gestures and voice during communication, and not being judgmental. Similarly, Reinhard, Given, Petlick, and Bemis (2008) concluded that it is important to provide information in a clear, understandable way through verbal, written, and electronic methods.

Caregivers' involvement in care of a sick child is essential in caring for sick children. Evagelou et al. (2003) reported that when families are involved in the care of children with special health care needs, children's psychosocial and physical health improves. Peeler (2011) in her study on experiences of parents and nurses of hospitalized infants requiring oxygen therapy for severe bronchiolitis in Australia revealed that mothers lack of knowledge and understanding of their child's illness, treatment and hospital routines led to increased fear and anxieties. The study concluded that health workers/nurses should clearly impart this knowledge or information about child's condition and treatment to caregivers for them to understand. While in United States of America, Picker Institute's Paediatric survey concluded that effective communication that is understandable between parents and nurses benefits the child, decreases parental stress and anxiety levels while increasing trust (Co, Ferris, Marino, Homer, & Pemni, 2003).

Similarly, a study conducted in Western Cape found that the mother of infant on CPAP who was given enough information about CPAP had also decreased levels of anxiety compared to other mothers that were not communicated properly (Hendriks, 2010). However, the study did not have enough participants to produce conclusive evidence and further research was suggested. Comparable results were produced in a qualitative descriptive study conducted in Canada. The aim of the study was to examine the experience of mothers whose very low-birth-weight infants required the delivery of supplemental oxygen during their hospitalization in the neonatal intensive care unit (NICU). The results showed that mothers were willing to participate in the care of their children but they needed communication and emotional support from the health workers (Cervantes et al., 2011).

However, despite the benefit of giving information to caregivers, Charchuk and Simpson (2005) found that the parents of infants admitted to the NICU faced challenges including access to information, disclosure about the diagnosis, and treatment and prognosis of their newborn, as well as a lack of control over the care of their newborn. Similarly, many studies highlight caregivers' dissatisfaction with the quantity or quality of information provided at the time of diagnosis (Ertmann, Reventlow & Söderström, 2011; Hinkson, Atenafu & Kennedy, 2006; Matziou et al., 2011). In addition, several studies have found that lack of a timely and easily accessible source of medical information, language barriers and ineffective communication skills by health care professionals are factors that may impede communicating health information to caregivers of hospitalized children (Gulati et al., 2012; Ameratunga, et al., 2010; Beckstrand, Rawle, Callister & Mandleco 2010; Coyne, 2006; Kiguli, et al., 2010).

Evidence has shown that although giving information to caregivers is essential during care of sick children, caregivers face challenges in accessing adequate information about their child's sickness (Ameratunga, et al., 2010). As such, intervention studies are therefore needed to find solutions on improving information giving to caregivers. Communicating treatment plan to caregivers is a very important intervention that should not be forgotten when taking care of sick children on bCPAP. However, the literature has only addressed importance of giving information to caregivers. More studies should be conducted to address what information should be communicated and how communication should be done for caregivers to understand the information well.

### **Perceptions and feelings of caregivers about bCPAP**

Perception is the process by which an individual selects, organizes and interprets sensory information, transforming it into meaningful objects and events (Myers, 2009). The perceptions help to formulate meaning in our life. The perceptions of two or more different people will rarely be the same even when reflecting on the same incident or event. Finucane (2012) reported that perceptions are shaped or distorted by the perceiver's past experiences, needs or motives, personality, values and attitudes. Finucane further described that they can also be influenced by the situation or setting and perceived object. Perceptions are important since they help an individual to give meaning to a situation.

On the other hand, feelings are an affective state of consciousness that result from: emotions, sentiments, or desires (Myers, 2009). Feelings may play multiple roles in judgment and decision processes, including providing information, enabling rapid information processing, directing attention to relevant aspects of the problem, facilitating abstract thought and communication, and helping people to determine social meaning and to

act morally (Finucane, 2012). Finucane, further explained that feelings are useful to tell people when their needs are being met - or not being met. If uncomfortable feelings are dealt inappropriately through unhealthy distraction, distress can be created.

Different people can interpret their experiences on use of bCPAP on their infants differently depending on their perceptions and feelings. Others may associate oxygen support with good outcome while others associate it with poor outcome. In a study conducted in Canada by Cervantes et al. (2011), most mothers felt strongly that oxygen therapy was responsible for saving the lives of their infants. Mothers also reported feeling that this experience had made both themselves and their infants stronger. However, in the same study, mothers also expressed worries they had concerning oxygen delivering methods. The mothers felt that oxygen delivering methods were painful and uncomfortable to their infants. They were also concerned with developmental delays associated with long use of oxygen delivering methods on their children.

While in Australia, a correlation quantitative study aiming at examining the effects of using head box oxygen and continuous oxygen positive airway pressure treatments for respiratory distress on stress and satisfaction of parents with infants in a special care nursery was conducted. In all the methods high stress levels were commonly reported which did not differ statistically. However, parents with babies receiving CPAP were more satisfied compared to the head box group (Foster, Bidewell, Buckmaster, Lees, & Henderson-Smart, 2008) as the parents with babies on CPAP were able to do some interaction with their babies compared to parents with babies on head box. In addition, a base line sleep study was conducted in United Kingdom. The aim of the study was to review children with obstructive sleep apnoea (OSA) for whom a trial of nasal continuous positive airway

pressure (nCPAP) was proposed (Massa, Gonzalez, Lavery, Wallis, & Lane, 2003). They found that, in 12% of cases, where nCPAP was effectively tolerated by the child during the trial, parents refused to continue the therapy at home because of poor perception of the therapy.

Studies above addressing perceptions and feelings of caregivers have shown that different caregivers have different perceptions about oxygen delivering methods. While others perceive it as important treatment plan to their sick children others perceive it as painful and uncomfortable treatment plan to their sick children. Most of these studies have general information about perception and feelings of caregivers about oxygen delivering methods. There was no specific study addressing perceptions and feelings of caregivers about use of bCPAP in infants. Hence a need for more studies to be done in the area. In addition, the studies have been done in developed countries, where most of caregivers already have good understanding of different treatment plan. In Malawi, there is no published study concerning the perceptions and feelings of caregivers of hospitalized infants who were on bCPAP. Therefore, more studies should also be conducted in Africa.

### **Psychological support given to caregivers of infants on bCPAP**

Psychology is the scientific study of behaviour and mental processes (Myers, 2009). Caring for sick infant can bring psychological effects on the caregiver. Care giving can also have significant consequences on mental health. Psychological support will help in relieving stress, anxieties, depression and even fear created by hospital environment, equipment used and disease process of sick children. The unfamiliar environment can cause feelings of anxiety, apprehension and exclusion and limit mothers' ability to verbally express their individual needs (Flacking, Ewald, Nyqvist, & Starrin, 2006).

In Canada, a study aiming at examining the experience of mothers whose very low-birth-weight infants required the delivery of supplemental oxygen during their hospitalization in the Neonatal Intensive Care Unit (NICU) revealed that mothers were particularly distressed by the physical barriers created by oxygen delivery methods (Cervantes et al., 2011). Some oxygen delivering methods prevented mothers from holding or sometimes seeing their babies. The mothers were more stressed if oxygen delivering method disturbed parent-child interaction. The study concluded that the health care workers should employ interventions which promote parent-child interaction when caring for infants on bCPAP. Comparable results were reported in a study conducted in Australia where use of head box was reported to be more stressful method than CPAP treatment (Foster et al., 2008).

In contrast, a study conducted in Australia, revealed that High Flow Nasal Prong Oxygen (HFNPO) was best for mothers than head box type of delivering oxygen to be used in their sick infants. This was because it was more conducive to parent - child interaction and decreased their anxiety than head box oxygen. The study also revealed that the mothers wanted to see, touch and talk to their children, so any machine that disturbed these, caused anxiety to parents (Peeler, 2011).

According to Brehaut et al. (2004), caregivers reported higher levels of stress/distress, depression, emotional problems, and cognitive problems compared to their non-caregiving counterparts. Literature review by Zarit (2006) on caregivers assessment suggest that between 40 to 70 percent of caregivers have clinically significant symptoms of depression, with approximately one-fourth to one-half of these caregivers meeting the diagnostic criteria for major depression. Comparable results were reported in Sweden on

mother's experience of having her baby admitted to a neonatal intensive care unit which was described as an 'emotional chaos' (Flacking et al., 2006).

Peeler (2011), therefore concluded that in order to reduce stress, enough information should be given to mothers caring for infants on any oxygen delivering method. Consequently, when information provided meets care givers needs, their stress is minimized (Punthmatharith, Buddharat, & Kamlangdee, 2007; Gale et al., 2004 ).

According to Johnson (2007), positive psychosocial support by nurses helped to facilitate mother infant attachment within the neonatal intensive care unit in Delaware, United States of America. In addition, nurses who provided support, assistance, privacy and had a positive and encouraging attitude towards mothers throughout their experiences helped to alleviate maternal anxiety. Furthermore, Johnston reported that mothers gained satisfaction and confidence from nurse who provided education, guidance, encouragement and emotional support throughout new experiences in the neonatal intensive care unit. Similarly, Mok & Leung (2006) in their study on nurses as providers of support for mothers of premature infants in Hong Kong found that nurses were of much help in providing support to mothers of premature infants.

In Sweden, a study of 25 mothers whose infants were admitted to neonatal units felt that they were 'encouraged and empowered' to participate in their infants cares by some nurses while feeling disempowered and unsupported by others. The study highlighted that nurses who were supportive and non judgmental were able to develop trustful staff- mother relationships. In addition, when mothers experienced trustful bonds with nurses their self esteem was enhanced. This study also highlighted that nurses have the authority to reject or include mothers and are crucial in assisting the mother to become involved and develop a

mother- infant bond (Flacking et al., 2006). Orapiriyakul et al. (2007) in a study to explore how mothers in Thailand develop maternal attachment to infants born preterm and requiring NICU hospitalization proposed that nurses need to work together with mothers to support their emotional grief and concern to help them work through the crisis situation and be facilitated in developing attachment to the baby

All these studies addressing psychological support of caregivers of infants on oxygen delivering methods have been done in high resource countries, where nurse –patient ratio is better than low resource African countries. If nurse-patient ratio is good, physical, spiritual, social and psychological care aspect of patient is well taken care of as compared to when nurse-patient ratio is high. In addition, most of the studies had general information not specific for psychological care of caregivers of infants on bCPAP. Thus, there is a need to investigate qualitatively psychological support caregivers receive during care of their infants on bCPAP at QECH in Malawi.

## **Conclusion**

In this literature review, few studies were identified that were relevant to the topic under study. Most information was general not specific to experiences of caregivers on use of bCPAP in infants. The studies provide information concerning different oxygen delivering methods. Most of studies were also done in high resource countries. Little is known about the topic worldwide and even in sub-Saharan, Africa. In Malawi, there are no published studies done so far to explore the experiences of caregivers who had cared for infants on bCPAP due to severe respiratory condition. Therefore, the literature has identified the gap that need to be filled by conducting a qualitative study on experiences of caregivers who had cared for infants on bCPAP at QECH.

## **CHAPTER 3**

### **Methodology**

#### **Introduction**

This chapter explains details of the study design; place; population; sample size and sampling methods; recruitment criteria; data collection procedure, data management, analysis and trustworthiness. Issues pertaining to pre-test, ethical considerations and dissemination of research findings will also be elaborated.

#### **Study design**

Descriptive qualitative design was used in this study to explore the experiences of caregivers of infants who were on bCPAP at QECH. Holloway (2005) explains that a qualitative approach is used to explore the behaviour, perspectives, feelings and experiences of people and what lies at the core of their lives. Therefore, the design was the best approach in this study since it assisted in exploring experiences of caregivers of infants on bCPAP.

#### **Study setting**

The study was conducted at QECH paediatric department; Chatinkha Nursery Ward (CNW) and Paediatric Nursery Ward (PNW) where sick infants with medical and surgical conditions are admitted. This is one of the central hospitals offering tertiary care, located in Blantyre district, in the southern region of Malawi. It is also a referral hospital for district hospitals, which offer secondary care in the southern region of Malawi, as well as health centres, which offer primary care, that are within the district. The hospital was chosen because infants who need bCPAP are admitted to the hospital's paediatric department; CNW and PNW. Apart from being a major teaching hospital for medical and nursing students from

various colleges, it is among the first hospitals to start implementing bCPAP therapy in Malawi.

### **Study population**

The study population was caregivers of infants who were on bCPAP at QECH paediatric ward, Chatinkha Nursery Ward (CNW) and Paediatric Nursery Ward (PNW). The caregivers who had spent time in hospital with sick infants, interacted with the health care workers and involved in care of their sick infants when on bCPAP were chosen. These caregivers were capable of providing rich information regarding their experiences when caring for their sick infants on bCPAP.

### **Inclusion and Exclusion Criteria**

Caregivers of infant (0-12 months) who were on bCPAP at CNW and PNW were invited to participate. The caregivers of infants, who had been weaned off from bCPAP (1-2 days post bCPAP) but still in the ward, were targeted. This enabled the researcher to reach them while still in the hospital. The data gave a description of their experiences regarding use of bCPAP in sick infants. Caregivers with infants currently on bCPAP were excluded as it was felt that participation for them could be too stressful and could not provide true information about their real experience.

### **Sample size**

The sample size was 12. Initially, it was anticipated that a sample size of 15 participants would achieve data saturation. However, in this study, there was saturation of data with 12 participants as there was repetition of the information and no new information could be obtained with further data collection. In qualitative studies, samples are typically small and based on information needs (Polit & Beck 2010). Whitehead and Annells (2007)

suggest that a common range in qualitative research is usually between eight and 15 participants but this can vary depending on data saturation. The small sample size is suitable because of the potentially detailed data that can be generated from each participant (Polit & Beck 2010). The sample size of 12 helped to gain detailed accounts of the responses concerning experiences of caregivers of infants who were on bCPAP. In addition, the sample of 12 participants was an ideal because of the in-depth nature of this study and the analysis of data required.

### **Sampling method**

Purposive sampling was used to select participants among those who met inclusion criteria. Parahoo (2006) explains purposive sampling as a method used in qualitative research. This involves the researcher intentionally selecting who to include in the study on the basis that those selected can present the required data. Purposive sampling was chosen because there was a need to have participants who were able to provide rich information pertaining to experiences in use of bCPAP on their infants. So, the caregivers who had actively been involved in caring of their infants on bCPAP were intentionally selected by the researcher as they were more likely to contribute appropriate data in terms of relevance and depth.

### **Data Collection Instrument**

In this study, semi-structured interview guide with open ended question was used (Appendix 5 & 6). The development of interview guide was guided by the study objectives and literature review on essential elements concerning experiences of caregivers of infants who have been on bCPAP. The main thematic areas were: experiences of caregivers of infants on bCPAP focusing on type of information given to caregivers by health care

workers, caregiver's perceptions on use of bCPAP and psychological care given by health care workers during care of their infants on bCPAP. In this study use of semi structured interview guide with open ended questions stimulated caregivers to give rich information about their experiences. In addition, Polit and Beck (2010), indicate that semi-structured interviews allow the researcher to have a framework in which open-ended questions are posed to encourage the participants to talk freely about their experiences.

### **Pre-test interviews**

The interview guide for data collection was pretested at QECH paediatric department in Paediatric Special Care Ward in order to assess the instrument for clarity of questions and to evaluate the content of the interview. The pre-test interview was conducted in January 2015 where 5 caregivers of infants who had been on bCPAP were interviewed. According to Polit and Beck (2010), the pre-test study improves study project since it assesses its feasibility, improves clarity, eradicates problems and refines methodology. This helped the researcher to become familiar with the questions and also to identify any gaps in the tool. The interview guide was then mended accordingly.

### **Data collection process**

After obtaining ethical and departmental approval, recruitment of participants was done in the wards mentioned above with the assistance from the unit matron and ward in charges. The participants were given detailed written information about the study (Appendix 1 & 2) and the consent form to read, understand and sign to indicate their willingness to participate (3 & 4). For those participants who could not read, the written information was explained to them. The participants who could not write, a thumb print was used as a

signature. The interviews were conducted in Chichewa (Malawi national language) to allow the participants understand and be able to share and express their experiences freely.

The place for the interview was agreed upon with the participants in order to maintain confidentiality and anonymity. Time for the interview was also considered in order to avoid any inconveniences such as child missing drugs in the ward. Each interview lasted approximately 40 minutes to one hour. The in-depth interviews (IDI's) were recorded using audio-digital recorder. This assisted in capturing the experiences of caregivers in their own words and to increase confirmability of the data. It also assisted the interviewer to maintain eye contact which is an important listening skill in an interview.

### **Data Analysis**

In qualitative studies, significance of data analysis is to discover themes and links among the themes (Polit & Beck, 2010). After the interviews, the researcher used Colaizzi's (1987) seven steps framework to analyze the data. The steps are reviewing the data, extracting significant statements, spelling out of the meaning of each significant statement, organizing the formulated meanings into the cluster of themes, integrating results into an exhaustive description of the phenomenon under study, extraction of fundamental structures and member checking.

#### **Stage 1: Reviewing the raw data.**

The researcher listened to audio-taped information soon after each interview to verify if important information had been captured. Then the audio taped data were transcribed verbatim manually soon after each interview. As interviews were done in Chichewa, they were translated to English. An independent person was used to translate the

English version back to Chichewa version to make sure that the exact words of participants were used.

### **Stage 2: Extracting significant statements.**

The transcripts were read several times to extract words and sentences relating to experiences of caregivers of infants who were on bCPAP at QECH. A highlighter pen was used to identify significant words and phrases. A total of 50 significant statements were identified.

### **Stage 3: Spelling out the meaning from extracted statements.**

The highlighted significant statements were then physically cut and sorted into groups of similar ideas that were pasted together to begin formulation of meanings. Thirty two formulated meanings were identified.

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

In this step, the researcher organized formulated meanings into clusters of themes concerning information, perception and psychological support according to research objectives.

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

In this step, the results were integrated into an exhaustive description of the topic being studied. The themes comprised of formulated meanings relating to information source, time, significance; feelings, impression about bCPAP, benefits of bCPAP; sources of psychological support, stress and parental involvement.

### **Stage 6: Identifying fundamental structures.**

The exhaustive description was then reduced to an essential structure which ended up into three themes which are; information given to caregivers, perception about bCPAP and the psychological support to caregivers. The researcher again referred back to the transcripts to find words that the participants had used during their descriptions which best fit the themes and incorporated them as quotations in the write up

### **Stage 7: Member checking.**

This stage aimed at validating the findings using member checking technique. This stage required the researcher to go back to the participants to verify the data. After analysis, the researcher went back to participants after 2 to 3 days to verify the data and managed to find 10 participants who were still in hospital by then. The participants verified that it was the information that they had given during first interview.

### **Data Management**

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

### **Trustworthiness of the study**

Munhall (2007) defined trustworthiness as the degree to which the participants have been fully included in the research process and have had the opportunity to reflect and comment on their story and retold by the narrative researcher. The researcher proposes to use a framework by Lincoln and Guba (1985) to increase the trustworthiness of this study (Polit & Beck, 2010). According to Polit and Beck, this framework encompasses four

criteria for developing trustworthiness of a qualitative study, which include credibility, dependability, confirmability and transferability.

**Credibility.**

Credibility refers to confidence in the truth of the data and interpretations of them (Polit & Beck, 2010). The researcher used probes to ensure that participants were encouraged to give detailed information. Member checking was also done with the participants by the researcher to validate information provided by the participants to ensure that there was no misunderstanding and misinterpretation of the information the participants gave. Participants were also given a chance to participate or refuse to participate in order to ensure that data collection involves only those who were genuinely willing to participate and prepared to answer questions freely and honestly.

**Dependability.**

To achieve dependability of the data, the researcher reported in details all processes within the study to allow other researchers to repeat the work and produce similar results. These processes include; the research methods, detailed collection of data and analysis of the study. The researcher had a log book of the steps and the decisions (including rationale for decisions) that the researcher had followed during the project, from the start of research project to reporting of the findings which are called audit and decision trails. The written report will also provide thorough understanding of the methods employed in the study.

**Confirmability.**

In this study, confirmability was achieved by recording all the words spoken by participants and the researcher during in-depth interview in order to distinguish the

participant's data from interviewer's view. The researcher acted as an active listener and facilitator to allow participants to give detailed information of their experience.

### **Transferability.**

Transferability describes how the results will be applicable and meaningful to individuals not involved in the research (Speziale & Carpenter, 2007). In this study, transferability was ensured by providing sufficient descriptive data in the research report so that anyone who wants to use it can evaluate the applicability of the data to other or similar contexts. The thick description of the phenomenon under investigation was also provided to enable someone interested in using the results to reach a conclusion.

### **Plan for Dissemination of Study Findings**

Study findings will be presented to academic staff at Kamuzu College of Nursing (KCN) during research seminars and QECH paediatric department during Journal club and Continuous Professional Development (CPD) meetings in addition to a written report. A copy of the thesis will be placed in KCN library. Other copies will be sent to Ministry of Health and QECH paediatric department. The results will be published in Nursing and Midwifery Journals. In addition, the results will be disseminated at conferences both locally as well as internationally.

### **Ethical Consideration**

Research proposal was submitted to College of Medicine Research and Ethical Committee (COMREC) for approval (Appendix 7). After approval, permission was sought from QECH and Paediatric department to pretest and conduct the study at the hospital (Appendix 8 & 9). Information about the study was given to the participants. Participants were asked to sign a written informed consent prior to participation in agreement to their

willingness to participate. The consent form (Appendix 3 & 4) contained information on the purpose, benefits, and risks of the study. Participants were informed of their right to refuse or withdraw at any point of the study and that no penalty was to be granted upon such a decision.

Participants were duly informed that there were no monetary and other benefits for taking part in the study but that their information will contribute to quality of bCPAP care for infants in the hospitals. Participants were also assured that their identification will not be known on publication or presentation of the findings. Furthermore, participants were informed that the study did not have any foreseeable physical harm (risks) to the respondents. However in cases of any emotional or psychological harm; participants were informed to forward their complaints and concern to the chairperson, COMREC secretariat at College of Medicine.

## **CHAPTER 4**

### **Presentation of Study Findings**

#### **Introduction**

This chapter presents the results of the study whose aim was to explore experiences of caregivers of infants who were on bubble Continuous Positive Airway pressure (bCPAP) at Queen Elizabeth Central Hospital in Blantyre. The results are presented in two sections; demographic characteristics of participants and qualitative results that contain the experiences of caregivers of infants who were on bCPAP. The qualitative results are presented under the following predetermined themes; information about bCPAP, Perception of caregivers about bCPAP and psychological support from health care workers. The verbatim quotes from the interviews will be provided where applicable in qualitative results to illustrate important points on the caregiver's experiences.

#### **Demographic characteristics of Participants**

All participants in this study had their infants on bCPAP for different periods of times ranging from 1 to 10 days. The ages of participants ranged from 18-38 years with the mean age of 26 years. The majority of participants were in the age group of 18-23 years, while few were in age group of 24-29 and 30-35 years. Only one participant was in age group of 36-41 years. Table 1 presents the age range of participants.

Table 1: Age groups of participants (n=12)

Age group in years	frequency
18-23	5
24-29	2
30-35	4
36-41	1

All participants were mothers of children who were on bCPAP. The marital status of the participants showed that the majority (9) were married, while (2) were single and only (1) had been separated from her husband. Regarding occupation, (5) were house wives, other (5) were doing small scale businesses, one had formal employment as secondary school teacher and only one participant was a school- going adolescent. On religion, majority of participants were Christians belonging to different denominations with few Moslems. All participants had some schooling; Majority of participants (9) involved in this study attended primary school level with only 3 who completed this level. Two of the participants had completed secondary school level (form 4) while one completed tertiary school level (graduate).

The age range of infants who were on bCPAP was from 5 days to 5 months of age. The majority of infants (7) were in the age group of 0 to 1 month old while (5) in age group

of 4 to 5 months old. The length of stay of these infants in hospital ranged from 2 to 14 days. The mean length of stay was 7 days. The majority of infants (8) were boys with only (4) girls. Regarding mode of delivery, majority of infants (8) were born through normal spontaneous vertex delivery with only (4) born through caesarian section. Majority of infants (6) were admitted due to prematurity while (3) had pneumonia. The least (3) had other causes of admission.

**Qualitative Findings**

The main objective of this study was to explore the experiences of caregivers of infants who had been on bCPAP. Data was collected using one to one in-depth interviews on 12 mothers. The caregivers of infants who were on bCPAP were asked about their experiences regarding the type of information received about bCPAP, their perception about bCPAP and the psychological support. The predetermined themes used during analysis were information given to caregivers about bCPAP, perception about bCPAP and psychological support. Table 2 divides the themes into subthemes and formulated meanings.

Table 2: Themes, subthemes and formulated meanings

Themes	Subthemes	Formulated
meanings		
Information given to caregivers	Knowledge about bCPAP	Name, Function,  Description of bCPAP
	Type of information	Infant feeding, Infant care and reason
		Disease condition
	Sources of information	Doctors, nurses,

		Students
	Time information given	
Before bCPAP		After bCPAP
	Significance of information	understand
bCPAP		Acceptability
Perception about bCPAP anxious	Feelings about bCPAP	Fear, crying,  Frightened, worried Fear of death, Hurt child, disappointed
	Positive impression about bCPAP	Good treatment
	Benefits of bCPAP	Good outcome
Psychological support	Sources of psychological stress	bCPAP machine  Parent-child interaction
providers	Sources of psychological support	Health care

influence		Family members
		Friends
		Religious
	Parental involvement	parental roles
		Role significance

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### **Information given to caregivers about bCPAP**

Subthemes that emerged from this theme were; knowledge about bCPAP, type of Information, Sources of information, time information was given and significance of information.

#### **Knowledge about bCPAP.**

The results showed that a lot of participants knew about bCPAP as treatment that provides extra oxygen to infants who are in severe respiratory distress after their infants were given bCPAP during their admission. One of the participants who attended tertially school level tried to give comprehensive difference between bCPAP and oxygen therapy via nasal prongs.

The participant explained:

I think it is the kind of treatment that is provided to babies who have developed the problems with breathing, it is beyond oxygen [nasal prong oxygen], yes, merely oxygen is too small and it should be beyond oxygen. That means that the baby is critically ill, that is my understanding. (Participant # 11)

Few participants reported that they did not know anything about bCPAP despite their infants being given bCPAP during their admission. However, all participants had no prior knowledge before their infants were admitted at the hospital and were given bCPAP. One of participants narrated this:

For me it was my first time to come here at Queen Elizabeth Central hospital and it was my first time to see this treatment they gave to my infant [referring to bCPAP]. So I just saw them on my child. There was nothing that really came out of mind as I knew I was here to receive treatment for my child so I just accepted it. (Participant # 10)

The knowledge that the participants narrated included the description of the bCPAP machine and the reasons why their infants were put on bCPAP. All participants were unable to name the machine except one participant who named it as CPAP, the rest were just giving general descriptions. One participant described: “Its oxygen, it was like a car that produced sound [bCPAP]. It also had lights. It also produces warmed air. It had tubes big in size, but it was able to fit in each nose” (Participant # 4).

The other participant added as follows:

At first they put oxygen with big tubes in the nose secured by the hat they put on the head [bCPAP]. I don’t know what type of gas it was as it was my first time to see this type of machine. (Participant # 5)

A lot of participants were able to explain the reasons why their infants were on bCPAP. Only one participant was unable to narrate the reason why her infant was put on

bCPAP. Upon probing, the participant said, no one said anything to her. She did not even ask any question to the health care providers as she was failing to cope with child's condition and the bCPAP treatment. She also came alone and there was no one to support her. One participant narrated a contrary reason why the infants are put on bCPAP. The participant said: "they said if they administer this [bCPAP], the baby will be like he is in the abdomen of its mother as he is not yet born, so that he should be feeling warm " (Participant # 2).

### **Type of Information given to the mother.**

The results have shown that there were different types of information narrated by the participants. A lot of participants reported that, they were told the reason why they wanted to put the infant on bCPAP. One of the reasons was the infant who was having difficulties in breathing. One of participants explained that they said that: "we want to administer this oxygen therapy [bCPAP] to the child because of her condition; she is having difficulties in breathing. So we must administer this oxygen therapy that is what I was told" (Participant # 6).

Another participant added as follows:

At first, I was asked if I would agree to have my child put on oxygen with big tubes [bCPAP]. But with the condition of my child, I could not have said no as I wanted my child to be fine. I just said yes. After sometime, he came again and started explaining to me that it was oxygen [bCPAP] because the child had stopped breathing.

Then after sometime, a white doctor [referring to foreign American doctor] came around and removed the oxygen [bCPAP] and put on a small one [nasal prong oxygen]. When I asked again he said that the breathing pattern had improved. (Participant # 5)

The other type of information that was given to the caregivers was about feeding the infants while on bCPAP. Few participants narrated that the type of information that was given was about how to feed the baby which was given after they had already administered bCPAP. They were told how to feed the baby while on bCPAP through the tube. Surprisingly, one participant reported that there was no information given to her concerning the infant's condition or about bCPAP. The participant said: "I was not told anything else. May be they had informed me but I do not think so" (Participant # 7).

### **Sources of information.**

The results showed that the participants got information from nurses or doctors. However, a lot of participants were unable to differentiate between a doctor and a nurse. Some of participants were referring to nurses or student nurses as doctors. Among the participants who were able to differentiate, a few got information from the doctors and only one got information from a nurse. One of the participants who got information from a doctor said that doctors were willing to give the information and give comprehensive information other than nurses who just shout at people because they do not know. The participants also said doctors are more approachable than nurses. Another participant who got information from a student nurse said that, she was the one who was open to her as she was able to answer her questions and assist her when approached. There was also one participant who

said she did not get any information from anyone. Regarding differences between doctors and nurses, a participant said: “It was a doctor; everybody calls him the ‘In-charge’ [referring to male nurse]. He always puts on green top and put on glasses they call him In-charge” (Participant # 5). Another participant said:

“It was a nurse; he puts on maroon top and green pair of trouser especially during the night. I also differentiate nurses from doctors in the way that nurses are females while doctors are males” (Participant # 8).

One participant narrated that she got comprehensive information from the white doctor [referring to foreign American doctor]. The participant said: “The white doctor [referring to foreign American doctor] explained to me that the breathing pattern of my child had improved so that they might change to smaller oxygen [nasal prong oxygen]” (Participant # 5).

One participant got a lot of information from the student nurse although she was referring to her as a doctor. The participant explained that she was unable to differentiate among nurses, doctors and student nurses as they look the same and all put on white uniform. Among the participants who were able to differentiate between the doctor and nurses, one participant narrated that she liked the way the doctors explains the information to her than nurses. The participant narrated:

I asked one nurse how much milk to give to my baby and she answered me rudely. She shouted at me ‘why did you not ask those who were there? Have you ever seen me before?’ I did not like it but I interpreted that she did not know what to tell me. Then the following day I met a doctor and I asked him, he explained to me, he asked

me how many kilograms the baby weighed, and I answered him, then he made his calculations and he advised me to give the baby 30 milliliters of milk. (Participant # 11)

However, despite that other participants liked the way doctors narrated the information; one participant liked the way the nurse narrated information to her. The participant explained:

There was one nurse who explained to me when I asked her why my child was breathing like that. She told me that it might be due to problem of the lungs which are not mature due to prematurity. She reassured me not to worry as my child will be fine. I liked that nurse very much. (Participant # 8)

**Time information given.**

The results showed that the information was given at different times depending on the ward. A lot of participants from paediatric nursery ward and few participants from Chatinkha nursery ward were given the information about bCPAP before they commenced it on their infants. However, few participants from Chatinkha nursery expressed a concern that they just found their infants already put on bCPAP when they went to breastfeed the infants. The participants also explained that the information about bCPAP was narrated to them after health care workers had already put their infants on bCPAP. One of participants explained:

I was not there when they commenced this oxygen [bCPAP] on my child, I found my child already on oxygen [bCPAP]. I did not feel good. When I asked, I was told that they have commenced it because the oxygen was not enough in the baby. (Participant # 8)

Another participant added this:

When I was going to breastfeed the baby, usually it is after 3 hours, I found the baby already on that thing [bCPAP]. When I went today, I found my child on another side of the ward and was put on the machine [bCPAP]. When I asked, they said the infant was having difficulties in breathing that is why they put him on it [bCPAP].  
(Participant # 3)

### **Significance of information.**

A lot of participants acknowledged that the information was helpful to understand their infant's condition and helped them to understand about bCPAP. One participant explained that the information helped her to know that her child had difficulties in breathing. Among the participants who were told about bCPAP before commencement on their child, few participants explained that they were helped with the information to accept the treatment. For these participants, the doctors influenced them a lot to accept the treatment because of the information they gave them. One of the participants said: "I accepted because the doctors told me that in order for the child to get well, the child needed to be treated with this type of oxygen [bCPAP]" (Participant # 6).

Few participants narrated that their acceptability to bCPAP was not linked to the information given by doctors or nurses before commencement of bCPAP as they already found their infants on bCPAP. They just accepted it because it was already put on the baby. One participant said that she already found her child on bCPAP so she just accepted it. Other few participants accepted bCPAP as part of treatment that will help the baby to be fine. They were influenced by the condition of the child as they wanted their infants to be fine. One

participant explained: “I accepted it as treatment so that my child should have life” (Participant # 10).

### **Perception about bCPAP**

Subthemes that emerged from this theme were; feelings about bCPAP, positive impression about bCPAP (satisfaction) and benefit of bCPAP.

#### **Feelings about bCPAP.**

The results showed that participants had different feelings and reactions about bCPAP when they saw it for the first time. Most of the participants reported that, they had fear when they saw their infants on bCPAP. The participants feared that their children may die on bCPAP or may be hurt by the bCPAP machine. The other few participants had different feelings such as broken heartedness, worry, disappointment, and anxiety and others were just crying. One participant explained: “I was worried to see them put the child on this oxygen [bCPAP]. I asked myself why they are placing my child on this type of oxygen [bCPAP]” (Participant # 5). Another participant added: “At first I was anxious because some people say that when a child is given oxygen therapy, he/she does not survive, but I just accepted whatever was to happen that was it” (Participant # 6).

According to the results, the common source of fear among the participants were; presence of bCPAP tubings, the big size of tubes, bleeding in the nose as a complication and strange sound produced by the machine. One participant narrated:

I was worried with the big tubes [bCPAP] because the tubes were big and also it was using electricity. The small tube[nasal prong oxygen] does not use electricity; there is something inside like a ruler which shows that it is working but not making noise

like that machine [bCPAP] produces. The sound disturbed me as I was thinking that my child might have died while on the machine [bCPAP]. (Participant # 5)

Another participant also added on this:

I was worried because the tubes were big in the nose, at the same time my child had difficulties in breathing. So I was wondering how it will assist my child and how the child is going to breathe. (Participant # 10)

**Positive impression about bCPAP (satisfaction).**

The results show that all participants were satisfied with bCPAP treatment as their children improved greatly after bCPAP. For them they perceived bCPAP as good treatment depending on treatment outcome which was positive in all children. One of participants narrated: “For me I cannot call this thing [bCPAP] bad treatment because I have seen how it has worked on my child who is well now.” (Participant # 5).

Another participant added:

It is a good treatment and I’m happy because my child has been removed from it [bCPAP] and is still alive. Sometimes you have the fear that my child is not going to be fine because other children die on that type of oxygen therapy [bCPAP]. But I thank God because by His grace, I have seen my child getting out of it alive. (Participant # 4)

### **Benefits of bCPAP.**

All participants expressed gratitude on how bCPAP treatment had helped their infants who were very sick. All participants concluded that bCPAP is effective treatment for infants who are in severe respiratory distress. One participant narrated:

The treatment is very effective because my baby's condition has improved; she had oxygen saturation of seventy two and now is ninety something. I told one of the student nurses in the morning to check the oxygen saturation; it was ninety three going up to ninety six. (Participant # 11)

The participant further expressed a need for government to buy and place the bCPAP machines in all hospitals in order for babies to survive. Other few participants perceived bCPAP as bad treatment at first but after having seen the treatment outcome for the infants; they concluded that it is good treatment. In addition, other few participants had a misconception about oxygen delivering machine (nasal prong and bCPAP) that it kills. However, upon having their infant on bCPAP, their misconceptions were cleared. One participant further commended herself for bringing the child to hospital to receive bCPAP treatment that had made her child well. One participant said: "Initially, I felt that this treatment [bCPAP] is not good and I was afraid. But now I can see it as a good treatment as my child has improved on it [bCPAP]" (Participant # 9).

Another participant added this:

People said oxygen is bad because oxygen kills children; that is what I heard from people. This gave me fears and worries. As such, I was asking myself if my child is

going to survive on this type of oxygen [bCPAP]. But my child is fine, I thank God for this. (Participant # 5)

## **Psychological Support**

The results showed that a lot of participants were psychologically affected with bCPAP treatment. As such different psychological supports were a source of strength to them. Subthemes that emerged from this theme were; Sources of psychological stress, Sources of psychological support and parent involvement in the care.

### **Sources of psychological stress.**

The two main sources of psychological stress under this sub-theme include parent-infant interaction and the bCPAP machine.

#### ***Parent-infant interaction.***

The results showed that, the participants were worried as bCPAP treatment disturbed the relationship with their sick infant. All participants expressed concerns that they were not able to interact well with their infants. When the infants were on bCPAP, parents expressed that they failed to carry their infants out of the baby cots onto their lap fearing tubes might come out. They also complained that, their infants were not being breastfed as they were feeding through the tube when on bCPAP. One participant narrated this:

It was very difficult for me to interact with my child. I remember one day I carried my child out of the cot then the oxygen tubes came off the nose then the nurse shouted at me. The nurse said, ‘we do not carry the child while on this type of machine [bCPAP]. We just feed them while they are there.’ When she told me I stopped carrying my child I was just feeding her while she was in the baby cot. (Participant # 4)

Another participant added:

I did not feel good. I just wished I could carry my baby in my arms and breastfeed her but this was impossible because of this type of oxygen therapy [bCPAP]. I was failing to carry the child because of these tubes. When I wanted to change the nappy, I changed her when she was in the baby cot. There was a tube in the mouth which I used to give the milk. (Participant # 8)

Another participant also added this:

A relationship with my baby was there but not sufficient. It's because of fear that if I touched the child the tubes might come out. Because of the tubings, you cannot hold the baby and you cannot take care of him properly, of course you can touch. (Participant # 3)

In addition participants from Chatinkha nursery complained that despite bCPAP, the policy of visiting their infants every 3 hours also complicated their interaction with their sick infants. One of the participants narrated:

It affects me. I would love to be together with that baby, to see him every time, even when sleeping we should sleep together. But this idea of sleeping somewhere and the baby also somewhere affects me psychologically to say the truth, but what else can I do. (Participant # 1)

Another participant added this:

What I would like is at least if the baby can gain some weight because the doctors said that if he gains weight, they can transfer me to Kangaroo mother care unit where

I can stay close with my child. I wish this will happen very fast so that I can see him close. (Participant # 2)

### ***The bCPAP machine.***

The bCPAP machine was also a major source of stress to the participants as it disturbed their interaction with the infant. The machine was also a source of fear to the participants. Some participants also associated the presence of their infant on bCPAP to critical illness and death. This also gave them stress during hospitalization of their infants. One participant narrated:

“Sometimes you fear that the child is not going to be fine because other children die on that oxygen [bCPAP]. But I thank God because by His grace, I have seen my child getting out of it alive” (Participant # 4).

A lot of participants complained of the presence of the tubes which disturbed the interaction with their baby as it was difficult to carry the infant out of the baby cot. Few were under stress from the sound and lights that the bCPAP machine was producing. Some participants also complained of the size of the tubes and how the tubes were fit in the nose as they thought their infants were hurt a lot by them. There was also one participant who was worried after seeing her baby bleeding in the nose while on bCPAP.

The participant said:

I just saw blood in the nose of my infant when I went to see her. Then I wiped properly. I just thought may be the time they were moving my child, they also moved the tubes that caused bleeding. (Participant # 8)

One participant also narrated her concern with bCPAP machine and said: “It was the big tubes in the nose which blocked my child’s nostrils. The machine also produced strange sounds. I was just worried that my child will not be fine” (Participant # 8).

Another participant said:

I was not able to carry him properly; they said that if I carry him maybe those tubes will get out, so the best way is to do everything right there, but when he grows up a little bit then we will start moving him. (Participant # 2)

### **Sources of psychological support.**

The results showed that the participants had different sources of psychological support. These sources include health care providers, family members (partner, mother and sister), friends in the hospital and religious influence.

#### ***Support from Health care providers.***

According to results, the health care providers played different roles in supporting the participants while on bCPAP; routine care of the infants like giving medication, monitoring the infants while on bCPAP if the tubes are in place and inserting feeding tubes. On monitoring the infants on bCPAP, one participant narrated this:

The nurses come frequently to see the child and to assess on how it [bCPAP] is functioning. Because other children may bleed from nose when put on it [bCPAP]. So nurses were coming frequently to observe how the children were adapting to the oxygen [bCPAP]. (Participant # 4)

Regarding psychological support, some participants acknowledged the encouragement and reassurance they received from health care providers as important to them while they were caring for their sick infants on bCPAP. One participant also said that after the health care provider explained about the condition of the baby and plan of treatment, she was able to understand the treatment better. Another participant acknowledged that she was able to ask questions and was answered properly by the health care providers. One participant narrated how the health care provider reassured and encouraged her and she said: “the health care provider reassured me that I should just leave everything in hands of God Almighty and that I should not cry because the child will be fine” (Participant # 9). Another participant added that: “the nurses have played a great role .....about the worries, they were just encouraging me that I should not worry the child will be fine with the treatment [bCPAP] he is receiving” (Participant # 5).

Among the health care providers that gave encouragement, one participant acknowledged the encouragement she received from one of the student nurses whom she was calling a doctor. Despite other participants’ acknowledging the encouragement and reassurance received from health care providers, one participant complained about the mood of nurses, that sometimes they look unapproachable. The participant said: “When the child removed the tubes, the nurses would come to fix them, they were supportive. Even though sometimes, it becomes difficult to approach them. It really depends on their mood on that day” (Participant # 11).

However, one participant expressed the concern that she did not receive any encouragement or reassurance from health care providers the time she was crying in front of them because of her child's condition.

***Support from family members.***

The results showed that despite health care providers' psychological support, some participants valued family members as major source of support. The family involvement in the care of infants was beneficial to some participants to deal with stress they had about bCPAP. The family members that took part in encouraging and reassuring the caregivers included the mothers, partners (husbands) and sisters. One participant said:

I shared my fears about treatment [bCPAP] with my mother and my husband. My mother said that I should put everything in God's hands as He makes a way where there may seem to be no way. While my husband said that I should not worry because the fact that the child is on this treatment [bCPAP] it means the doctors want the child to be well. (Participant # 4)

***Support from friends in the hospital.***

Few participants were relieved from stress they had about their infant being on bCPAP through encouragement by their friends. They were encouraged by their friends in the hospital whose infants had also received bCPAP and they were fine by then. The participants reported that when they heard from these mothers and saw how their infants were looking at that time, they were less anxious. This also gave them hope that their infants will also improve after bCPAP. One participant narrated: "I met another woman who had a child on the same machine [bCPAP] and by that time her child was well. She reassured me

that her child was also on the same treatment [bCPAP] and has improved” (Participant # 12).

### ***Religious influence.***

The results show that, there was one participant who got support through her faith in God. The participant explained that she depends on prayer as she knows that there is power in prayer. The participant said: “I did not verbalize my fears and worries to health care workers, because I had time to pray on my own as I know there is power in prayer. When I prayed, I felt relieved” (Participant # 5).

### **Parental involvement in the care.**

Parental involvement is one of the psychological supports that the participants appreciated while caring for their infants on bCPAP. The participants felt happy when they participated in the care of their infants. In this subtheme, two areas come out as parental roles and role significance

### ***Parental roles.***

All participants narrated different roles they played when caring for their infants while on bCPAP. The participants mentioned breastfeeding and changing nappies as important roles they played when their infants were on bCPAP. The participants explained that, they were able to express milk and give their babies through the feeding tube when the babies were on bCPAP. The other roles that participants performed were: cleaning the infant, turning the baby and doing tepid sponging if applicable. Some participants also reported that they were able to hold the baby if bored, calm him when crying and also chat with the baby. Few participants reported that they were ensuring that the bCPAP machine was functioning properly. They did this by checking if the tubes were in place, notifying the nurses if tubes

were out of place or if water stopped bubbling. One participant said: “When water stops bubbling, I was struggling with it, fixing it, and then later I would notify the doctors to fix it” (Participant # 7).

Another participant added this:

When the infant was on the machine [bCPAP], he would remove the tubes while crying or fighting the tubes out, I would then notify the nurses and doctors that the baby has removed the tubes and they could come and fix them. (Participant # 2)

### ***Role Significance.***

Majority of participants were happy to be involved in the care of their infants when they were on bCPAP. Some participants felt that it was important for them to be involved so that their infants must also be helped. The participants were also less anxious when they came near their babies while doing some roles. The participants also kept an eye on their infants while on bCPAP and notified the health care providers.

### **Conclusion**

This chapter presented the study findings according to 3 major themes. The themes include; information about bCPAP, perception of caregivers about bCPAP and the psychological support from health care workers.

## **CHAPTER 5**

### **Discussion**

#### **Introduction**

This chapter presents a discussion of findings of the study which aimed at exploring the experiences of caregivers of infants who were on bubble Continuous Positive Airway pressure (bCPAP) at Queen Elizabeth Central Hospital in Blantyre. The discussion is mainly focusing on the information given to caregivers about bCPAP, perceptions of caregivers about bCPAP and psychological support offered to caregivers. The recommendations, areas for further research and limitations of the study are also presented in this chapter.

#### **Information given to caregivers about bCPAP**

Caregivers in this study had no prior knowledge about bCPAP until their infants were put on bCPAP. This was in line with systematic review by Verhaeghe et al. (2005) where family members showed a need to have a better explanation about the care, the unit, the equipment and what they could do for their patients as most of them were not knowledgeable enough on hospital care. Assessing prior knowledge also assist health care providers in planning for educational needs of caregivers for them to understand well about the treatment. In addition, it is important to develop trusting relationship with families from the beginning and ensure that they have access to continuous information as research has shown that when information meets parents needs, their stress is minimized (Cockcroft, 2012; Punthmatharith, Buddharat, & Kamlangdee, 2007).

The caregivers in this study were able to describe bCPAP machine according to its appearance. The reason why their infants were put on bCPAP was also narrated by most of

the caregivers. However, some caregivers were unable to name the bCPAP machine except one, who had tertiary education level. Other caregivers were unable to describe anything about bCPAP despite their infants being on it. The failing of caregivers to name the machine or describe anything about bCPAP can be associated with type of information narrated to them by health care providers or level of understanding of the caregivers. Similarly, in Canada, Gulati et al. (2012) also found that immigrant parents of children with cancer had difficulties in understanding health information about cancer due to communication and language challenges. In a similar study, they found that parents preferred health care providers to use simple language to explain complex medical issues. Furthermore Schwartzberg, VanGeest, Wang et al. (2005 ) alluded that limitation in literacy skills affect how a parent describes her child's symptoms, understands and remembers information or participates in medical decision. Most of the caregivers in this study attained primary school level which may also explain the reason why they were unable to name or describe anything about bCPAP. Education level of women is important as it enables them to understand health information better. When women understand, they are in a better position to comply with health care provider's instructions. In addition, this study has also revealed that women with better education are in a position to demand better services as well as understand health information better than their counterparts with low education. It is therefore important for health care providers to evaluate caregiver's level of education when planning and giving information to promote understanding. Furthermore, it might happen that due to fears that caregivers had about bCPAP treatment they were unable to remember the information that they were given. Similarly, Reid, Bramwell, Booth, and Weindling (2007) in United Kingdom assert that under stress parents are not able to remember most conversational

interactions. As such Jones, Woodhouse, and Rowe (2007) highlighted the importance of reinforcing and repeating information and allow time for parents to ask questions to clarify their understanding.

The caregivers described different types of information given to them by health care providers. The information included; reason why their infants were on bCPAP and how to feed their infants while on bCPAP. Another caregiver complained that no information concerning bCPAP treatment was given to her. The study findings showed that different types and inadequate information were given to caregivers. This might be due to shortage of nurses, congestion and increased workload in the wards (Schell et al., 2011). The findings are also in line with studies in Canada, California, Greece and Denmark which found that parents of infants admitted to Neonatal Intensive Care Unit (NICU) and paediatric units face challenges including access to information, disclosure about the diagnosis, and treatment and prognosis of their newborn/infants, as well as a lack of control over the care of their newborn/infants (Ertmann, Reventlow & Söderström, 2011; Matziou et al., 2011; Hinkson, Atenafu & Kennedy, 2006; Charchuk and Simpson, 2005). However, Soderback & Christenson (2008) point out that if communication is inadequate it can compromise compliance to treatment. In addition, they suggested that communicating health information between children, caregivers and health care providers should be considered as an aspect of paramount importance irrespective of cultural circumstances. Therefore, it is recommended that the information given to caregivers of sick children should include information concerning the child's illness, medical treatment, nursing care provided, purpose and side effects of drugs, outcome and prognosis. Verhaeghe et al. (2005) further alluded that information which is accurate, complete and comprehensive helps to relieve negative

feelings and facilitates the understanding and development of realistic hope among family members which was not reflected much in this current study. This was also demonstrated in a study by Hendricks (2010) in South Africa who found that parents who were well communicated about CPAP that was given to their infants had minimized stress and no emotional anxiety compared to those who were not communicated to.

In addition to obtaining informed consent before subjecting a patient to any procedure or treatment except in emergency conditions, it is important to provide adequate information and educate the patient/guardians about realities (Rao, 2008) . In this study, the information given to caregivers was inadequate and was given at different times depending on the ward. Caregivers from paediatric nursery ward got information before commencement of bCPAP while caregivers from Chatinkha nursery got information after bCPAP was already commenced on their infant. In Chatinkha nursery ward, caregivers stay on a different ward and visit their children every 3 hours. So when a neonate's condition changes health care workers just implement procedures with the aim of saving life while Paediatric nursery ward caregivers are always available. These findings are not in line with recommendations by Rao (2008) that informed consent must be preceded by disclosure of sufficient information which include diagnosis, recommended treatment, expected benefits, side effects, complications, alternative treatment and even anticipated recovery implications before any treatment or procedure. In this study, the caregivers who found their infants already commenced on bCPAP before informing them were more stressed than their counterparts who were given some information before commencement. As such, it is the responsibility of the health care providers to provide adequate information before any

treatment to allow the caregivers make informed decision about the care of their infant and this reduces stress.

The findings in this study indicated that there was no standardized information to be communicated to caregivers caring for infants on bCPAP. Use of standardized information when communicating about treatment plan reduces variation in the treatment of patients, improves the quality of care, prevents errors of omission, misinterpretation, saves time and reduces redundancies in care (Leonard, Graham, & Bonacum, 2004). This suggests that, there is a need to have standardized information to communicate to caregivers not only to assist them to understand about bCPAP but also for uniformity. Studies are needed to evaluate the type of information needed to be given to caregivers in order for them to understand bCPAP treatment.

In the study, caregivers got information from either a doctor or a nurse. However, there was a challenge among the caregivers to differentiate between a nurse and a doctor. The caregivers also failed to differentiate between student nurses and qualified nurses. The reason could be level of understanding among the participants as most of participants had low education level. The other possibility could be that health care providers do not introduce themselves to caregivers when caring for their infants and do not wear identities such as prescribed uniforms and identity cards for identification. Slade et al. (2015) in Hong Kong having followed patient journey through accidents and emergency department with the aim of assessing effective health care worker patient communication, found that no health care worker who had contact with the patient introduced him/herself and described their role to the patient. As such, they recommended that communication strategies which balance the communication of medical knowledge with interpersonal communication are

essential features of effective health care worker-patient interaction. They further reported that, in turn, optimal patient health outcomes, including satisfaction, understanding of treatment, positive engagement and adherence with their health care workers' treatment recommendations are achieved. In a study by Skorupski and Rea (2006), the patient and their families discussed being confused when nurses did not wear identifying clothing. As such, uniforms are important to patients or caregivers to identify health care providers when receiving care.

Among the caregivers who were able to differentiate between a nurse and a doctor, they were pleased in the way doctors narrated information compared to nurses. When parents ask questions relating to their baby, they feel assured in the competency of staff when information has been passed on correctly (Cockcroft, 2012). Cockcroft further reported that, when information is not shared effectively, parents can lose trust and partnership breaks down.

Further analysis of the findings revealed that White doctors were also preferred in information giving to caregivers. The white doctors were preferred in this study in giving information as they are used to giving a lot of information in their countries during consultations. Gordon, Street, Shard, and Slouched (2006) in USA; Schouten and Meeuwesen, (2006) in Netherlands found that black patients received less information from their doctors as they were less active than white patients who got a lot of information from their doctors as they are more active. The reason for black patients to have less information is because they are less often engaged in communication behaviours (asking questions, sharing concerns and assertions) that typically elicit more information from doctors. In addition the studies have also shown that black patients were somewhat less likely to have

education beyond high school as compared to white patients which can be also a contributing factor for them not to actively participate in their care during consultation with a doctor or health care provider (Gordon et al., 2006 ;Schouten & Meeuwesen, 2006). The doctors and nurses working in black community patients were unlikely to give comprehensive information to black patients as the black patients are less often engaged in communication behaviours (Gordon et al., 2006).

### **Perception about bCPAP**

The caregivers in this study had different perceptions about bCPAP treatment. Caregivers described several positive aspects of their infants being on bCPAP treatment. For example, caregivers perceived the bCPAP treatment as “life saving treatment” as their infants survived during hospitalization. Cervantes, Feeley and Lariviere (2011) in Canada; Black, Holditch-Davis and Miles (2009) in USA and Foster et al. (2008) in Australia found that mothers of infants cared for in the NICU perceived that use of technology like oxygen therapy, had ensured their infants survival and is life saving .

In addition, the caregivers also thought that the experience of having their infants on bCPAP cleared the misconceptions they had about bCPAP that it kills. Similarly, in a qualitative study by Stevenson, Edwards, Langton, and Kennedy (2012) in Malawi, participants feared oxygen therapy and believed that it was dangerous or risky for their patients as they had observed or heard of patients dying after they had been treated with oxygen. However, after participating in the study, participants felt that they did not know much about oxygen which made them to believe that it was dangerous. They reported that, the participants further identified a need for education in local communities and at health care facilities for them to understand about oxygen therapy. Then, they further

recommended sensitization campaigns in communities about oxygen therapy so as to correct the misconceptions.

### **Psychological support**

The caregivers in this study described the interruption of parent-infant interaction due to bCPAP as major source of stress during their experience. The caregivers described that their inability to carry or hold their infants and breastfeed them as worrying and distressing aspects of their experience. Oxygen delivering methods create a barrier between a mother and an infant such that mothers are afraid to hold the baby, have skin to skin contact and even unable to see baby's face (Cervantes et al., 2011; Peeler, 2011; MacDonald, 2007). Furthermore, the caregivers reported that a bCPAP machine acts as an obstacle to parent-infant contact due to type of tubings which was distressing to caregivers. In addition, the policy of visiting their infants every 3 hours in Chatinkha also disturbed the interaction. In a study in Ghana by Affram, Laryea, Allen and Oliver-Commey (2008) mothers reported that being there for their children was their obligation and responsibility. Furthermore, Phillips and Tooley (2005) alluded that mothers who did not see or touch or stayed close to their babies often felt distressed.

The physical proximity is needed to develop parent-infant attachment (Ludington-Hoe, 2013). Nonetheless, there are number of studies that support the benefit of physical contact between the mother and the infant. The studies have shown that mother - infant skin to skin contact facilitates bonding between mother and infant, facilitates neurodevelopment in the neonate, infants have less pain and stress when receiving medical procedures and that mothers have few depressive symptoms when caring for their infants (Ludington-Hoe, 2013; Charpak et al., 2005). In addition, it has shown that the human oxytocin hormone released

during physical contact has good effect on mother-infant attachment and has effects on postpartum maternal mood and behaviour (Galbally, Lewis, Van IJzendoorn, & Permezel, 2011). As such health care providers must facilitate contact between the mother and their infant when on bCPAP treatment. The health care providers must create an opportunity for the mothers to hold their babies when on bCPAP in order to facilitate mother-infant bonding. To facilitate physical contact between parents and their infants, neonatal unit staff need to welcome parents' participation in the care but also guide parents when adapting parental touch into daily care, as touch may induce stress in very ill infants (Flacking et al., 2012). In addition, when women are able to participate in their infants care, feelings of involvement, confidence and connections are established (Fenwick, Barclay, & Schmied, 2008). Cockcroft (2012) further alluded that participating in the care of sick infants by caregivers helps bonding between the mother and infant as they will be in physical contact. Kearvell and Grant (2008) recommended that nurses should encourage parental involvement in the care of infants to promote mother-infant attachment. Nurses who encourage nurturing actions and contacts such as touching, talking, singing, comforting, changing nappies, feeding, turning their infants and behaviour cues are central in the establishment of mother-infant attachment (Johnson, 2007). However, studies have shown that, parents lack support and guidance from nurses on how they are going to participate (Söderbäck & Christensson, 2008; Coyne & Cowley, 2007). It is therefore important that nurses should offer support to caregivers and clearly define caregiver's role in the care of their children. Despite the proof that mothers who breastfeed have decreased maternal depression and improves mother - infant bonding (Allen & Hector, 2005), in situations where the infant is on bCPAP, health

care providers must explain clearly the reason of feeding the breast milk through the tube rather than from the breast for them to understand in order to prevent maternal stress.

In addition, the sound of machine, lights and big size of the tubes in the nose of infants were alarming to caregivers and caused stress in them. This was also alluded to by Cervantes, et al. (2011) where equipment necessary for oxygen delivery was a major cause of fear among the mothers as they were worried that the child may be hurt and the sound that the machine produced was terrifying. In addition, the mothers were not comfortable with oxygen delivering methods like CPAP as they thought it was horrible, painful, and uncomfortable to their infants and had fear of death of infants. Similarly, Cervantes et al. (2011) in Australia found that medical equipment and alarms in NICU are particularly distressing and overwhelming for parents. Nonetheless, with time the caregivers learnt about it and became increasingly comfortable with bCPAP machine. This suggests a need for support from health care providers to explain about treatment plan comprehensively which may include; benefit, risks, functions of the machine and even complications as these will prepare the caregivers psychologically and help them adapt well to the situation.

The majority of caregivers in this study were young and were in the age group of 18-23 years. The young mothers may have difficulties in adjusting extra responsibility of caring for an infant on bCPAP. First time adolescent mothers may need extra guidance, education, and support, as well as acceptance and reassurance (DeVito, 2010). As such, the health care providers must support them psychologically when caring for their infants on bCPAP. The length of stay in the hospital had both positive and negative aspects in this study as far as psychological well being was concerned. The average length of stay was 7 days with 2 days as a minimum and 14 days as a maximum. Long hospital stay was helpful to caregivers in

the way that, it helped caregivers to understand better about the bCPAP treatment compared to those that stayed in the hospital for short period of time. The caregivers who stayed long were less anxious about bCPAP than those who stayed for a short time. However, some caregivers who stayed long complained about the care of other siblings at home. This is in line with a study finding done in Mozambique where caregivers found it natural to stay with sick child in the hospital even if it created practical problems in the household (Söderbäck & Christensson, 2008). As such it is important for health care providers to inquire about other possible situations that may cause extra stress on caregivers which may complicate the care of their infant on bCPAP.

Caregivers had different preferred sources of psychological support rather than health care providers. Health care providers rarely supported caregivers psychologically with infants on bCPAP. The health care providers were much involved in offering routine care of sick infants such as giving medication, initiating bCPAP, inserting feeding tubes and monitoring infants on bCPAP. In Malawi, this could be due to shortage of nurses as alluded to by Schell et al. (2011) that average day time nurse-patient ratio is 1:38 while the night time ratio is 1:77. The recommended nurse patient ratio in intensive care level babies is 1-1 but due to shortage of nurses this is not adhered to; as such there is increased workload that cause technical aspects of nursing to be prioritized which limit the focus on family support (Cooper et al., 2007; Jones, Woodhouse, & Rowe, 2007). When nurses are overworked, it can impact on their ability to develop a therapeutic relationship with family (Cockcroft, 2012; Higman & Shaw, 2008).

This study has also revealed that, psychological support from family members such as husbands, mothers and sisters was also vital to the psychosocial well being of the

caregivers of infants who were on bCPAP. The majority of caregivers were married thus appreciated the presence of their husbands as a source of psychological support during care of their infants on the bCPAP. The husbands were consulted about the bCPAP treatment the infants were receiving thus encouraged them to continue with the treatment. This is in line with MDHS 2010 report that men are main decision makers in Malawi regarding health care of the family and household decisions (National Statistical Office, 2011). Suggesting that the health care providers should ensure that close family members like spouses, have also good understanding about bCPAP treatment given to their infants so that they can support the mothers properly. However the drawback was the restriction by rules and regulation at the unit that only allowed the mother of the child to visit the sick infant in high care. As such, the family members were indirectly involved in the care of sick infants who were on bCPAP. The hospitals need a liberal visiting policy for parents, siblings and grandparents in neonatal intensive care units except when there is disease outbreak (Latva, Lehtonen, Salmelin, & Tamminen, 2007).

Caregivers were also encouraged by fellow women who had their infants on bCPAP. They appreciated encouragement offered by fellow women which made them less anxious, although it was done informally. This can be formalized in hospitals where nurses are few so that they can assist in offering psychological care. Religious belief was also one of the sources of support the caregivers valued. Religion has the benefit of empowering the individual through connecting him/her to a community and to a superior force that might in turn give psychological stability (Basu-Zharku, 2011). This ability to empower could be used by health care providers to help those caregivers who struggle coping with bCPAP treatment in the hospital. Majority of caregivers in the study were Christians belonging to

different churches with few Moslems. This indicates that the majority of people in Malawi are Christians compared to Moslems. It is a responsibility of health care providers to be aware of religious beliefs of caregivers and utilise them when providing psychological support to caregivers with infants on bCPAP. The trust that the mothers of sick infants put in God, gave them courage that they and their babies would go through whatever situation (Ntswane-Lebang & Khoza, 2010; Affram et al., 2008) . As such, Partridge et al. (2015) recommends that physicians should have adequate religious discussions with mothers about the care of their children and decision making to help them to be less anxious.

### **Conclusion**

The study has shown that there are gaps in providing support to caregivers of infants on bCPAP at QECH in terms of information giving and psychological care. The information given about bCPAP was inadequate and was not standardized for caregivers to understand bCPAP treatment. The caregivers had difficulties in differentiating between a nurse and a doctor in the hospital. The findings show that the doctors and student nurses were among the preferred health care providers in information giving and offering support to caregivers with infants on bCPAP than nurses. The time information was given differed depending on the ward as others were given before while others after commencement of bCPAP.

Most caregivers in the study perceived bCPAP as a good treatment that saved life of their babies and helped them in clearing some misconceptions they had about bCPAP that it kills the infants. The caregivers expressed the feelings of fear, anxious, frightened, worried, fear of death, disappointed while others were crying when they saw their infants on bCPAP.

The major sources of stress to caregivers in this study were interrupted parent-infant interaction and bCPAP machine as they prevented mothers to be in physical contact with their infants and its appearance. The family members, friends and religious beliefs were

among preferred sources of psychological support rather than the health care providers. Involvement of caregivers in the care of infants was also a source of strength for caregivers as it facilitated physical contact with their infant although there was a need for proper guidance.

The findings of this study can assist health care providers in developing specific interventions to minimize psychological distress and promote psychological health of caregivers with sick infants on bCPAP. This will have a positive impact on parent-infant interaction and health outcome of the infant in the long run.

### **Recommendations**

According to the study findings presented in this paper, the researcher recommends the following;

#### **Ward**

The health care providers should evaluate the level of education when planning and giving information to caregivers to promote understanding about bCPAP.

The health care providers should ensure that information about bCPAP should be communicated to caregivers if present before commencement of bCPAP for them to give informed consent. The caregivers who are not present in Chatinkha nursery ward may be called from postnatal ward or contacted by phone to explain about treatment if it is not visiting time or the bCPAP can be commenced and inform the caregiver later when present.

The health care providers should facilitate physical contact between the mother and their infants when on bCPAP by involving the caregivers in the care of their infants and define their roles properly.

## **Management**

The head of department to ensure that there is standardized information to be used by health care providers to be communicated to caregivers caring for infants on bCPAP to ensure that adequate and relevant information is given. The information may include; description of bCPAP, how it works, the indications for bCPAP in an infant, how to care for the baby, benefits, risks, complications of bCPAP and other relevant information.

The nursing management should find a way of providing psychological care to caregivers of infants on bCPAP despite the shortage of staff. The possible solution could be establishing the support group of caregivers of infants on bCPAP and utilize the caregivers that have adapted well to share their experiences during support group meetings. The support group can be organized 2 to 3 times in a week. The member present in support group include caregivers, nurses and support staff to ensure continuity.

In future, if the space will be adequate, the hospital management should consider of having liberal visiting policy of allowing close family members like spouses, siblings and grand-parents to see the infants while on bCPAP to assist in supporting the mother of the infant psychologically.

## **Study Limitations**

The study was conducted at QECH hence findings will be limited to QECH only. However, the findings may provide useful insight regarding experiences of caregivers who have cared for infants on bCPAP due to severe respiratory conditions in similar settings.

### **Areas for Further Research**

In regards to the study findings that only caregivers of infants who improved on bCPAP shared their experiences regarding bCPAP, another study is recommended to explore experiences of caregivers of infants who died while on bCPAP.

In view of study findings that there was knowledge and understanding differences between caregivers with different education background levels there is a need for another study to compare experiences of caregivers of infants on bCPAP with different levels of education (Tertiary versus Secondary education or Primary versus Tertiary level).

The study was conducted at one central/tertiary hospital as such there is a need for a study to compare experiences of caregivers with infants on bCPAP at another central/tertiary hospital.

In regards to the study findings that the hospital does not have standard information to be communicated to caregivers for them to understand, there is a need for a study to evaluate type of information needed to be given to caregivers in order for them to understand better bCPAP treatment.

This study has only explored the experience of caregivers of infants who were on bCPAP. It will be very important to conduct another study to assess perceptions of health care providers on psychological care given to caregivers with infants on bCPAP as well.

## Reference

- Affram, C. K., Laryea, J., Allen, M., & Oliver-Commey, J. O. (2008). The experiences of mothers with children hospitalized in a children's emergency unit, Ghana. *Africa Journal of Nursing and Midwifery*, 10(1), 44–58.
- Allen, J., & Hector, D. (2005). Benefits of breastfeeding. *New South Wales Public Health Bulletin*, 16(4), 42–46.
- Ameratunga, S., Abel, S. & Tin Tin, S., Asiasiga, L., Milne, S., Crengle, S. (2010) Children admitted to hospital following unintentional injury: perspectives of health service providers in Aotearoa/New Zealand. *BMC Health Services Research*, 10(333), 1-9.
- Basu-Zharku, I. O. (2011). The influence of religion on health. *Student Pulse*, 3(01),1-3.
- Beckstrand, R.L., Rawle, N.L., Callister, L. & Mandleco, B.L. (2010). Paediatric nurses' perceptions of obstacles and supportive behaviours in End-of-Life Care. *American Journal Critical Care*, 19, 543-552
- Black, B. P., Holditch-Davis, D., & Miles, M. S. (2009). Life course theory as a framework to examine becoming a mother of a medically fragile preterm infant. *Research in Nursing & Health*, 32(1), 38–49.
- Bonner, K. M., & Mainous, R. O. (2008). The nursing care of the infant receiving bubble CPAP therapy. *Advances in Neonatal Care*, 8(2), 78–95.
- Brehaut, J. C., Kohen, D. E., Raina, P., Walter, S. D., Russell, D. J., Swinton, M., Rosenbaum, P. (2004). The health of primary caregivers of children with cerebral

- palsy: how does it compare with that of other Canadian caregivers? *Pediatrics*, 114(2), e182–e191.
- Brown, J., Machen, H., Kawaza, K., Mwanza, Z., Iniguez, S., Lang, H., ... Richards-Kortum, R. (2013). A high-value, low-cost bubble continuous positive airway pressure system for low-resource settings: technical assessment and initial case reports. *PloS One*, 8(1), e53622.
- Bryce, J., Boschi-Pinto, C., Shibuya, K., & Black, R. E. (2005). WHO estimates of the causes of death in children. *The Lancet*, 365(9465), 1147–1152. doi:10.1016/S0140-6736(05)71877-8
- Cervantes, A. C., Feeley, N., & Lariviere, J. (2011). The experience of mothers whose very low-birth-weight infant requires the delivery of supplemental oxygen in the neonatal intensive care unit. *Advances in Neonatal Care*, 11(1), 54–61.
- Charchuk, M., & Simpson, C. (2005). Hope, disclosure, and control in the neonatal care unit. *Health Communication*, 17(2), 191–203
- Charpak, N., Gabriel Ruiz, J., Zupan, J., Cattaneo, A., Figueroa, Z., Tessier, R. & Worku, B. (2005). Kangaroo Mother Care: 25 years after. *Acta Paediatrica*, 94(5), 514–522. doi:10.1111/j.1651-2227.2005.tb01930.x
- Cockcroft, S. (2012). How can family centred care be improved to meet the needs of parents with a premature baby in neonatal intensive care? *Journal of Neonatal Nursing*, 18(3), 105–110.

- Co, J.P., Ferris, T.G., Marino, B.L., Homer, C.J. & Perri, J.M. (2003). Are hospital characteristic associated with parental views of pediatric inpatient care quality. *Pediatrics*, 111(2),308-314.
- Cooper, L. G., Gooding, J.S., Gallagher, J., Ledshy, R. & Berns, S.D. (2007). Impact of a family centered care initiative on NICU care, staff & Families. *Journal of Perinatology*, 27(1), S32-S37
- Coyne, I., & Cowley, S. (2007). Challenging the philosophy of partnership with parents: a grounded theory study. *International Journal of Nursing Studies*, 44(6), 893–904.
- Coyne, I. (2006). Consultation with children in hospital: children, parents and nurses perspectives. *Journal of Clinical Nursing*, 15, 61–71.
- Dalton, J. (2005). Client–caregiver–nurse coalition formation in decision-making situations during home visits. *Journal of Advanced Nursing*, 52(3), 291–299.
- DeVito, J. (2010). How adolescent mothers feel about becoming a parent. *The Journal of Perinatal Education*, 19(2), 25.
- Ertmann, R.K., Reventlow, S. & Söderström, M. (2011). Is my child sick? parents. management of signs of illness and experiences of the medical encounter. *Scandinavian Journal of Primary Health Care*, 29, 23-27.
- Evangelou E, Iordanou P, Lemonidou C. H, Patiraki E, Kyritsi E, Bellou P. (2003) Parental participation in their hospitalized child's physical and psychological care: nurses' perceptions. *ICUs and Nursing. Web Journal*, 13: 1-13

- Fenwick, J., Barclay, L., & Schmied, V. (2008). Craving closeness: A grounded theory analysis of women's experiences of mothering in the Special Care Nursery. *Women and Birth*, 21(2), 71–85.
- Finucane, P. M. L. (2012). The Role of Feelings in Perceived Risk. In S. Roeser, R. Hillerbrand, P. Sandin, & M. Peterson (Eds.), *Handbook of Risk Theory* (pp. 677–691). Amsterdam, Netherlands: Springer
- Flacking, R., Ewald, U., Nyqvist, K. H., & Starrin, B. (2006). Trustful bonds: a key to “becoming a mother” and to reciprocal breastfeeding. Stories of mothers of very preterm infants at a neonatal unit. *Social Science & Medicine*, 62(1), 70–80.
- Foster, J., Bidewell, J., Buckmaster, A., Lees, S., & Henderson-Smart, D. (2008). Parental stress and satisfaction in the non-tertiary special care nursery. *Journal of Advanced Nursing*, 61(5), 522–530. doi:10.1111/j.1365-2648.2007.04547.x
- Fuhrman, B. P., & Zimmerman, J. J. (2011). *Pediatric critical care: expert consult premium* (4<sup>th</sup> Ed). Philadelphia: Elsevier/Mosby
- Galbally, M., Lewis, A. J., Van IJzendoorn, M., & Permezel, M. (2011). The Role of Oxytocin in Mother-Infant Relations: A Systematic Review of Human Studies: *Harvard Review of Psychiatry*, 19(1), 1–14. doi:10.3109/10673229.2011.549771
- Gale, G., Franck, S. L., Kools, S., & Lynch, M. (2004). Parents' perceptions of their infant's pain experience in the NICU. *International Journal of Nursing Studies*, 41(1), 51–58

- Gordon, H. S., Street, R. L., Sharf, B. F., & Soucek, J. (2006). Racial differences in doctors' information-giving and patients' participation. *Cancer*, 107(6), 1313–1320. doi:10.1002/cncr.22122
- Gregory, G.A., Kitterman, J.A., Phibb, R.H., Tooley, W.H & Hamilton, W.K. (1971) Treatment of the idiopathic respiratory-distress syndrome with continuous positive airway pressure. *New England Journal of Medicine*, 284, 1333-40
- Gulati, S., Watt, L., Shaw, N., Sung, L., Poureslami, I. M., Klaassen, R., ... Klassen, A. F. (2012). Communication and language challenges experienced by Chinese and South Asian immigrant parents of children with cancer in Canada: Implications for health services delivery. *Pediatric Blood & Cancer*, 58(4), 572–578.
- Hendriks, H. J. (2010). *Is CPAP a feasible treatment modality in a rural district hospital for neonates with respiratory distress syndrome?* Stellenbosch: Stellenbosch University. Retrieved on 12 March 2015 from <https://scholar.sun.ac.za/handle/10019.1/20453>
- Higman, W., & Shaw, K. (2008). Nurses' understanding about the delivery of family centred care in the neonatal unit. *Journal of Neonatal Nursing*, 14(6), 193–198.
- Hinkson, D.A., Atenafu, E., Kennedy, S.J., Vohra, S., Garg, D. & Levin, A.V. (2006). Cornelia de Lange Syndrome: parental preferences regarding the provision of medical information. *American Journal of Medical Genetics Part A*, 140(20), 2170-2179.

- Holloway, I. (2005). *Qualitative research in health care*. New York: Open University Press.
- Huang, C., Kenzik, K.M., Sanjeev, T.Y., Shearer, P.D., Revicki, D.A. & Nackashi, J.A. (2010). Quality of life information and trust in physicians among families of children with life-limiting conditions. *Patient Related Outcome Measures*, 1, 141-48.
- Johnson, A. N. (2007). The maternal experience of kangaroo holding. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*, 36(6), 568–573.
- Jones, L., Woodhouse, D., & Rowe, J. (2007). Effective nurse parent communication: A study of parents' perceptions in the NICU environment. *Patient Education and Counseling*, 69(1), 206–212.
- Kattwinkel, J., McGowan, J. E., Zaichkin, J., Bloom, R. S & Cropley, C., American Academy of Pediatrics, & American Heart Association. (2011). *Textbook of neonatal resuscitation*. New York: American Academy of Pediatrics ; American Heart Association.
- Kearvell, H. & Grant, J. (2008). Getting connected: How nurses can support mother/infant attachment in the neonatal intensive care unit. *Australian Journal of Advanced Nursing* 27(3), 75-82.
- Khilnani, P. (2005). *Practical approach to paediatric intensive care*. New York: Oxford University press
- Kiguli, S., Mafigiri, D., Nakigudde, J., Van Dalen, J., & Van der Vleuten, C. (2011). A qualitative study of caregivers' expectations and communication desires during medical consultation for sick children in Uganda. *Patient Education and Counseling*, 84(2), 217–222.

- Kirsten, G. F., Kirsten, C. L., Henning, P. A., Smith, J., Holgate, S. L., Bekker, A., & Harvey, J. (2012). The outcome of ELBW infants treated with NCPAP and InSurE in a resource-limited institution. *Pediatrics*, *129*(4), e952–e959.
- Lam, L. W., Chang, A. M., & Morrissey, J. (2006). Parents' experiences of participation in the care of hospitalised children: a qualitative study. *International Journal of Nursing Studies*, *43*(5), 535–545.
- Lang, H.J., Jeffries, O., Ward, J., Cook, J., Mbale, E., Katangwe, T.,... O'Hare, B. (2011). *Use of bubble CPAP in Malawi*. Cambridge: Paediatric Intensive Care Society
- Latva, R., Lehtonen, L., Salmelin, R. K., & Tamminen, T. (2007). Visits by the family to the neonatal intensive care unit. *Acta Paediatrica*, *96*(2), 215–220.
- Leonard, M., Graham, S., & Bonacum, D. (2004). The human factor: the critical importance of effective teamwork and communication in providing safe care. *Quality & safety in health care*, *13*(Suppl 1), i85–i90. doi:10.1136/qshc.2004.010033
- Levetown, M. (2008). Communicating with children and families: from everyday interactions to skill in conveying distressing information. *Paediatrics*, *121*, e1441.
- Ludington-Hoe, S. M. (2013). Kangaroo care as a neonatal therapy. *Newborn and Infant Nursing Reviews*, *13*(2), 73–75.
- MacDonald, M. (2007). Mothers of pre-term infants in neonate intensive care. *Early Child Development and Care*, *177*(8), 821–838.

- Mai, C. L., Yaster, M., & Firth, P. (2013). The development of continuous positive airway pressure: an interview with Dr. George Gregory. *Paediatric Anaesthesia*, 23(1), 3–8. doi:10.1111/pan.12075.
- Massa, F., Gonzalez, S., Lavery, A., Wallis, C., & Lane, R. (2002). The use of nasal continuous positive airway pressure to treat obstructive sleep apnoea. *Archives of Disease in Childhood*, 87(5), 438–443. doi:10.1136/ad.87.5.438
- Matziou, V., Boutopoulou, B., Chrysostomou, A., Lachioti, E., Mantziou, T. & Petsios, K. Parents.satisfaction concerning their child.s hospital care. *Japan Journal of Nursing Science*, 8, 163-173.
- McCollum, E. D., Smith, A., & Golitko, C. L. (2011). Bubble continuous positive airway pressure in a human immunodeficiency virus-infected infant. *The International Journal of Tuberculosis and Lung Disease*, 15(4), 562–564.
- Meeks, M., Hallsworth, M., & Yeo, H. (2010). *Nursing the Neonate*. John Wiley & Sons.
- Meshkani, Z.S. & Bavarian, B. (2005). Parents’ fear and distress during child inpatient care. *Acta Medica Iranica*, 43(5), 355-358.
- Mok, E., & Leung, S. F. (2006). Nurses as providers of support for mothers of premature infants. *Journal of Clinical Nursing*, 15(6), 726–734
- Munhall, P.L. (2007). *Nursing research: a qualitative perspective*. (4<sup>th</sup> ed). London: Jones & Bartlett.

- Nair, H., Simões, E. A., Rudan, I., Gessner, B. D., Azziz-Baumgartner, E., Zhang, J. S. F., ... Campbell, H. (2010) Global and regional burden of hospital admissions for severe acute lower respiratory infections in young children in 2010: a systematic analysis. *The Lancet*, 381(9875), 1380–1390. doi:10.1016/S0140-6736(12)61901-1
- National Statistical Office and ICF MACRO (2011). *Malawi Demographic and Health Survey, 2010*. Zomba, Malawi
- Ntswane-Lebang, M. A., & Khoza, S. (2010). Mothers' experiences of caring for very low birth weight premature infants in one public hospital in Johannesburg, South Africa. *Africa Journal of Nursing and Midwifery*, 12(2), 69–82.
- Orapiriyakul, R., Jirapaet, V., Rodcumdee, B., Kiatlaekakul, S., Taboonpong, S., & Suttharangsee, W. (2007). Struggling to get connected: the process of maternal attachment to the preterm infant in the neonatal intensive care unit. *Thai Journal of Nursing Research*, 11(4), 251.
- Parahoo, K. (2006). *Nursing research: principles, process, and issues* (2<sup>nd</sup> Ed). New York: Palgrave /Macmillan.
- Partridge, J. C., Martinez, A. M., Nishida, H., Boo, N.-Y., Tan, K. W., Yeung, C.-Y., ... Victor, Y. H. (2005). International comparison of care for very low birth weight infants: parents' perceptions of counseling and decision-making. *Pediatrics*, 116(2), e263–e271.

- Peeler, A. (2011). *The experiences of parents and nurses of hospitalised infants requiring oxygen therapy for severe bronchiolitis: a phenomenological study*. Australian Catholic University. Retrieved August 18, 2013 from <http://dlibrary.acu.edu.au/digitaltheses/public/adt-acuvp362.07032012/02whole.pdf>
- Phillip, J.A., Kazembe, P.N., Nelson, E.A., Fisser, J.A. & Grabosch, E.(2008) *A paediatric handbook for Malawi* (3<sup>rd</sup> ed). Limbe: Montfort press
- Phillips, S. J., & Tooley, G. A. (2005). Improving child and family outcomes following complicated births requiring admission to neonatal intensive care units. *Sexual and relationship therapy*, 20(4), 431–442.
- Polit, D. F., & Beck, C. T. (2010). *Essentials of nursing research: appraising evidence for nursing practice* (7th ed.). Philadelphia: Lippincott Williams & Wilkins.
- Punthmatharith, B., Buddharat, U., & Kamlangdee, T. (2007). Comparisons of needs, need responses, and need response satisfaction of mothers of infants in neonatal intensive care units. *Journal of Pediatric Nursing*, 22(6), 498–506. doi:10.1016/j.pedn.2006.05.015
- Rao, K. S. (2008). Informed consent: An ethical obligation or legal compulsion? *Journal of Cutaneous and Aesthetic Surgery*, 1(1), 33.
- Reid, T., Bramwell, R., Booth, N., & Weindling, M. (2007). Perceptions of parent–staff communication in neonatal intensive care: the development of a rating scale. *Journal of Neonatal Nursing*, 13(1), 24–35

- Reinhard, S. C., Given, B., Petlick, N. H., & Bemis, A. (2008). Supporting family caregivers in providing care. In R. G. Hughes (Ed.), *Patient safety and quality: an evidence-based handbook for nurses*. Rockville (MD): Agency for Healthcare Research and Quality (US). Retrieved February 20, 2014 from: <http://www.ncbi.nlm.nih.gov/books/NBK2665>
- Schell, E.S., Rankin, W.W., Chipungu, G., Rankin, S. & Weiller, R. (2011). Building the nursing workforce in Malawi helping a developing African country solve its nursing shortage. *American Journal of Nursing*, 111(6), 65-67
- Schouten, B. C., & Meeuwesen, L. (2006). Cultural differences in medical communication: a review of the literature. *Patient Education and Counseling*, 64(1), 21–34. doi:10.1016/j.pec.2005.11.014
- Schwartzberg, J. G., VanGeest, J. B. & Wang, C. C. (2005). Understanding health literacy. *Chicago (IL): American Medical Association*. Retrieved August 18, 2015 from: [http://www.ghdonline.org/uploads/Rudd\\_R.E.\\_Rezulli\\_D.\\_Pereira\\_A.\\_et\\_al.\\_2005.\\_Literacy\\_Demands\\_in\\_Health\\_Care\\_Settings..pdf](http://www.ghdonline.org/uploads/Rudd_R.E._Rezulli_D._Pereira_A._et_al._2005._Literacy_Demands_in_Health_Care_Settings..pdf)
- Skorupski, V. J., & Rea, R. E. (2006). Patients' perceptions of today's nursing attire: exploring dual images. *Journal of Nursing Administration*, 36(9), 393–401.
- Slade, D., Chandler, E., Pun, J., Lam, M., Matthiessen, C., Williams, G., Espindola, E., Veloso, F.D., Tsui, K.L., Tang, S.Y & Tang, K.S. (2015). Effective healthcare worker-patient communication in Hong Kong accident and emergency departments. *Hong Kong Journal of Emergency Medicine*, 22(2), 69.

- Söderbäck, M., & Christensson, K. (2008). Family involvement in the care of a hospitalised child: A questionnaire survey of Mozambican family caregivers. *International Journal of Nursing Studies*, 45(12), 1778–1788.
- Speziale, H. S., & Carpenter, D. R. (2007). *Qualitative research in nursing: advancing the humanistic imperative* (4th ed). Philadelphia: Lippincott: Williams & Wilkins
- Stevenson, A. C., Edwards, C., Langton, J., & Kennedy, N. (2012). P248 Barriers to uptake of oxygen therapy in Malawi: a qualitative study. *Thorax*, 67 (Suppl 2), A173–A173.
- Strohbuecker, B., Gaertner, J., & Stock, S. (2011). Informing severely ill patients: needs, shortcomings and strategies for improvement. *Breast Care*, 6(1), 8–13.  
doi:10.1159/000324563
- Trigg, E. & Mohammed, T.A. (Eds.). (2010). *Practices in children's nursing: guidelines for hospital and community* (3<sup>rd</sup> Ed). Edinburgh: Churchill Livingstone Elsevier
- UNICEF. (2007). *UNICEF Malawi Annual Report 2006*. New York.
- Vamvakiti, E., Saha, A., & Linney, M. (2010). 510 Use of nasal Cpap in infants with bronchiolitis in the South of England: a prospective, multicentre, observational study. *Pediatric Research*, 68, 261–261.
- Van Den Heuvel, M., Blencowe, H., Mittermayer, K., Rylance, S., Couperus, A., Heikens, G. T., & Bandsma, R. H. J. (2011). Introduction of bubble CPAP in a teaching hospital in Malawi. *Annals of Tropical Paediatrics: International Child Health*, 31(1), 59–65.

- Verhaeghe, S., Defloor, T., Van Zuuren, F., Duijnste, M., & Grypdonck, M. (2005). The needs and experiences of family members of adult patients in an intensive care unit: a review of the literature. *Journal of Clinical Nursing*, 14(4), 501–509.
- Wahl, H., Banerjee, J., Manikam, L., Parylo, C. & Lakhanpaul, M. (2013). Health information needs of families attending the paediatric emergency department. *Archives of Disease in Childhood*, 96, 335-339.
- Walsh, B. K., Czervinske, M. P., & DiBlasi, R. M. (2010). *Perinatal and pediatric respiratory care*. Saunders/Elsevier. Retrieved June 19, 2015 from: <http://www.lavoisier.fr/livre/notice.asp?ouvrage=1792482>
- Whitehead, D., & Annells, M. P. (2007). Analysing data in qualitative research. In: Z. Schneider (Ed.). *Nursing & midwifery research: methods and appraisal for evidence-based practice*. NSW, Australia: Elsevier
- WHO. (2006). *Neonatal and perinatal mortality*. Chicago: World Health Organization
- Wilson, P. T., Morris, M. C., Biagas, K. V., Otupiri, E., & Moresky, R. T. (2012). A randomized clinical trial evaluating nasal continuous positive airway pressure for acute respiratory distress in a developing country. *The Journal of Pediatrics*, 162(5), 988-992.
- Zarit, S. H. (2006). A research perspective. *Caregiver assessment: voices and views*. Retrieved February 14, 2014 from: <http://caregivertoolkit.ca/caregiver%20assessment%20volume%202.pdf#page=18>

## Appendices

### Appendix 1: Letter to caregivers of Infants who have been on bCPAP at QECH

#### Dear participants

My name is Mtisunge Joshua Gondwe and I am currently registered as a student at University of Malawi, Kamuzu College of Nursing for Master of Science degree in Child Health. I am conducting a research project on **“The experiences of caregivers of infants who have been on bubble Continuous Positive Airway Pressure at Queen Elizabeth Central Hospital.”** and I write this letter to ask you to participate in the study mentioned above. The aim of the study is to explore the experiences of caregivers of hospitalized infants who have been on bCPAP at QECH.

Participation in the study is entirely voluntary. You may choose to participate or withdraw from the study at any time, which will not have any effects on the services that you are receiving from the health care providers in this hospital. Furthermore, the study does not have any foreseeable physical harm (risks); however in cases of any emotional or psychological harm you may forward your concern and complaints to the researcher at Kamuzu College of Nursing.

I appreciate that you will derive no benefit from participating in the study. However, exploring the experiences of caregivers of infants on bCPAP will assist in responding to caregivers’ needs and guide nursing care to minimize parental stress during bCPAP care in infants with severe respiratory conditions. No reports in this study will identify you in any way and results of the study will be given to you should you so wish. Should you agree to participate, I will ask you to sign a consent form or put a finger print on the space provided to indicate that you have accepted to be interviewed. It is anticipated that the interview will

take 40 minutes to one hour of your time. The interview will be conducted at a time that is most suitable and convenient to you in a quiet environment to avoid any disturbances.

The study has been approved by College of Medicine Research Ethics Committee (COMREC) and Queen Elizabeth Central Hospital.

Thank you for taking time to read this information letter.

Should you require any further information regarding the study or your rights as study participant you are free to contact me on the following number: 0884460581 or The chairperson, COMREC Secretariat, P/Bag 360, Chichiri, Blantyre 3 or you may call on 01989766.

## **Appendix 2: Chichewa version of Letter to caregivers of Infants on bCPAP at QECH:**

Kalata yofotokoza za kafukufuku pa zomwe makolo anakumana nazo pomwe ankasamalira mwana ochepera chaka chimodzi yemwe adali pa mpweya odzela m”mashini otulutsa mababo pa chipatala cha QECH

Wokondedwa.....

Ndine Mtisunge Joshua Gondwe, wophunzira zaunamwino kusukulu yaukachenjeda ya Malawi ku Kamuzu Koleji, amene ndikuphunzira zokhudza umoyo waana ndipo ndikupanga kafukufuku wokhuza maganizo amakolo ndi zomwe adakumanananzo pa chithandizo cha mpweya odzela m”mashini atulutsa mababo yemwe mwana wawo adaikidwapo pa chipatala cha QECH.

Ndalemba chikalatachi ndi cholinga chofuna kukupemphani kuti mutengepo mbali polowa nawo mukafukufukuyu. Cholinga cha kafukufukuyu ndi kusathula maganizo amakolo pa chithandizo cha mpweya odzela pa mashini otulutsa mababo chomwe mwana amaikidwapo akamapuma mobanika. Izi zizathandiza ogwira ntchito kuchipatala kugwira bwino ntchito yawo ndi makolo pomwe akuyanganira mwana amene ali ndi vuto lobanika kwambiri ndipo ali pa mashini a mpweya wotulutsa mababo .

Dziwani kuti simukukakamizidwa kutengapo mbali komanso muli ndiufulu ngati mukufuna kusiya nthawi imene mungafune popanda vuto lina lililonse ndipo muli omasuka kufunsa mafunso alionse okhudza kafukufukuyu. Mukuyeneranso kudziwa kuti mayankho anu adzasungidwa mwachinsisi ndipo sizizadziwika kuti anayankha mafunsowa ndindani chifukwa mayina anu sadzayikidwa pamapepala a mafunso m’ malo mwake tizagwiritsa ntchito manambala. Dziwaninso kuti palibe chiopsezo china chili chonse pakafukufukuyi.

Ngati mwavomereza kutengapo mbali pakafukufukuyi muzapemphedwa kusayina fomu kapena kusindikiza chala chanu ndiponso kuyankhapo mafunso kwanthawi yosachepera mphindi 40 kapena ola limodzi.

Ngati pangakhale mafunso kapena nkawa ina ili yonse yokhudzana ndikafukufukuyu khalani omasuka ndikubweretsa madandaulo anu kwa wapampando, COMREC P/Bag 360, Chichiri, Blantyre 3 kapena muyimbire telefoni pa nambala iyi 01989766.

### **Appendix 3: Caregivers Consent Form**

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

**I..... (Name/ Thumb Print), voluntarily give permission to participate in the study.**

I have read or have had another person read to me and understood the content of the information letter and I have been given the opportunity to ask questions, where deemed necessary, about the study.

I understand that the information I give will be kept confidential and will only be accessed by the researcher and/or those people who are directly concerned with the study

I know that I do not have to suffer any injury or harm during the research process and the information that I will give to the researcher will not be used against me in future.

.....

Participant's Signature

Date

.....

Researcher's Signature

Date

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

#### **Appendix 4: Chichewa Version of Caregivers Consent Form**

Kalata yapepha chilolenzo kwa oyang'anira mwana.

#### **Sayinani dzina lanu kapena sindikizani chala chanu ngati mwavomereza kutengapo mbali pakafukufukuyu**

Ine..... (Dzina)/Sindikizani chala) ndavomera ndikupeleka chilolezo mosaumilizidwa kutengapo mbali pakafukufuku uyu. Ndawerenga kapena kuwerengeredwa ndi munthu wina, komanso ndamvetsa cholinga chake, ndiponso ndapatsidwa mwayi ofunsa mafunso ngati pangafunikire pa kafukufuku uyu. Ndamvetsa kuti zomwe nditayankhule pa kafukufuku uyu, zizasungwidwa mwa chinsinsi ndipo zizagwiritsidwa ntchito ndi mwini kafukufuku yekha komanso omwe ali okhudzidwa ndi kafukufukuyu.

Ndikudziwa kuti palibe chiopsezo china chilichonse panthawi yomwe ndikutengapo mbali pakafukufuku uyu, komanso kuti mayankho ndikupereka kwa mwini kafukufukuyu sadzagwiritsidwa ntchito motsutsana ndiine mtsogolo muno.

.....

Dzina la otengambali

.....

Mwini kafukufuku

.....

Tsiku

.....

Tsiku

Ngati pangakhale mafunso kapena nkhwana iliyonse yokhudzana ndikafukufukuyu bweretsani madandaulo anu kwa wapampando wa COMREC pa telefoni nambala iyi 01989766.

## **Appendix 5: Question guide for in-depth interviews for participants.**

### **SECTION A: DEMOGRAPHIC DATA AND INFANT INFORMATION**

1. Can you please tell me a little about yourself; (how old you are, what do you do/occupation, level of education, marital status, relationship with the child, religion, home area (district).
2. Can you please tell me a little about your patient; (how old is he/she, date of birth, status at birth, common ailments since birth, problem that brought you to hospital, date of admission and type of treatment the child has received/ been receiving.

### **SECTION B: IN-DEPTH INTERVIEW GUIDE**

1. What do you know about bCPAP?

**PROBE:** What is it, how does it work, why was your child put on bCPAP, and how many days was your child on bCPAP.

2. What was your experience of having your infant on bCPAP?

**PROBE:**, How did you feel when you heard that your infant needed bCPAP, what was your reaction, what was your perception about bCPAP treatment in infant, what information were you given about bCPAP, how did they give this information to you written or verbally, when was the information given (before, during or after bCPAP), Who gave you the information (Doctor/Clinician , Nurse or if others specify ), how important was this information during the care of your infants on bCPAP).

3. How much were you involved in the care of your infant when on bCPAP?

**PROBE:** What care were you giving to your infant while on bCPAP? how important was your involvement, what role did the health care workers play in supporting you when caring for your infant on bCPAP (reassurance, proper answering of questions, approachable, giving enough information), how important was their role during care of your infant on bCPAP).

**THANKS FOR YOUR PARTICIPATION!**

**Appendix 6: Chichewa version of Question guide for in-depth interviews for participants.**

**Mafuso a kholo kapena oyanganira mwana pakafukufuku wa zomwe makolo anakumana nazo pomwe ankasamalira mwana ochepera chaka chimodzi yemwe adali pa mpweya odzela m'mashini otulutsa mababo pa chipatala cha QECH.**

**GAWO LOYAMBA (A): MBIRI YA OYANG'ANIRA MWANA NDI MWANA**

1. Mungandifotokozeleko za mbiri yanu; (Muli ndi zaka zingati, tsiku lobadwa, mumapanga chiyani kuti mupeze ndalama zothandizila pakhomo, munaphunzira kufika pati, muli pabaja, ubale wanu ndi mwanayu ndi otani, mumapemphera mpingo wanji, mumakhala kuti).
2. Mungandifotokozereko pang'ono za mbiri ya mwana yemwe akudwalayu; (Ali ndi zaka zingati, anabadwa liti, ndiwamwamuna kapena wamkazi, mabadwidwe ake anali bwanji, matenda wadwalapo chibadwireni, muli mchipatala chifukwa cha vuto liti, munabwera mchipatala liti, Chibwererani ndi chithandizo chanji chomwe mwanayu walandila).

**GAWO LACHIWIRI (B): MAFUSO AKUYA A OYANG'ANIRA MWANA**

1. Mukudziwapo chiyani za chithandizo cha mpweya otulutsa mababo (bCPAP);  
**Funso lothandiza kupeza zambiri:** Ndi chithandizo chotani, chimagwira ntchito bwanji,  
nanga nchifukwa chiyani mwanayu anaikidwa pa chithandizo chimenechi, anakhalapo masiku angati.
2. Tandifotokozerani mmene zinalili ndi mmene munaonera chithandizo cha mpweya wotulutsa mababo chomwe mwanayu adalandira?

**Funso lothandiza kupeza zambiri:**

Mudamva bwanji pamene adakuuzani kuti mwanayu ayenera kupatsidwa mpweya wotulutsa mababo, nanga mudachilandila bwanji, kodi mudachiona bwanji chithandizo chimwenechi, Mudauzidwa chiyani kapena uthenga wanji wokhudzana ndi chithandizonchi, mudauzidwa motani za chithandizochi (munawerenga pa pepala kapena anangonena pakamwa), Munauzidwa nthawi yanji za uthengawu (asanamuike, atamuyika kapena atamuchotsa), adakuuzani za uthenga umenewu ndi ndani, nanga inali nthawi yanji), Mudauzidwa ndi ndani za uthengawu( dokotala, namwino kapena ena) unathandiza bwanji unthengawo pamene mumkasamalila mwanayu.

3. Mungandifotokozereko gawo lomwe munatengapo panthawi yomwe mumasamalira mwanayu?

**Funso lothandiza kupeza zambiri:**, kunali kofunikira bwanji kutengapo mbali kwanu, ndimbali yanji yomwe ogwira nchito mchipatala anatengapo yomwe inali yofunikira kwambiri kwainu pamene mumasamalira mwanayu (Kukulimbisani mtima, amakuyankhani mafunso bwino mukawafunsa, mumatha kuwafusa kapena kuwayankhula bwinobwino, uthenga munalandira unali omveka bwanji), nanga mbali yomwe ogwira ntchito mchipatala adatengapoyo, inali yofunikira bwanji panthawiyi yomwe munkasamalira mwanayu.

**ZIKOMO POTENGA NAWO GAWO PA KAFUKUFUKUYI.**

## Appendix 7: Authorization letter from COMREC



## Appendix 8: Authorization Letter from Hospital Director QECH

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

All communications should be addressed to:  
The Hospital Director



In reply please quote **No.**

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

Ref No. QE/10

14<sup>th</sup> July, 2014

Mtisunge Joshua Gondwe  
Kamuzu College of Nursing  
Blantyre Campus  
P.O. BOX 415  
**BLANTYRE 3**

Dear Mtisunge,

### **PERMISSION TO CONDUCT A RESEARCH**

This is to inform you that permission has been granted to conduct a pretest and research on **“Experiences of care givers of Infants who have been bubble continuous positive Airway Pressure”** at Queens Elizabeth Central Hospital.

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

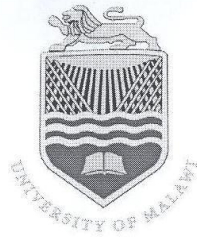
All the best in your studies.

Yours faithfully,

A handwritten signature in dark ink, appearing to read 'Lucy Chigwenembe'.

Lucy Chigwenembe (CNO.)  
**FOR: HOSPITAL DIRECTOR**

## Appendix 9: Authorization Letter from Head of Paediatric Department at QECH



### UNIVERSITY OF MALAWI

Principal

Prof. K. Maleta PhD

College of Medicine  
Private Bag 360  
Chichiri  
Blantyre 3  
Malawi

Telephone: 01 871 911  
01 874107  
Fax: 01 874 700  
Email: nkennedy@medcol.mw

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

16<sup>th</sup> July 2014

Chair COMREC  
College of Medicine  
Blantyre

Dear Sir,

**RE: 'Experiences of care givers of Infants who have been bubble Continuous Positive Airway Pressure'**

I am writing to support this proposal submitted by Sr. M Joshua Gondwe. The research is low-risk and of value to the department. I hope it will provide valuable information regarding psycho-social care of care givers caring for infants on B-CPAP.

Yours sincerely

**Dr Q Dube**  
Acting Head – Department of Paediatrics & Child Health