PARENTAL INVOLVEMENT IN NEONATAL PAIN MANAGEMENT AT QUEEN ELIZABETH CENTRAL HOSPITAL, MALAWI

MASTER OF SCIENCE (CHILD HEALTH) THESIS

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Declaration

I, the undersigned declare that this thesis is my own original work and effort and has never been submitted To any other institution of higher learning for similar purposes.

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Full legal Name

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Signature

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Date

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 thesis to my late mother Esnart Mataka Chimenya and my Dad, Happy Chimenya, without them, I would not be here.

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Abstract

Parental involvement in neonatal pain management is an area that is receiving attention under neonatal pain care worldwide because parents can provide non-pharmacological pain management interventions (NPPMI) like therapeutic touch, kangaroo mother care, breast milk, containment or swaddling when their babies undergo painful procedures (Kyololo and Marete, 2014; Golianu et al., 2007). In Malawi, it was observed that involving parents in neonatal pain management is not practiced in most neonatal units as parents are routinely not involved during or after invasive procedures like lumbar puncture, therapeutic tapping, wound dressings, after a baby has undergone surgery and during collection of blood specimens. The involvement of parents in pain care can be of benefit in limited resource countries like Malawi (Molyneux, 2012) to promote pain management. Therefore, this study aimed at describing how parents are involved in neonatal pain management at Gogo Chatinkha neonatal Unit, Queen Elizabeth Central Hospital, Blantyre, Malawi. A descriptive study that used qualitative data collection and analysis method was employed. Participants were parents/guardians of babies who had undergone invasive procedures in the neonatal unit. Data was collected using a voice recorder then it was transcribed word by word, then coding was done to categorise it. Based on the meaning of the coded data, themes and sub themes were developed. Data were analysed manually using thematic content analysis.

Findings showed that parental involvement in neonatal pain care is poor. However, parents expressed willingness to take part in invasive procedures in order to provide NPPMI's. This would in turn improve parental involvement in neonatal pain care and promote the use of NPPMI in Malawian neonatal units hence improve neonatal health. Therefore it was concluded parents should be involved in neonatal pain care with an emphasis on use of NPPM to improve neonatal health.

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List of Main Abbreviations

QECH	Queen Elizabeth Central Hospital
NICU	Neonatal Intensive Care Unit
ICU	Intensive Care Unit
KMC	Kangaroo Mother Care
LP	Lumbar Puncture
NPPM	Non-Pharmacological Pain Management
NPPMI	Non-Pharmacologic Pain Management Interventions
IASP	International Association for the Study of Pain
IDIs	In-Depth Interviews
COMREC	College of Medicine Research Ethics Committee

Operational Definitions

Neonate:	An infant within the first 28 days of birth
Pain:	A physical sensory experience, causing discomfort irritation and annoyance but also creating a profound sadness, distress and despair
Parent:	A person who is or acts as a mother or father to a child
Health worker:	A qualified individual who provides health services to promote or improve the lives of people, families or communities
Parental involvement:	Allowing parents to take part in care of their babies during hospitalisation
Invasive procedure:	A medical technique that involves introduction of instruments or objects into the body or body cavities
Pharmacological management of pain:	Using drugs to treat pain
Non pharmacological management of pain:	Treatment of pain without using drugs

CHAPTER 1

Introduction and Background

Introduction

Globally many advances in practice of neonatal health care have occurred in technology and neonatal care practice, and neonatal pain has received much attention. Many countries have developed measures and interventions to assess and manage neonatal pain. Acute and chronic neonatal pain has been effectively treated using drugs like opiates, non-opioids and local anaesthetics (Meek, 2012; Slater et al., 2010). In addition, several studies have identified various parent provided non-pharmacological pain management interventions (NPPMI) that are effective in minimizing pain in neonates like kangaroo mother care, containment, breastfeeding, therapeutic touch and swaddling (Riddell et al., 2011;Kyololo and Marete, 2014; Fernandes, Campbell-Yeo and Johnston, 2011; Modarres, Jazayeri, Rahnama and Montazeri, 2013).

In Sub-Saharan Africa, pharmacological pain relief is a challenge due to limited resources. Non pharmacological pain management interventions would be a better option because they utilise readily available resources that are not financially demanding. These interventions can be adopted in the region as an affordable way to manage pain in neonates (Kyololo and Marete, 2014).

In Malawi, the situation is similar to most of the countries in sub-Saharan Africa where management of pain in new born babies is poor due to financial constraints (Molyneux, 2012). Evidence from a Kenyan neonatal unit shows that almost all invasive procedures done on neonates especially in the first few hours of admission were done with no analgesics (Kyololo, Stevens, Gastaldo and Gisore, 2014).This can be solved by involving parents, who play a role in

providing non-pharmacological pain management interventions like breast feeding and kangaroo mother care.

In addition, health care workers lack knowledge and skills on neonatal pain assessment and management leading to poor pain identification and management (Albertyn, Rode, Millar, and Thomas, 2009). This lack of knowledge and skills on pain management leads to inability to utilise parents in providing non-pharmacologic pain management interventions that are available because they do not know the importance of parental involvement in pain care. Sometimes it is also because of the attitudes of the health workers towards neonatal pain management, for example, some health workers have the knowledge but they do not apply it in practice (Nimbalkar, Dongara and Phatak, 2014). The result is that neonates are left with untreated pain.

Scientific evidence from the American Academy of Paediatrics, Committee on Fetus and New born and Section on Surgery (2006) indicates that untreated pain can lead to prolonged hospitalisations and also bring acute and chronic adverse effects like physiological compromise, altered pain sensitivity, behaviour alterations and adverse neuro developmental compromise in the course of a neonate's life. Findings from Herman et al.,(2006) and Hohmeister, (2010) indicated that children who were exposed to pain in their neonatal period when they were admitted in the neonatal intensive care unit (NICU) showed high pain perception indicating altered central sensitization. This was evidenced by the behaviour of the children who were included in the studies towards painful stimuli. The children demonstrated increased pain thresholds when they were pierced with a needle and even high perception when exposed to prolonged heat than the control group.

Poor involvement of parents during invasive procedures is a known issue in neonatal units (Franck, Cox, Allen, and Winter, 2004) and the interventions which are supposed to be

provided by parents may not be adequately utilised if they are not involved. In neonatal units like Queen Elizabeth Central Hospital, it was observed that parents were afraid to witness invasive procedures like lumber puncture. Some of the reasons that are given are that the procedures add stress on them while on the other hand it is like a routine for health workers to send parents out of the procedure room if their child is undergoing a painful procedure.

Nevertheless, some parents have expressed willingness to be involved in neonatal pain care (Franck et al., 2012) while some ask the health workers to allow them to step out of the procedure room so that they should not see their baby suffering from the traumatic procedures. In addition, no ward policy to guide whether parents should be involved in pain care is available at QECH. Therefore, it is not known whether parents want to be involved in pain care and this study aims to describe their views and understanding on pain management when their babies undergo invasive procedures.

Background

Parents are an important resource in neonatal pain management and involving them in pain care should not be an option because they have been found to be accurate in assessing pain in their babies than health care workers (Carter and Simons, 2014). They also take an active role in providing comfort measures categorised as non-pharmacological pain relief interventions like swaddling, containment and skin to skin if they are involved (Carter and Simons, 2014).

Clinically older children and adults can verbalise pain according to the feeling and assessment and management are easy because they depend on the level of pain described by the person (International Association for the Study of Pain, 2012). The International association for the study of pain (IASP), in their revised definition of pain included that even if an individual is not able to verbalise pain, the presence of pain should not be ignored (IASP, 2014). This was

added in the definition to accommodate patients who cannot verbalise the feeling of pain like neonates.

In the past, pain management in neonates has been either disregarded or underestimated. Various painful procedures, sometimes performed on a daily basis, have been performed with no or only minimal pain relief measures provided (Weissman, Aranovitch, Blazer, and Zimmer, 2009). However, things have changed and it has been shown that neonates experience pain and there is a need to minimise it by using either pharmacologic or non-pharmacologic interventions (Weissman et al., 2009). Carbajal et al., (2008), adds that several painful procedures are performed on neonates during the first 14 days of intensive care, and that these procedures continue throughout hospitalization. Some common procedures even require four or more attempts to be terminated in almost one-fifth of neonates, and that many of the documented painful procedures were not accompanied by analgesia (Carbajalet al, 2008; Kyololo et al., 2014).

Studies done in Malawi and Kenya also showed that painful procedures were done without any analgesia, documentation about pain assessment and management was not available and that health workers had little knowledge on the use of analgesics (Molyneux, 2012; Kyololo et al., 2014). In addition, parental involvement is optional and sometimes nurses and doctors do not allow mothers to be present during procedures. Proper explanations about what is happening to the baby in regards to invasive procedures are not done, and most mothers expressed that they are stressed because they do not know what is happening to their baby if they are not involved (Simons, Franck and Roberson, 2001).

In developed countries, parental involvement in neonatal pain management is a well known issue and it is being given a lot of attention. This is evidenced by several studies on

parental involvement in neonatal pain management and the willingness of health workers especially neonatal nurses to involve parents in invasive procedure like insertion of endotracheal tubes and chest drains (Simons et al., 2001; Carter and Simons, 2014; Kyololo et al., 2014; Franck, Oulton, and Bruce, 2012). The nurses also take time to provide pain information to the parents and how they can assist in providing comfort (Carter and Simons, 2014). In addition to available evidence on parental involvement in neonatal care, various tools for pain assessment and management have been developed and are used (Meek, 2012; Balda and Guinsburg, 2007). As a result, proper pain treatment protocols using both pharmacological and non-pharmacological interventions are available to help nurses and parents in managing neonatal pain (Meek, 2012; Harrison, Loughnan, and Johnston, 2006; American Academy of Paediatrics et al., 2006). The protocols developed for parents use are also used as a health education tool and they are written in small pamphlets using simple language so that the parents are able to understand.

However, a few studies on parental involvement in neonatal pain management have been done in Sub-Saharan African countries, and none have been identified in Malawi. Kyololo et al (2014) have conducted studies on procedural pain in neonatal units in Kenya and on parental perceptions on neonatal pain (Kyololo et al., 2014; Kyololo and Marete, 2014). A study for paediatric pain management was done by Molyneux (2012) on paediatric oncology pain management (palliative care) in Africa and it focused much in Malawi. In both studies, it was highlighted that staff working in paediatric units had problems in assessment and management of pain, lacked documentation on pain and no parents were utilised to assist in pain care.

Problem Statement

Neonatal pain management is a well-known issue and is being given a lot of attention worldwide. Parental involvement in neonatal pain management is another area receiving

attention under neonatal pain care because parents can provide non pharmacological pain relieving interventions like therapeutic touch, kangaroo mother care, breast milk, containment or swaddling when their babies undergo painful procedures (Kyololo and Marete, 2014). However, it was observed that involving parents in neonatal pain management is not practiced in most Malawian neonatal units. Parents are routinely not allowed or educated on how they can participate in pain care during or after invasive procedures like lumbar puncture, therapeutic tapping of hydrocephalus babies, collection of blood specimens, wound dressings, insertion of chest drains, minor surgeries and major surgeries.

The involvement of parents during invasive procedures can be of benefit in limited resource countries like Malawi (Molyneux, 2012) to promote pain management using the non-pharmacologic interventions like kangaroo mother care, breast feeding, use of therapeutic touch, containment and swaddling (Golianu et al., 2007). Therefore, this study aimed at describing how parents are involved in pain care.

Significance of the Study

This study was done to describe parental involvement in neonatal pain management at Queen Elizabeth Central hospital's neonatal unit in order to promote the use of parent oriented non-pharmacologic interventions for pain relief in neonates. The study will help in identifying pain care practices in the unit and inform nurses and clinicians on how they are managing neonatal pain. This will promote pain assessment and management by health workers in Malawian neonatal units. It will provide knowledge to health practitioners working in neonatal units on views and experiences of parents on neonatal pain management. This knowledge will promote parental involvement in neonatal pain management and utilisation of non-pharmacological pain management interventions therefore improving good neonatal outcomes.

The study will also assist in developing clear hospital policies on parental involvement during invasive procedures.

Study Objectives

Broad objective.

To describe parental involvement in neonatal pain management at Queen Elizabeth Central Hospital, Chatinkha Neonatal unit, in Malawi.

Specific objectives.

1. To describe parents' understanding on non-pharmacological pain relieving interventions.
2. To assess parents' knowledge on their involvement in neonatal pain management.
3. To explore how parents are prepared for involvement in neonatal pain management.
4. To describe factors that affect involvement of parents in neonatal pain management.

CHAPTER 2

Literature Review

Introduction

This chapter presents a comprehensive review of the literature relating to parental involvement in neonatal pain care globally and in Africa. The areas discussed are on existing literature surrounding non-pharmacological pain management interventions (NPPMI) used for neonates, Parents' opinion on involvement in pain management, how parents are prepared for neonatal pain management and the factors that affect parental involvement in neonatal pain management. The literature review was done in an attempt to find out what is already known on the topic and to identify any gaps as regards the context as well as methodologies which were used in previous studies.

Literature Search Strategy

Articles were searched on the internet using the online University of Cape Town health sciences Library databases and Health InterNetwork Access to Research Initiative (HINARI). Different search engines were used to access articles from EBSCO HOST, Cumulative Index to Nursing and Allied Health Literature (CINHAL) and Pub-Med online. The literature review focused on English written studies that were done between 2005 and 2015. However, a few studies that were done before 2005 were incorporated because they had relevant information. This was done to offer a good overview of the research that has been done so that relevance of present study can be determined. Boolean phrases were also used to search the databases. The search terms used were "parental involvement AND 'neonate' OR 'new born' AND Pain management", "non-pharmacological pain management AND neonatal pain", 'Neonate' OR 'new born' AND non-pharmacological pain management AND parent involvement".

Non Pharmacological Pain Management Interventions Used For Neonates

There are several non-pharmacological pain management interventions that can be used to manage neonatal pain. These interventions include kangaroo mother care (KMC), breast feeding, swaddling, containment, therapeutic touch and the use of pacifiers.

Kangaroo mother care can help in minimising procedural pain in babies. Johnston et al. (2008) explored the means of involving mothers to provide comfort during painful events. Their study on the use of Kangaroo mother care to manage pain after heel lance indicated that very preterm neonates appeared to have endogenous mechanisms elicited through skin-to-skin maternal contact that minimize pain response. The study also supports that Kangaroo mother care can help in reducing pain during minor procedures like heel lance in new born's (Castral et al., 2011; Maia, Azevedo and Gontijo, 2011). Kangaroo care appears to contribute to pain relief because it calms the child, reduces the level of stress, behavioural signs of discomfort, and is associated with reduced crying in response to pain. In addition, it also acts as a physiological response mediator and determines better autonomic stability. Furthermore, kangaroo care promotes mother-child bonding, increasing maternal confidence, promotes exclusive breastfeeding and benefiting the baby's growth and development (Maia, Azevedo and Gontijo, 2011).

Pillai Riddell et al. (2011) further support the use of KMC in their review on non-pharmacological management of infant and young child procedural pain. The studies analysed indicated that using kangaroo care is significantly efficacious in reducing pain reactivity other than using no intervention at all for preterm neonates. Therefore the use of KMC for pain management should be encouraged in Malawian neonatal units as it is easy, low cost and can be performed both before and during invasive procedures.

There is also evidence that swaddling, containment and facilitative tucking reduces procedural pain in neonates. Morrow, Hidinger and Wilkinson-Faulk (2010) in their study on reducing neonatal pain during heel lance procedures measured the difference in pain scores for new born's who were held and swaddled while undergoing routine heel lance procedures compared to new born's who were lying on their backs and not swaddled during heel lance. The NIPS score for neonates who were swaddled and contained during the procedure (experimental group) was significantly lower than the score for infants in the standard position (control group). A Cochrane review by Pillai Riddell et al. (2011), also support that there was sufficient evidence to support the use of swaddling/tucking as an effective intervention for reducing pain reaction in pre-term infants.

Breast feeding is another most effective way in reducing procedural pain distress in babies. Shah, Aliwalas and Shah (2006) did a literature search on the use of breastfeeding to reduce procedural pain and their findings indicate that like sucrose, breastfeeding neonates before and during a painful procedure resulted in decreased heart rate and reduced crying time unlike babies who are not. Modarres, Jazayeri, Rahnama and Montazeri (2013) also examined the effect of breastfeeding in full term neonates receiving immunisation. The results showed low scores for the experimental group on the Douleur Aiguë du Nouveau-né pain score. Therefore from these two studies, breastfeeding was recommended to be an effective non-pharmacological intervention for reducing pain for neonates undergoing single minor painful procedures.

Although use of pacifiers is not allowed in Malawian hospitals, it comes under non-nutritive sucking and has also shown that it helps to reduce pain in neonates. An object (e.g., pacifier or non-lactating nipple) is placed into an infant's mouth to stimulate orotactile or sucking behaviours during a painful event (Riddell et al., 2011). Supporting this intervention is

Liaw et al. (2010) who found that non-nutritive sucking effectively reduced pain, particularly mild to moderate pain. Their suggestion is that nurses should offer this intervention to relieve pain in preterm infants undergoing invasive procedures (Liaw et al., 2010). Liu et al. (2010) also compared the use of non-nutritive sucking and oral glucose and the findings showed that non-nutritive sucking was more effective to relieve procedural pain than glucose.

Parents' Opinion on Involvement in Pain Management

According to Franck et al. (2012) and Kyololo et al. (2014) parents expressed willingness to be present during procedures and to have information on all procedures that are done to their babies. Gibbins (2008) supports that parents have expressed concerns that their infants are often left without pain treatment and this adds stress to them as they cannot bear to see their babies in pain. The parents who were not involved in pain care reported high stress levels, than parents who had information about pain practices and how they can be involved. The study therefore recommends that parents need to be involved in pain care in the neonatal unit to promote family centered care and the use of non-pharmacological pain treatment as most of them expressed willingness to be part of their infants pain care.

Axelin et al. (2010) also suggested that nurses should take time to assess if mothers prefer to be involved in pain care in order to encourage them to take part. Other studies add that parents find a loss of parental role if they are excluded in pain care for their babies on top of the stressful aspect of having a child who is experiencing pain in the intensive care setting, and they found that if parents are involved in pain care, they learn parenting skills and the experience improves their parenting role in the next hospitalisation (Skene et al., 2011; Johnston et al., 2008).

Preparation of Parents for Involvement in Neonatal Pain Management

Parents need to be prepared for involvement during invasive procedures and neonatal pain management for them to understand their role in neonatal pain management. According to Axelin et al., (2010) thorough explanations of the procedures a baby will undergo helps to prepare the parent psychologically so that they get ready for involvement and participation in pain management. Therefore health workers need to take the responsibility of preparing parents when their child is expected to undergo invasive procedures in the neonatal unit.

The principles of family centred care in the neonatal unit emphasize the involvement of parents to bring out optimal health outcomes as family members provide emotional, physical and social and developmental support (Gooding et al., 2011). Carter and Simons, (2014) adds that parents have a key role in neonatal pain management and health workers especially nurses need to take the responsibility of assessing whether they want to be involved and encouraging parents to assist in pain care.

Grzyb et al. (2014) explored the views of medical students and qualified nurses to involve parents during neonatal unit ward rounds. The findings of the study showed that the views between the two groups were mixed. Some health workers felt that caregiver involvement inhibits the level of effective care provision; therefore they did not like providing care in the presence of parents. On the other hand some health workers found it useful to work together with parents as the parents helped comforting the baby and brought in new information they would use in care (Grzyb et al., 2014). McAdams et al. (2014), adds that a lot of health care providers prefer making decisions on their own rather than involving parents. Though this study was on involving parents in decision making in neonatal resuscitation, these results may be applied to pain care the NICU. These findings shows that the preparation of parents to be involved in

neonatal pain care might depend on personal preference as some health workers might find it useful to involve parents while some might not be comfortable to work together with parents during procedures and in neonatal pain management.

Factors that Affect Parental Involvement in Neonatal Pain Care

There are several factors that prevent effective management of pain in neonatal units which can also be compared to Malawi.

Nimbalkar et al. (2014) in their study on knowledge and attitudes regarding neonatal pain among nursing staff of the paediatric department in India showed that that the nurses lack knowledge on pain assessment and management and that their attitudes also were hindering pain management. One of the barriers identified by the nurses was that physicians do not prescribe analgesics for managing neonatal pain. So not only the nursing staff, but all of the health care providers involved in neonatal care may be lacking knowledge and hold perceptions and attitudes that hamper neonatal pain management (Nimbalkar et al., 2014).

The findings by Nimbalkar et al. (2014) are in line with what Akuma and Jordan found in 2012 in the neonatal intensive care units in United Kingdom. They found that analgesia and comfort measures were not usually administered for most procedures. Nurses followed guidelines on administering analgesia and some comfort measures and clinicians on the other hand, had knowledge about neonatal pain but they did not use the knowledge in practice (Akuma and Jordan, 2012).

Cong et al. (2013) also found that barriers to effective pain management were resistance to change, lack of knowledge, perceived fear of side effects of pain medication and incorrect interpretation of pain signals, lack of time, and lack of trust in the pain assessment (Cong, Delaney, and Vazquez, 2013). Other barriers to effective pain management using breast feeding,

KMC and sucrose during heel lance and venepuncture were identified by Desrosiers et al. (2014) in a study done in Ontario. Health Care Professionals factors included workload and time which prevented them from putting babies in skin to skin contact, on the breast or to use sucrose.

Baby feeding patterns also acts as a barrier to pain management. This is because baby may not be due for breast feeding when blood work is required or that the baby may not be breastfeeding well during the time of the procedure (Desrosiers, 2014). Parental factors included parental comfort and stress as most parents request not to be present when blood work is being completed because they do not like to see their babies undergoing traumatic procedures (Desrosiers, 2014).

Analysis of Literature Review

A lot of studies on neonatal pain assessment and management have been done in the world. A few studies have been done in Africa and a few studies have been found for Malawi. Several pain scales have been developed to aid in assessment and management of pain in neonates but are rarely used in our neonatal units. Nurses and doctors may have knowledge on assessment and management of neonatal pain but the gap in using the knowledge in practice is wide. Assessment of knowledge and attitudes towards assessment and management of pain in neonates has to be done in the Malawian setting.

Kangaroo mother care, breast feeding and parental involvement are basic aspects of new born care practised in Malawian hospitals but they are done for other reasons like family centered care other than pain care. Queen Elizabeth Central hospital is one of the leading hospitals in providing KMC in the region and also called ‘baby friendly’ because it encourages exclusive breast feeding in the first six months of life. However the use of these interventions for neonatal pain management has to be determined. In addition there are no protocols for pain

management specially designed for neonates and most often, parents are not allowed to be present when various painful procedures are done on their babies.

Barriers to inadequate provision of analgesics range from financial challenges to procure adequate pain medications for babies and hospitals like Queen Elizabeth central hospital do not prioritise babies' pain medication even if there is enough in stock. The only pain medications that are mostly found are oral syrup Paracetamol and Brufen. Intravenous or rectal Paracetamol which would be very suitable for this group of patients is rarely available and if it is a very serious condition the babies are referred to the palliative care department for opioids. In addition, nurses working in the neonatal unit are afraid to use morphine because it is not commonly used and they did not receive proper training on how they can give morphine to neonates.

However, the use of parent oriented non-pharmacological interventions like KMC, breast feeding, swaddling, facilitative tucking and non-nutritive sucking have proven to be effective in providing pain relief for neonates. This would be useful in low resource areas like Malawi, where drugs for pain management are limited.

Various studies on non-pharmacological pain management have been done but the people who are to be involved in providing these interventions are still left out when these procedures are carried out because from observation, most nurses and doctors don't want the parents to be present during painful procedures like lumbar puncture or when they are collecting specimens for various reasons. It is important then to promote pain care practices that utilise parent driven non-pharmacological interventions especially in low resource settings like Malawi to promote neonatal pain management and parental involvement/family centred care in Malawian neonatal units.

CHAPTER 3

Methodology

Introduction

This chapter describes the methodology that was used to conduct this study. It describes the design that was used, the study setting, the inclusion and exclusion criteria, the sampling method and how data was collected. It also describes the trustworthiness of the study.

Research Design

A descriptive qualitative design was used to conduct this study. The design was used in order to describe and give a narrative account (Brink, van der Walt, & van Rensburg, 2012) of parents' knowledge and experiences on neonatal pain management. It further assessed if parents' were involved in neonatal pain management and described the factors affecting involvement in neonatal pain management.

Study Setting

The study was conducted at Chatinkha Neonatal Unit of Queen Elizabeth Central Hospital (QECH). QECH is in Blantyre district, in the southern region of Malawi. It is the biggest referral hospital in Malawi with a bed capacity of 1320. It has the biggest neonatal unit in the country with a bed capacity of 85. The neonatal unit has 3 sections which are: the high dependency section where critically ill babies are admitted, the low risk section where babies who do not need medical support are admitted and the kangaroo mother care ward. The unit is run by ten nurses and three doctors. This setting was chosen because it had the right population needed for the study which are the neonates who undergo invasive procedures and their parents'.

Target Population

The target population of the study was parents of babies who had undergone an invasive procedure in Chatinkha Neonatal Unit. This population was chosen as it can give the required information for the study having had an experience of their baby undergoing an invasive procedure. Invasive procedures are diagnostic or therapeutic techniques that involve introduction of instruments or objects into the body or body cavities (Mosby's Medical dictionary, 2009).

Inclusion criteria.

The inclusion criteria for the proposed study was:

a. Parents of babies who had undergone invasive procedures in the unit. The invasive procedures that were included were lumbar puncture, ventricular tapping of cerebrospinal fluid from babies with hydrocephalus, collection of blood specimens, wound dressings, minor surgeries like suturing small lacerations sustained during birth and major surgeries like laparotomy .

Exclusion criteria.

The exclusion criteria for the proposed study was:

a. All parents whose babies had not undergone invasive procedures like lumbar puncture, ventricular tapping of cerebrospinal fluid from babies with hydrocephalus, collection of blood specimens, wound dressings, minor surgeries like suturing of small lacerations and major surgeries like laparotomy.

Sampling

The sampling method that was used for the study was purposive. This sampling method involves selecting participants according to the judgement of the researcher that they will give the required information (Brink et al., 2012)**.**

Sample Size

The sample size comprised of 18 parents'. A small sample size in qualitative research makes it possible for the researcher to establish a close relationship and spend adequate time with the participants. It also promotes the collection of adequate data from the in-depth interviews.

A sample size of 18 participants was used because no new information was generated thereafter hence a saturation point was reached. Data saturation occurs when additional participants do not give different or new information (Brink et al., 2012).

Data Collection Instrument

A semi structured interview guide (appendix 1A) was used to collect data from the parents'. The tool was developed and guided by the objectives of the study. The interview questions explored parents' understanding on neonatal pain management, and parents' knowledge on non-pharmacological pain management interventions. In addition, the questions assessed how parents' are prepared for involvement in pain management and explored factors that affect involvement of parents' in pain management.

The interview guide was translated to Chichewa (appendix 1B) a local language in Malawi, for easy communication with the parents'. Two independent translators were involved in translating the interview guide to make sure that it gives the same meaning of the questions that will be asked.

Pre-testing

Pre-testing of the interview guide was done at Queen Elizabeth Central hospital's paediatric nursery. This setting had similar characteristics to the study setting. It admits neonates and the invasive procedures that are carried out are similar to those carried out in Chatinkha

Neonatal Unit. 3 participants were involved in the pre-testing for the principle investigator and the research assistant to get familiar with the study tool, check its clarity and to modify the questions if required, so they capture the required information (Brink et al., 2012). The pre-testing was done to determine how much support will be needed in terms of assistance in data collection and to check willingness of participants to participate in the study.

Data Collection

Data collection was done in Gogo Chatinkha side room by conducting in-depth interviews with parents with babies who had undergone invasive procedures. The interviews were done on the day of discharge. This was done because during this period, parents have reduced levels of stress as Latour et al. (2011) narrates. In addition, parents are likely to give a lot of information as the condition of their baby has improved. Data were collected from 12 December, 2016 to 6 January, 2017 by the investigator and one research assistant. Data were collected using a digital voice recorder. In addition, some notes were written down by the data collectors as the interviews were being conducted.

Research assistant training on data collection.

The research assistant who was involved in data collection was trained by the principal investigator for 2 days on how to conduct the in-depth interviews. He was also involved in the pre-test and he was oriented to the study setting within the 2 days of training to get familiar with the study setting and the data collection tool.

Trustworthiness of the Study

Trustworthiness in qualitative study is compared to validity and reliability in quantitative research. In this study, trustworthiness was ensured by credibility, transferability, dependability and confirmability.

Credibility.

Credibility is compared to internal validity in quantitative research and it means that the researcher has confidence in truthfulness of the data and the interpretation. To ensure credibility of the study, the in-depth interview guides were reviewed by experts in the child health department. Comprehensive questions were asked during the IDIs by the data collectors to make sure that adequate information has been collected. A summary was done after each Interview and participants were asked if the summarised data was in agreement with what they said. This was done to make sure that there is truth in the findings. Reflective commentary was done by the data collector to ensure effectiveness of the collected data.

Transferability.

Transferability is compared to external validity in quantitative research. Transferability refers to the extent that the results can be generalised or transferred to other settings or contexts (Trochim, 2006). To ensure that findings can be applied to other situations, the researcher made sure that sufficient data was collected and that the phenomena under study has been comprehensively explained for the readers to understand the topic under study. Results of the study were compared to similar projects which were done in other settings, using the same research methods to see if results are correlating.

Dependability.

Dependability is compared to reliability in quantitative research and it refers to the need to account that findings can be consistent if the research is repeated (Trochim, 2006). To ensure dependability, proper explanations on each step of the research process were done in the study. Rationales for each step were clarified to make sure that everyone understood. Audit trails for the findings, field notes and reflective journals were kept so that people can refer to or that people

can trace where the data came from so that they may use them for other research and to ensure consistency.

Confirmability.

Confirmability is compared to objectivity in quantitative research. It refers to providing evidence that findings, conclusions and recommendations have been supported by data (Brink et al., 2012). To ensure confirmability, the researcher listened actively to the conversations during the interviews to avoid mixing of the researcher's views and those of participants. The interviews were recorded using a voice recorder so that there is evidence that the data is true. An audit was also done to provide evidence that the investigations, recommendations and conclusion are supported by data (Brink et al., 2012).

Data Analysis

Data were analysed manually using thematic content analysis as described by Brink et al. (2012). Data analysis was done concurrently with data collection to guide decisions for the next interviews (Merriam, 2009). During each interview, key points were noted and participants were asked if what has been summarised is what they said to make sure that the collected information was correct.

The investigator and the research assistant listened to each in-depth interview before the next one to make sure the data collected was correct and clear. Once all the IDIs were done, data was organised by listening to the recorded interviews over and over again and the researcher got familiar with the data and got the true meaning. The recorded data was then transcribed verbatim and proof read against the recorded interviews (Brink et al., 2012). Then translation was done. An independent person was asked to back translate to validate the meaning of the data. Then coding was done to categorise the data. Similar data were grouped together to ease the coding

process. Based on the meaning of the coded data, themes and sub themes were developed. Similar themes with their sub themes were grouped further from all the interviews and further descriptions were made. Another independent person was asked to help in encoding the data to validate if the data was giving a true reflection of the original data and to verify if there was an agreement.

Data Management

The interviews were given numbers for easy identification and sorting and to ensure anonymity. Data collected were checked for completeness and accuracy. Written data and the voice recorder were kept in a lockable locker for safety and confidentiality.

Ethical Considerations

The research proposal was submitted to College of Medicine Research Ethics Committee (COMREC) for approval (appendix 5). Approval was also given in a written form by Queen Elizabeth Central hospital's director (Appendix 4), the unit matron and Head of department and the ward in-charge of the unit.

Consent was sought from willing participants after explaining to them about the study and the relevance of the study in our hospitals. A consent form (appendix 3) was designed for the participants to sign after accepting to participate. Interviews were done in Chatinkha neonatal unit KMC side room, which is a neutral place, not intimidating, conducive for voice recording and private. Each participant was ensured that whatever was discussed during the interviews, will not be discussed with anyone other than the research members. Numbers were used to identify each participant to ensure anonymity.

Study Limitations

The study was conducted in one hospital because of limited time. If multiple hospitals were used data would have been generated from different neonatal units and geographical areas, and the number of participants would have increased too. There are also limited studies on parental involvement in neonatal pain management in Malawi, therefore difficult to make comparisons with other studies from a similar setting.

Dissemination of Findings

The research report will be disseminated through a number of methods. The dissertation will be put in Kamuzu college of Nursing Library and it will be accessible to students and staff at KCN. Two copies will be submitted to Elma philanthropist for Health as the study was funded by them. Other copies will be submitted to COMREC and the department of paediatrics at QECH. Presentation of the study findings will also be done at QECH and relevant forums and it will be published in journals if accepted. The supervisor and the researcher will also have their own copies.

Conclusion

The in-depth interviews that were conducted enhanced deep understanding of parental knowledge and experiences in neonatal pain management using non-pharmacological interventions. The investigator believes that the findings generated from this study have contributed to the understanding of how parents' can be involved in neonatal pain management in the neonatal units and therefore will improve the management of neonatal pain using NPPMI in Malawian neonatal units.

CHAPTER 4

Findings of the Study

Introduction

This chapter presents findings of the study. Narrative data have been presented under the following pre-determined themes: parents' understanding of neonatal pain, parents' understanding of NPPMI's that are used to manage neonatal pain, parents' knowledge of their involvement during invasive procedures, current practice on parental involvement in neonatal pain management in the unit, parents' opinion on involvement in neonatal pain management and factors affecting involvement of parents in neonatal pain management.

Parents' Understanding of Neonatal Pain

One subtheme emerged from this theme; signs of neonatal pain.

Signs of neonatal pain.

Most of the participants realised that babies feel pain and they show that they are feeling pain by showing behaviour cues like crying, being restless and sad facial expression. The mothers felt that babies are human beings and as human beings they have senses, so they feel pain. One participant (PT) said;

> "*It is obvious that a baby is not fine in comparison to its usual condition because at times when it is well, it is cheerful and the times it feels pain, you see some changes in the way it behaves and changes of the body, then you know that the baby is not fine. Therefore, pain can be detected in a baby like this one when its body temperature rises or when it cries". (PT 11, Female, Mother of baby)*

However, some of the participants did not know that a neonate feels pain.

"*About the pain of babies, I don't know if a new born baby feels pain, so most of the times when the baby is crying I regard it that it's just a baby". (PT 12, female, mother of baby).*

Parents' Understanding of NPPMI's that are used to Manage Neonatal Pain

Some of the participants demonstrated understanding on non-pharmacological pain management interventions. Majority of those who demonstrated understanding mentioned breastfeeding, comforting and therapeutic touch as interventions to minimise pain when their babies undergo an invasive procedure. One of the participants said

"When a baby feels pain, it cries, so we are required to breast feed it to give it some relief" (PT 1, female, mother of baby).

Some of the participants however had no knowledge on what they can do as parents' to control pain when their babies are undergoing or have undergone invasive procedures. Some of them failed to list what they can do as parents' to soothe the pain when their babies have undergone invasive procedures without using drugs. However, those who lacked knowledge in non-pharmacological pain relieving measures, reported taking their baby to the breast as a routine for comforting the baby after the baby has been given an intramuscular injection for the purpose of silencing the baby if it is crying, therefore breastfeeding was not done as a way of relieving pain, but as a parenting routine for baby who is crying. One of the participants said;

"When my baby is crying, I breast feed it, this is because I cannot just leave it to cry, we are required to comfort it". (PT10, female, mother of baby).

Parents' Knowledge of their Involvement during Invasive Procedures

Majority of the participants did not know that it was important for them to be present and be involved in managing pain when their baby is undergoing invasive procedures. Most of the participants felt that it was the duty of the health workers to give any type of treatment including pain treatment if their baby has been admitted to the unit, therefore making their presence and involvement irrelevant. One participant narrated;

> "*When I bring my baby to the hospital, I trust that the doctors will treat my baby accordingly, therefore, I should not interfere when the doctors are doing their job because they are the ones who know what is wrong with my baby". (PT 14, female, mother of baby).*

Current Practice on Parents' Involvement in Neonatal pain Care in the Unit

Most of the participants were not called to be present and be involved in pain management. When they came to the unit to breastfeed, they found that their babies have already undergone one or multiple procedures while they were out in postnatal ward.

> *"I was not around when blood was collected from my baby, even when they were performing lumbar puncture".* She added, *"The time they collected fluids, I was not present and the time I came to breastfeed the baby I saw that the baby was injected at the back and they sealed where they injected with something. (PT 11, female, mother of baby).*

Some participants were told directly to go out of the procedure room, and the health workers performed the procedures while they were out waiting.

"If they want to provide drugs they say that 'lie the babies down and get out, time up and we want to give them drugs'. We don't know the drugs they provide to the baby, what is it suffering from. We don't know what the baby is suffering from, they just provide drugs and we don't even know for what illness". (*PT 19, female, mother of baby).*

Another participant adds;

"*Actually, when the baby is being administered injection at the incubator, people are not present. Of course as a person you wish to be present because of love that you have on that baby, but when administering injection to babies they command everybody out. So it's not possible for a person to be present. But you really wish to be present when they administer injection to the baby but it happens that they command you out saying that they want to administer injection to babies, then everybody gets out. So it's not possible if you are there at the incubator because they chase you out". (PT 4, female, mother of baby).*

Another participant also added; "*Injections, drawing blood and collection of water from the back* (Lumbar Puncture) *are done when mothers are not around. Sometimes you are just in luck to find them doing the procedures during feeding time and you may watch". (PT 13, female, mother of baby).*

For those who were present during the procedures, some were allowed to be involved and provide pain management, while some were allowed to support or help the health worker perform the procedure without much difficulty as some babies are shaky. One participant narrates;

"*I was allowed to help hold my baby when they were inserting cannula so that the nurse should do it properly". (PT 18, female, mother of baby).*

Some were present in the procedure room just to watch the health workers perform the procedure on their baby but they were not allowed to be involved to provide pain management.

"When they were collecting blood from my baby, I sat on the bench and I just watched while they were doing the procedure". (PT 10 female, mother of baby).

Of the participants who were allowed to be present, a majority of them did not see the health workers providing pain relief measures in any way during or after the procedures.

"*I was there when doctors were searching for a vein on my baby, so it happened that they did not find the straight one after searching it and then they left that place and injected on another place and this happened for several times. When the cannula was inserted, they injected and noticed that the drugs were not going in, then they took it off and injected on another place. When they saw that had also failed, they went to seek help from their colleagues. All this time, my baby was crying and I did not see the doctor providing drugs to relieve pain or telling me to breastfeed the child before reattempting the procedure". (Patient 11, female, mother of baby).*

Some of the respondents were allowed to be involved and provide pain management to their babies during and after the procedures. For those who were involved, they expressed satisfaction and were happy because they were able to take part in pain management by breastfeeding or provide therapeutic touch for their babies.

"They should give us a chance to breastfeed and comfort the baby while they are giving treatment, on top of that we are able to see what they are doing". The participant added "*when we are allowed to be present, we breastfeed the baby so that it should not feel too much pain, or maybe we hold it in a tenderly way like protecting and caring it so that maybe it should not feel too much pain". (PT 19, female, mother of baby).*

Those that were not involved, expressed dissatisfaction on the care provided. When asked how they felt when they were not involved, one participant said;

"*I was not pleased, but I just accepted. The doctor was helping my baby, and the treatment required the baby to undergo a painful experience, so I accepted that she is being assisted as required". (PT 3, female, mother of baby).*

Another participant added;

"They said that they were busy with other doctors. I sat somewhere like there and they were treating the baby there, so it was somehow difficult at that particular time to hold and help my baby". (PT 10, female, mother of baby).

The participants were asked if health workers take time to explain to them before and after their baby undergoes an invasive procedure. Most of the respondents said that this is not routinely done. In most cases, the parents' are outside and they find most of the procedures already done. In other cases, the parents' can be available, but the health workers perform the procedures on their own like the mothers do not exist.

In the rare cases where mothers are called mostly is for the surgical babies, either because the baby is undergoing a major procedure, so the doctors cannot avoid explanations. For

example, one participant had a baby who had undergone spina bifida repair and was scheduled for shunting because the baby had hydrocephalus. Before the shunting, its pre-operative routine to do cerebral spinal fluid tapping to rule out infection. Before, the doctors used to do the procedure on their own, but mothers started asking questions and getting scared when they come to the ward and find their babies with a bandage on the head, and sometimes the bandage would be found wet because of leaking cerebral spinal fluid after the injection. Rumours started spreading that doctors are getting blood and some samples not known to the parents' for their own benefit. So to prevent these rumours, doctors started calling mothers so that they should be available to see what procedure they are doing to their baby, and they explain every step to them. The participant reported;

> "*The doctors used to collect the water from the head on their own without inviting us. One time they did this to a certain baby and his mother was angry with them. She told them they were collecting blood from the baby without her knowledge. It reached the extent where the doctor went back to the laboratory to get the water that was collected to show the mother that this was what we collected from your baby, but the mother was not convinced and kept insisting that they collected more. From that time, they tell us when they want to collect water from the babies and they invite us to be present". (PT 2, female, mother of baby).*

On health workers taking time to explain to the mothers on how to provide non-pharmacological pain management interventions, the majority of the respondents said that it is not done. Therefore, health workers do not provide information on non-pharmacological pain management interventions and they do not encourage the mothers to practice them when their babies are undergoing invasive procedures.

"Those kind of things have never been communicated to me" (PT 1, mother to baby).

PT 1 denied when she was asked if a health worker explained to her about NPPMI's she can provide to her baby when she was given an injection.

Parents' Opinion on Involvement in Pain Management

A majority of the respondents expressed willingness to be involved during most of the procedures and take part in providing non-pharmacological pain management interventions to promote pain care and parental involvement during procedures. They also verbalised that when parents' are involved, some complications that come due to the painful procedure like bleeding and excessive crying may be avoided. One participant verbalised;

> "*I think parents' should be present, they administered an injection to my baby today, they injected it on the thigh and when I came I found that there was blood all over here, from the thigh flowing down all over this place, it was stuck down here showing that there was too much bleeding. It seems that the baby was doing its legs like this and had with blood all over the legs. I even said can you see how the baby is, it was injected but has bled too much today. I was concerned because if the parent is present when that cotton is applied like this the blood cannot come out like that". (PT 15, female, mother of baby).*

The parents' also reported that health workers should make an initiative to encourage the mothers to be present or ask the mothers if they want to be present or not. They reported that personal preference should be respected because involvement depends on how one feels and the level of understanding. On the other hand, they emphasised that health workers should avoid judgement of parents' preference to be present or not without explaining to them.

"If a mother is afraid to be present, then don't involve them, but for those who are willing to be present, involve them". (PT 1, female, mother of baby).

Factors Affecting Involvement of Parents' in Neonatal Pain Management

A number of factors affect parental involvement in neonatal pain care. Two themes emerged from the findings. These themes are facilitating factors and hindering factors. On facilitating factors one subtheme emerged which was good attitude from health workers. On hindering factors, three subthemes emerged. The themes are poor attitude from health workers, fear from women and health workers judgement. The parents' were also asked on how the hindering factors could be addressed. One subtheme was found; change of health workers attitude.

Facilitating factors.

Health care workers attitude.

A number of the participants expressed satisfaction on how other health workers treat them. They reported that some health workers do not perform procedures when the mothers are not around. If the mothers are in the postnatal ward, they call them or they send their fellow mothers to call them. When they come to the unit, the doctors give them clear explanations on what will happen to their baby, and how they should be involved. Some even allow them to breast feed their baby while an injection is being given or during blood specimen collection. Some mothers even reported that they provide non-pharmacological pain management to their babies, without themselves knowing that it is for pain management, they just do it as a routine to prevent the baby from crying.

One participant reported;

"Some health workers are approachable. When you ask questions, they answer nicely and they even encourage you to ask them if you have any questions. They explain the procedure and allow you to be present and involved". (PT 2, female, mother of baby).

Hindering factors.

Poor attitude from health workers

Most of the respondents reported that health workers shut down mothers. On many occasions some participants felt like the health workers acted as if the mother is not there.

"When I arrived in the ward, the nurse just started helping the baby, when they finished, they gave the baby back to me, and it was like I was not there". (PT 12, female, mother of baby).

This promotes fear among the women because they cannot ask questions, and one participant reported that it increases stress, as explanations on what is happening to their baby are not done. One participant reported with a sad tone;

"You need to inform parents' that 'we have assessed your baby and we have diagnosed so and so, therefore we will provide this treatment or maybe not even mentioning what kind of treatment you will provide but just say these are the results from what I assessed', that's all we want". (PT 15, female, mother of baby).

One participant whose child had undergone spina bifida repair reported on poor communication;

"They just leave us, they don't say anything. When we are back and if the baby is conscious after theatre, they tell us 'breastfeed the baby' sometimes they say that 'come

at 2 O'clock to breastfeed the baby'. We breastfeed at 2 O'clock and they don't tell us that 'you hold the baby like this because the baby feels pain', no, we hold the baby anyhow. They don't tell us that 'you are required to hold the baby like this because the baby feels pain', no, they don't even say that 'today the baby is going for operation', no, they don't tell us". (PT 19, female, mother to baby).

Parents' fear to witness invasive procedures.

Majority of women expressed that sometimes they fear being present to witness their baby experiencing trauma.

"When they were injecting my baby, I felt pain, and I was hurt. I felt sorry for my baby". (PT 19, female, mother of baby).

Another participant reported;

"When they started giving my baby the injection, the baby started crying so I just walked away". (PT 7, female, mother of baby).

One of the participant added;

"The crying of the baby makes us feel sorry, because we think the baby is feeling a lot of pain". (PT 1, female, mother of baby).

Some even ask the health workers to go outside so they should not be present and see their baby undergoing through a traumatic experience.

Health worker's judgement.

Some participants reported that health workers give prior judgement on the mother's readiness to be involved during invasive procedures. They think mothers are fearful to witness

some procedures so they try to exclude those who seem fearful, and include those who they think are not fearful.

> *"Doctors are able to see that this woman is afraid and should not be present and that woman is courageous enough so they should be present when providing treatment to her baby". (PT 1, female, mother of baby).*

On the other hand the practice in the ward shows that procedures like LP are mostly done in the absence of mothers because they think mothers can feel sorry to see their baby undergoing through the traumatic procedure.

Minimizing barriers.

Change of health worker's attitude.

Most of the respondents felt that most of the barriers can be solved if the health workers do their best to accommodate the mothers when their babies have been admitted in the unit. The mothers felt that the health workers should make it a routine to call mothers and encourage them to take part in pain care. They also need to give proper explanations on what is happening to their babies, what procedures the babies will undergo, the importance of their presence and how they can provide non pharmacological pain management interventions during or after invasive procedures.

> *"If the doctors have not given you freedom even if you are able to walk, if they have not given you freedom of calling you to come, you cannot be present, but if they call you, it's like you have been given permission to be present and assist your baby". (PT 10, female, mother of baby).*

On health workers judgement on whether a mother is ready for involvement or not, one participant said;

> *"As women we understand things differently. The invasive procedures to some is ill treatment while to others, it is proper treatment. So health workers should be able to ask if a woman is afraid or not and involve them according to preference. Those who feel too much sorrow when they see their baby crying, might be excused while those who are courageous can be involved to help in providing pain care to their babies". (PT 1, female, mother of baby).*

Summary of the Findings

Results from this study show that parents' involvement in neonatal pain care is poor. A lot of parents' do not know what NPPM is as health workers do not take time to explain about NPPM nor encouraging them to take part in providing NPPMI. The findings presented in this study also show that a lot of parents' expressed willingness to take part in invasive procedures in order to provide NPPMI's. In addition, the findings also pointed out barriers that need to be addressed to promote parents' involvement in neonatal pain care.

CHAPTER 5

Discussion of Findings

Introduction

This chapter discusses findings of a study on ‘parental involvement in neonatal pain management’ in relation to available literature. The discussion is done under five predetermined themes: parents’ understanding of non-pharmacological pain management interventions (NPPMI) that are used to manage neonatal pain, parents’ knowledge of their involvement during invasive procedures, parental involvement in neonatal pain management in the unit, parents’ opinion on involvement in neonatal pain management and factors affecting involvement of parents in neonatal pain management.

Parents’ Understanding of NPPMI that are used to Manage Neonatal Pain

The study findings showed that a majority of the mothers practice one or two of NPPMI but did not realise what they are. When asked if they know what NPPM is, a lot of them demonstrated little knowledge. However, when probed, a few explained that they breastfeed or comfort their baby through swaddling to minimise pain. This may imply that parents have little knowledge on NPPM and the interventions that are be provided under it. This finding is consistent with findings from a study which was done in China by He, Pölkki, Pietilä, and Vehviläinen-Julkunen (2006) on parent's use of non-pharmacological methods in children's postoperative pain relief . In the study they described the different non pharmacological methods parents use to manage postoperative pain in children and other associated factors. The findings pointed out that parents have limited knowledge on non-pharmacological interventions they can use to manage pain and health workers need to take the role of educating them so that they are able to play their role to assist in managing pain in children.

Similarly, Pölkki, Vehviläinen-Julkunen and Pietilä (2002) also support that parents need proper education to equip them with knowledge on providing non-pharmacologic pain management interventions to their children in the hospitals. Health workers therefore need to take the responsibility of educating mothers comprehensively on NPPM so that parents know and understand what NPPMI's are and how they can provide them. A majority of the parents also demonstrated knowledge by mentioning the signs babies show when they are in pain. Crying was mentioned by many as a common sign of neonatal pain or any other discomfort. This shows that the mothers are able to know when their baby is feeling pain and they are able to take action.

These findings are also consistent with what Gibbins (2008) found in his study done in Canada that parents have little knowledge of neonatal pain and what they can do to provide comfort. Gibbins indicates that parents have little understanding of the behavioural cues their baby might show when in pain and how they can provide comfort measures mainly because health workers do not take time to provide pain information and how they can comfort their babies using NPPMI. If proper information is provided to parents on NPPMI and how they can play their role, parents will be equipped with adequate knowledge on pain management and they will have confidence to provide NPPMI. Parents will also be comfortable to be involved during invasive procedures.

Despite parents having minimal knowledge on NPPMI and how they can be involved in neonatal pain care, a lot of them verbalised that they practice these interventions without knowing that they are NPPMI. Therefore, health workers should reinforce the knowledge by taking time to explain to the mothers and make them realise that the routine care they provide

when they suspect that their child is feeling pain is NPPMI and educate them how they can correctly provide these interventions to promote effectiveness.

Parents' Knowledge of their Involvement during Invasive Procedures

A number of the participants did not know that they were supposed to be involved during procedures. They also did not know what they were expected to do, for example, the interventions they were supposed to provide to their babies when they are involved. When asked if they are supposed to be present during procedures, a majority of them felt that the responsibility of treatment once they step in the procedure room should be left to health workers as they are the ones who have better knowledge and understanding of the baby's condition. A number of them thought that it is the duty of the nurse or doctor to provide both pharmacological and non-pharmacological pain management interventions because they are qualified to provide better care. They also expressed trust in health workers expressing that as long as their baby gets to the hospital and is in the hands of health workers, they trust that the baby is in safe hands. However, Carter and Simons (2014), support parental involvement in neonatal pain management. They argue that if parents are involved during procedures and in pain management, it reduces length of stay in the hospital which in turn saves hospital resources, reduces stress to both the parent and the baby and promotes parental satisfaction towards the care that their baby has received.

Srouji R et al. (2010) in their study on 'assessment and non-pharmacological pain management in children' agree that the child's family should be allowed to be active in participating in procedures and pain management. They add that parents need to be provided with pain management information with an emphasis on non-pharmacological pain management information, so that they become knowledgeable on NPPMI and how they can provide the

interventions. They also state that when parents are trained to be assistants in pain care, it reduces procedural time and stress to the baby (Srouji et al., 2010). The assistance that parents provide also reduces work for the health workers and improves the care provided to the baby and other patients in the unit. In a study conducted by Desrosiers (2014), nurses mentioned workload as one of the factors that prevents them from providing proper pain management. Therefore, parents should be allowed to assist in pain management to improve neonatal outcomes.

On the contrary to the research findings which are in agreement with parental involvement in neonatal pain management, Grzyb et al., (2014) argue that parents should not be allowed to participate in care because they prolong procedural time. They argue that parents need proper explanations and teaching for them to understand and carry out the required interventions properly. When health workers do the procedures without involving mothers, no thorough explanations are needed, shortening procedural time thereby allowing them to attend to other patients.

Parental Involvement in Pain Management in the Neonatal Unit

The findings show that health workers do not involve parents in neonatal pain management in the unit. A majority of the parents expressed that most of the procedures are done when they are in postnatal ward or when they are in the waiting room. Parents also added that health workers do not take time to explain how they can provide NPPMI's when the baby is undergoing an invasive procedure if they are allowed to be present.

These findings are in line with what Franck, Oulton and Bruce (2012) found. In their study titled "Parental Involvement in Neonatal Pain Management: An Empirical and Conceptual Update" which was done in four neonatal units in London using randomised controlled trials. They found that parents are not involved in neonatal pain management. The parents expressed

that health workers do not encourage them to be involved in pain management and they do not provide enough information on pain management for them to provide NPPM. Similarly, Simons et al. (2001) agree with the findings. In their phenomenological study which was done in England, parents expressed that nurses do not actively involve them in pain management. Therefore, health workers need to take the responsibility of encouraging mothers to be involved in pain management and educate the parents on the benefits of their involvement.

Parents' Opinion on Involvement in Neonatal Pain Management

The findings show that a lot of parents wanted to be involved and assist in pain management when their baby is undergoing invasive procedures. The parents expressed that if doctors and nurses allow them to be present during procedures and let them provide NPPMI's, they will feel happy and important and this will help them know how their baby is being assisted rather than having speculations. They also said that most of the rumours that come along, are because doctors perform procedures on their own allowing parents to have false assumption on the type of care they are providing to the babies. This especially happens in terms of collection of blood samples where a lot of women speculate that doctors get blood samples for reasons best known to themselves. Therefore, doctors and nurses should consider involving parents in pain care to improve neonatal pain management, improve neonatal outcomes and to promote transparency and accountability in terms of the procedures that are done.

These findings are in line with the findings of Franck, Oulton and Bruce (2012), that parents feel loss of control when they see health workers performing procedures without involving them. They describe when doctors or nurses perform procedures on their own, it shows like the parents cannot contribute anything towards the care of their baby. Therefore doctors and nurses need to consider involving parents in every aspect of care for their children while teaching

them how they can continue the care at home since the child spends most of the time with the parent.

Karapinar, Yirmaz and Egemen (2005) did a study in Turkey and they support that parents want to be involved in every aspect of care for their baby for them to know what is happening to their baby thereby reducing hospitalisation stress. In their study titled 'Mothers attitudes towards their own presence during invasive procedures on their children' where they involved 742 mothers, it was found that a lot of mothers preferred to be present during invasive procedures performed on their children. However, willingness varied with social economic status, education background, age and level of invasiveness of the procedure that will be performed. Mothers who were more educated and those who had a high social-economic level were more willing to be present during invasive procedures. The lesser invasive the procedure is, the more the mothers preferred to be present too. The results obtained in this study did not determine the socio-economic status or the education background, however, a lot of parents preferred to be involved during invasive procedures regardless of their level of education and socio-economic status. Therefore health workers need to assess and consider parent preference on involvement and provision of NPPMI to promote parental satisfaction towards care, neonatal pain care and to enforce parent-health worker relationship (Karapinar et al., 2005).

Carter and Simons (2014) agree that parents feel valued if they are involved in neonatal pain management as this allows them to provide their caring role as a parent. Parental involvement also encourages them to ask questions about the progress of care and promotes their satisfaction towards the care that their baby is receiving while in the NICU. Hospitalisation itself leads to stress, so if health workers are excluding parents from the activities that happen in the NICU, the parents stress levels go high. On the other hand, some parents felt that it is the

responsibility of health workers to provide all care when their child is hospitalised. The parents felt that since the health workers are the ones who are well trained and knows exactly what is going on with their child, they should be the ones providing all the total care the baby needs. However, the participants in this group agreed that they still needed information about what was happening to their baby so that they know and understand about the condition of their child and the progress.

Factors Affecting Parental Involvement in Neonatal Pain Care

The findings show that there are a number of factors that affect parental involvement both positively and negatively. The facilitating factors include good communication and good attitude of health workers towards parents. The hindering factors include health workers bad attitude, fear and health workers judgement.

Facilitating factors.

Good communication between parents and health workers was found by the participants to be a facilitating factor towards parental involvement in neonatal pain management. Good communication encouraged parents to ask questions pertaining the care of their baby and in turn promoted involvement in procedures and pain management during the study. If a health worker showed a positive attitude towards a mother, she was free to ask questions and was willing to assist in the care of the baby. Nimbalkar et al. (2014) in a study titled 'Knowledge and Attitudes Regarding Neonatal Pain among Nursing Staff of Paediatric Department: An Indian Experience' agree that the attitude of health workers affects parental involvement. In their study, mothers expressed that they were free to assist in care and ask questions if the health worker allowed them to do so. Therefore, health workers need to show a welcoming attitude towards parents and

take a lead in explaining to the mothers about NPPMI to encourage them to ask questions in order to promote involvement during invasive procedures and neonatal pain management.

The findings also show that some health workers even took an initiative to call the parents who were not around during procedures. This is good because parents feel like they are an important aspect of care for their baby when they are called for explanations or when they are asked to assist and it motivates them to learn more and provide better care.

Hindering factors.

The study findings show that poor attitude from health workers and their prior judgement on involving parents during procedures hinders parent's involvement in pain management. The parents expressed that some health workers do not show a welcoming attitude when they want to ask questions or when they show interest to be involved during routine activities that are done on their babies in the unit. The parents also observed that some health workers prefer to perform procedures on their own. A number of studies indicate that parents get discouraged from getting involved in pain management when health workers have a poor attitude towards them (Nimbalkar et al., 2014; Desrosiers, 2014 and Cong, Delaney and Vazquez, 2013). McAdams, McPherson, Batra and Gerelmaa (2014) also agree that parents feel dejected when nurses or doctors perform the procedures on their own without asking the parents whether they want to be present or not.

In addition, some health workers have a preconceived judgement on the parents that some parents fear being present during some procedures depending on the level of invasiveness, so they go ahead without asking if the parent will prefer to be involved or not. This has led to a lot of parents not being involved during procedures because they feel excluded or they fear that the health workers do not want them present or as an assistant in managing pain for their babies. The

prior judgement and the poor attitude hinders neonatal pain management because if a parent is not invited to be present or to take part in managing the pain of her baby, the NPPMI that are supposed to be provided by parents cannot be provided. Health workers also need to take the responsibility of explaining to the parents that invasive procedures are painful, so babies cry as a natural response to pain. This will promote understanding and minimises fear to the mothers who feel sorry when their baby is crying and avoid involvement during procedures therefore encouraging them to be present and take their role as providers of NPPM to their babies.

Health care workers should encourage parents to be involved in procedures that they feel traumatic and avoid judging that parents might not prefer or be scared to be involved. As Karapinar, Yilmaz and Egemen (2005) in their study on ‘Mothers' attitudes towards their own presence during invasive procedures on their children’ done in Turkey, it was indicated that mothers preferred to be involved in invasive procedures done on their children. In addition, a study on ‘Knowledge and attitudes of nursing staff regarding neonatal pain', Nimbalkar et al. (2014), acknowledge that some health workers have knowledge in pain care, but they don’t apply it in practice. In the cases where parents lack knowledge in NPPM, health workers should take time to provide information about NPPM and encourage them to use them in practice. If this is done, parents will be able to acquire knowledge and better skills on provision of NPPMI to their babies.

Recommendations

From the objectives and the findings of the study, the following recommendations have been drawn;

Parents' knowledge on non-pharmacological pain management (NPPM)

Hospitals should consider including NPPM in their daily health education sessions. The education should be delivered in Antenatal care clinics, Post natal wards and in the Neonatal care units to impart knowledge of NPPM and encourage practice among parents whose babies have been admitted in the neonatal unit.

Hospitals should consider developing posters on parental involvement in neonatal pain care and the use of NPPMI's and these should be posted in neonatal units and all hospitals in Malawi. This is to inform parents or guardians on the importance of their involvement during invasive procedures and to encourage them to be involved and actively participate in providing NPPM to their babies.

Clinical practice

Hospitals or neonatal units should consider developing clear protocols that promote parental involvement in neonatal pain care. Small leaflets that properly explain in layman's language to parents on involvement in pain management and its importance should be developed and given to parents to prepare them for involvement in neonatal pain management.

The ministry of health should consider developing guidelines on neonatal pain management including NPPM to be used for neonatal care. These guidelines should be made available at primary, secondary and tertiary levels of health care in Malawi.

Malawian hospitals should encourage the use of neonatal pain management scales during invasive procedures to guide NPPM. Nurses and Doctors need to embrace the use of pain scales

and use the knowledge they have in practice. This knowledge should also be imparted to the parents because they are part of the team and relevant hospital support staff.

Education

Continuous professional development education sessions that take place in hospitals should include neonatal pain management. This will enable nurses and doctors gain knowledge in NPPM and use it in practice.

Nursing and medical education should include NPPM in their curriculum and the students should be encouraged to transform the knowledge they have acquired in school into practice.

Minimizing barriers to parental involvement in pain management

Health workers should have a welcoming attitude towards parents so that they are encouraged to ask questions on neonatal pain management. Health workers should also take the initiative of encouraging parents to be involved in neonatal pain management on admission.

Neonatal units should consider developing ward policies that support parental involvement in neonatal pain management. A policy that encourages doctors and nurses to call parents/guardians of babies who are undergoing invasive procedures when they are outside the unit as most parents are accommodated in the postnatal ward.

Health workers should also minimize parents' fear of involvement in invasive procedures by doing proper explanations of the procedure and how they expect the parent to be involved.

Conclusion

Parental involvement in neonatal pain care is poor at Queen Elizabeth Central Hospital and the use of NPPMI's is substandard. Many parents do not know what NPPM is because health

workers do not take time to educate or encourage them to practice it. This indicates that there are no proper guidelines to guide neonatal pain management practices including the use of NPPM. Many parents expressed willingness to take part in invasive procedures in order to provide NPPM. Therefore, health workers should take the responsibility of educating parents on NPPM and also allow/encourage them to be involved during invasive procedures and practice NPPMI. This will improve neonatal pain care and promote the use of NPPMI in Malawian neonatal units and in turn improve neonatal health.

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Appendices

Appendix 1A: Interview Guide for Parents

Part A

Understanding on non pharmacological parent oriented interventions used in neonatal pain management

1. What do you know about pain in babies
2. How do you know that your baby is in pain?
3. What kind of invasive procedures has your baby undergone?
4. What do you think you can do as a parent to stop your baby's pain during procedures apart from using medicine?

Part B

Parental knowledge on their involvement during pain management

1. Were you involved when your baby was undergoing an invasive procedure?
    i. How were you involved during the invasive procedure?
    ii. Explain what you noticed during the procedure?
    iii. What did health workers do to stop your baby's pain?
    iv. What is your say on the pain management that your baby received from health workers during the procedure?
    v. What other things do you think they should have done to stop your baby's pain?
    vi. How will involving/how did involving you during or after painful procedures make you feel?

Part C

Preparing parents for involvement in neonatal pain management

1. Do doctors or nurses take time to explain when your baby is scheduled to undergo a painful procedure? What do they say?

2. Do they take time to explain how you can be involved as a parent to minimise pain to your baby? What do they say?

3. What is the current practice at this facility if a baby is undergoing invasive procedures?

Part D

Facilitating or hindering factors to involving parents in pain care

1. What facilitates your involvement in managing your baby's pain when she/he is undergoing or has undergone an invasive procedure?
2. What hinders you to be involved in soothing your baby's pain when your baby is undergoing or has undergone an invasive procedure?
    i. Explain how the barriers to involving parents in neonatal pain management can be removed?

Thank you for participating.

Appendix 1B: Chichewa Translation of Interview Guide for Parents

Part A

Kumvetsa kwa makolo pa njira zosagwiritsa ntchito mankhwala pochepetsa ululu wa makanda

Kodi mukudziwa chani pa zaululu wa makanda?

1. Mumadziwa bwanji kuti mwana wanu ali ndi ululu?
2. Ndi njira iti yomwe mwana wanu wapangidwa yoyambitsa ululu?
3. Ndichiyani chimene mukuganiza kuti mungapange ngati kholo kuti ululu wamwana wanu uchepe kupatulapo kugwiritsa ntchito mankhwala?

Part B

Kumvetsa kwa makolo pa kutenga kwawo mbali pochepetsa ululu wa makanda

1. Kodi ndi chithandizo chotani chimene mwana wanu ankalandila chimene munaloledwa kutenga nawo mbali?
    i. Kodi munatenga nawo mbali yanji pamene munaloledwa kuti muthandizile mwana wanu akulandila chithandizo choyambitsa ululu?
    ii. Munaonapo chani pa nthawi imene mwana wanu amalandila chithandizo choyambitsa ululu?
    iii. Kodi ogwira ntchito zaumoyo anapangapo chani kuti achepetse ululu wa mwana wanu?
    iv. Fotokozani ngati munali okhutitsidwa ndi chithandizo chimene mwana wanu analandila?
    v. Nanga mukuganizapo kuti akanapangapo china chani kuti ululu wa mwana wanu uchepe?

vi. Kodi munamva bwanji mmene munaloledwa/kapena mungamve bwanji kuti muziloledwa kutengapo mbali pochepetsa ululu wa mwana wanu mmene akulandila chithandizo choyambitsa ululu?

Part C

Kukonzekeletsa makolo kuti atengepo mbali pochepetsa ululu wa makanda

1. Kodi madotolo kapena anamwino amatenga nthawi kufotokoza pamene mwana wanu akukalandila chithandizo choyambitsa ululu? Fotokozani kuti amati chani?
2. Fotokozani zimene anamwino ndimadotolo amanena mmene mungatengele mbali kuthandiza kuchepetsa ululu wa mwana wanu?Fotokozani kuti amati chani?
3. Kodi pakadali pano ana akamalandila chithandizo choyambitsa ululu mu wodimuno, chimene chimachitika ndi chani?

Part D

Zopititsa patsogolo kapena zoletsa zomwe zimalepheletsa opeleka chisamalilo kutengapo mbali pa chisamalilo chochepetsa ululu kwa makanda

1. Fotokozani zomwe zimakuthandizilani kuti muzitenga nawo mbali pochepetsa ululu wa mwana wanu?
2. Fotokozani zomwe zimakulepheletsani kutenga nawo mbali pochepetsa ululu wa mwana wanu?
    i. Fotokozani mmene tingapangile kutitithane nazo zolepheletsa kuti inu mutenge nawo mbali pochepetsa ululu wa mwana wanu?

Zikomo potenga nawo mbali!!

Appendix 2A: Information Letter to Parents

Study title: parental involvement in neonatal pain management at Queen Elizabeth Neonatal Unit

Dear participant

My name is Netsayi Chimenya Gowero, currently a student pursuing my Master of Science Degree in Child health at the University of Malawi, Kamuzu College of Nursing. I am conducting a research study as partial fulfilment of my Master's Degree programme and the title is **'Parental involvement in neonatal pain management at Queen Elizabeth Central Hospital'**. I therefore request you to participate in the study. The aim of the study is to describe the understanding and experiences of parents on their involvement in pain care at QECH neonatal unit. 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 at this health facility. 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.

It is also important for me to let you know that you will derive no incentives or immediate benefits from participating in the study. However, exploring the views of parents on involvement during invasive procedures done on neonates at QECH neonatal unit will help to identify current pain care practices and promote parent involvement when their babies have undergone invasive procedures. It will also help in identifying which areas need improvement to improve the quality of pain management in babies to improve outcomes in the unit. The study will also help in alerting policy makers on the need for designated policies to be adopted or

formulated to improve pain care in neonates. The study has been approved by College of Medicine Research Ethics Committee (COMREC) and Queen Elizabeth Central hospital.

For further information about the study, please contact;

The Principal Investigator: Netsayi Chimenya Gowero (Miss)

Postal address: Kamuzu College of Nursing,

P.O. Box 415

Blantyre

Email address:ngowero@yahoo.com

Cell: +265999760823

OR you may forward your concerns or clarifications regarding the study to;

The research supervisor: Ezereth Kabuluzi (PhD)

Kamuzu College Of Nursing

P/Bag 1

Lilongwe

Email address: ezekabuluzi@kcn.unima.mw

Cell: +265995984612

Or the following contacts for information on your rights and safety;

The Chairperson

College of Medicine Ethics Review committee (COMREC),

P/Bag 360,

Chichiri,

Blantyre 3.

Email address: comrec@medcol.mw

Telephone number: 265 187 4377

Fax Number: 265 187 4740

Physical address: University of Malawi College of Medicine,

Mahatma Gandhi Campus,

Postgraduate Building Ground Floor,

Room number 822.

Institution website address: http://www.medcol.mw/comrec/

Thank you for taking time to read this information letter.

Appendix 2B: Chichewa Translation of Information Letter

Mutu wa kafukufuku: **kufufuza ngati opeleka chisamalilo angaloledwe kutengapo mbali pochepetsa ululu kwa makanda pa chipatala chachikulu cha Queen Elizabeth.**

Kalatayofotokozandondomekoyakafufukuotiamayiaziloledwakutengapombali pa chisamalilo cha makanda.

Okondedwa otenga mbali,

Dzina langa ndine Netsayi Chimenya Gowero. Ndine ophunzira wakusukulu ya ukachenjede ya anamwino ndi azamba ya Kamuzu yomwe ili gawo la University of Malawi ndipo ndili mu chaka cha chiwiri chomwenso chili chomaliza pa maphunziro anga a kuzama pa umoyo wa ana (Masters degree in child health).

Monga gawo la maphunziro ozama pa umoyo wa anawa, ndikuyenera kupanga kafukufuku okhudzana ndi sukuluyi. Mutu wakafukufuku wangayu ndi *'kufufuza ngati opeleka chisamalilo angaloledwe kutengapo mbali pochepetsa ululu kwa makanda pa chipatala chachikulu cha Queen Elizabeth.'*

Cholinga cha kalatayi ndikukupemphani ngati mungalore kutenga nawo gawo pa kafukufukuyi.Kutenga nawo gawo ndikosakakamizidwa ndipo mutha kusankha kusavomera kutenga nawo gawo, kapenaso kusiyira panjira panthawi yomwe mwavomela kutenganawo gawo pa kafukufukuyu ndipo izi sizizasokoneza thandizo lomwe mungalandile pa Chipatala pano. Moonjezera apo, kafukufukuyu alibe chiopsezo chomwe chingachitike kwa inu pamene mwatenga nawo mbali, komabe ngati mungaone chiopsezo chilichonse muli omasuka kutumiza dandaulo lanu kwa mwini kafukufukuyu kusukulu ya anamwino ndi azamba ya Kamuzu college.

Chinaso chomwe mungadziwe ndi chokuti palibe ndalama kapena mphatso zilizose zomwe mungalandire popeza mwatenga nawo gawo, koma mutha kuthandiza apabanja panu, m'delalanu kapena dziko lose la Malawi mu zotsatira zakafukufuyu zomwe zingathandize kukonzaso ndondomeko zina zopititsa patsogolo chisamalilo cha ana kuti tichepetse ululu omwe ana amamva akamalandila chisamalilo, komanso zizathandiza kuti makolo aziloledwa kutengapo mbali pamene ana awo akulandila chithandizo

Tikadziwa ngati makolo akufuna kuti aziloledwa kutengapo mbali pa chisamalilo cha makanda awo pamene akulandila chithandizo choyambitsa ululu, zizatithandiza kuti ana alndile chithandizo chopambana komanso kukonza malamulo ndi ndondomeko kuti makolo aziloledwa kutengapo mbali pamene makanda akulandila chithandizo choyambitsa ululu, kuti tipititse patsogolo miyoyo ya makanda athu.

Kafukufukuyu wavomerezedwa ndi a komiti yaikulu yoona za kafukufuku ndi fulu ya College of medicine (COMREC) komanso office ya ikulu ya pa Queen Elizabeth Central Hospital.

Kotero, mukafuna kudziwa zambiri zokhudzana ndi kafukufukuyi, apezeni anthu awa ;

Mwini wa kafukufukuyi: Netsayi Chimenya Gowero (Miss)

Keyala : Kamuzu college of Nursing, P.O. Box 415 , Blantyre

Email : ngowero@yahoo.com. ngowero@medcol.mw

Nambalayafoni : +265999760823

Kapenaso ngati mukufuna kudziwa zambiri zokhudzana ndi kafukufukuyi kapena muli ndi madandaulo ena okhudzana ndi kafukufukuyi, mutha kuwapeza amene ali ondiyang'anira pa kafukufukuyi**:**

Dzina: Ezereth Kabuluzi (PhD)

Mphunzitsi wamkulu ku: Kamuzu College Of Nursing

P/Bag 1

Lilongwe

Email address: ezekabuluzi@kcn.unima.mw

Nambala ya foni yawo: +265995984612

Mukafunaso kudziwa zambili za ufulu ndi chitetezo chanu mu kafukufukuyi mutha kufunsa ku:

A pampando a College of Medicine Ethics Review committee, pa keyala iyi:

College of Medicine Ethics Review Committee

P/Bag 360,

Chichiri, Blantyre 3.

Email: comrec@medcol.mw

Nambala ya foni : +265 187 4377

Nambala ya fax: +265 187 4740

Komwe amapezeka: University of Malawi College of Medicine, Mahatma Gandhi Campus, Postgraduate Building Ground Floor, Room number 822.

Zikomo potenga nthawi yanu kuwerenga kalatayi.

Appendix 3A: Consent Form

Study title: parental involvement in neonatal pain management at Queen Elizabeth Neonatal Unit

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

Informed consent for clients consenting to be subjects for a study titled '**Parental involvement in neonatal pain management at Queen Elizabeth central hospital'** whose results will help in identifying non pharmacological pain management practices in the neonatal units and help identify which areas need improvement to improve the quality of pain care in neonates and promote parental involvement when their babies have undergone invasive procedures.

I have read/ 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 have understood 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. That is why I am voluntarily consenting to participate in the study.

…… …….

Participant's Signature/thumb print Date

…….. ……

Witness's signature Date

....

Researcher's Signature Date

Appendix 3B: Chichewa Translation of consent Form

<u>Mutu wa kafukufuku</u>: **<u>kufufuza ngati opeleka chisamalilo angaloledwe kutengapo mbali pochepetsa ululu kwa makanda pa chipatala chachikulu cha Queen Elizabeth.</u>**

Kalata yovomeleza kulowa mu kafukufuku wa oona ngati opeleka chisamalilo angaloledwe kutengapo mbali pochepetsa ululu kwa makanda pa chipatala chachikulu cha Queen Elizabeth**.**

Ndawerenga/ndawerengeledwa ndipo ndamvetsetsa uthenga onse uli mukalata yokhudzana ndi kafukufukuyu, ndipo ndapatsidwa Mwayi ofunsa mafunso pomwe pamafunika kutero, okhudzana ndikafukufukuyu. Ndamvetsetsanso kuti zones zomwe ndingafotokoze/ kupereka zisungidwa mwachinsisi ndipo amene angazifikile ndimwini kafukufuku yekha kapena ena amene ali oyenera kutero. Ndikudziwaso kuti sindikuyenera kukumana ndi chiopsezo cha mtundu wina uli wonse mu nthawi ya kafukufukuyi ndipo uthenga omwe ndipereke kwa mwini kafukufukuyu suzagwilitsidwa ntchito mondiukila mtsogolo muno. Kotero,ichi ndi chifukwa chake ndikulora kutenga nawo mbali mu kafukufukuyi mosakakamizidwa.

…… …….

Posainila otenga mbali / chidindo Tsiku

…… ……...

Posainila mboni Tsiku

……. ……..

Posainilamwinikafukufukuyu Tsiku

Appendix 4: Permission Letter from Queen Elizabeth Central Hospital

College of Medicine
Private Bag 360
Chichiri
Blantyre 3
Malawi
Telephone: +265993630543

September 26th 2016

To: Chair, COMREC

From: Head of Department, Paediatrics and Child Health

Re: Parental involvement in neonatal pain care

I am writing in support of this research proposal to evaluate parental understanding of and involvement in neonatal pain care. The principal investigator has actively requested and incorporated feedback from the department in terms of methodology, which should ensure its feasibility. The study raises an important and relevant question and we anticipate that the findings will help improve pain care practices in our neonatal units and therefore improve neonatal health.

I therefore fully support this important study

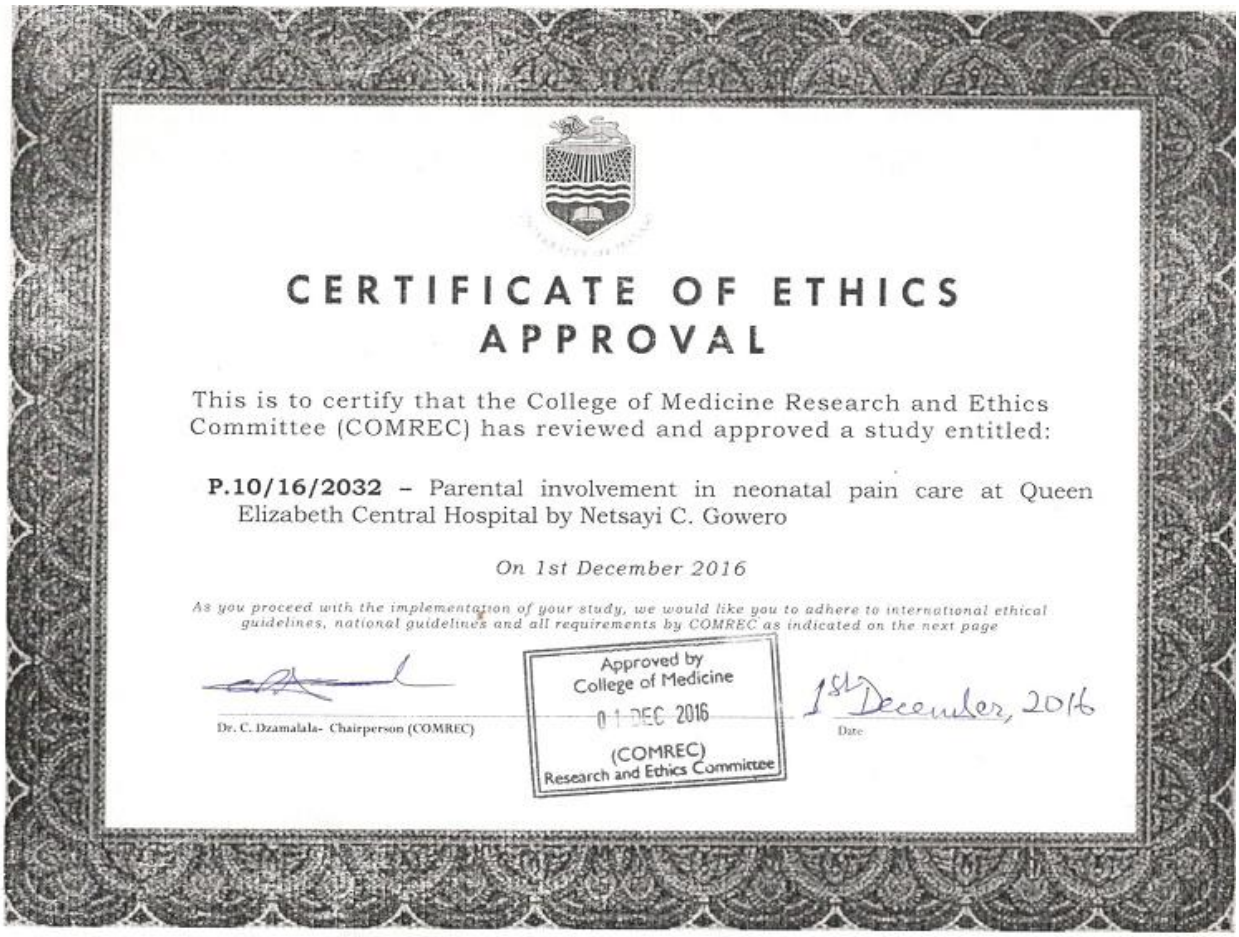
Yours sincerely

Dr Josephine Langton

MBChB, MRCPCH

Academic Head of Department, Paediatrics and Child Health

Appendix 5: COMREC Approval



CERTIFICATE OF ETHICS APPROVAL

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

P.10/16/2032 – Parental involvement in neonatal pain care at Queen Elizabeth Central Hospital by Netsayi C. Gowero

On 1st December 2016

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

Dr. C. Dzamalala- Chairperson (COMREC)

Approved by College of Medicine
01 DEC 2016
(COMREC) Research and Ethics Committee

1st December, 2016
Date