UNIVERSITY OF KWAZULU-NATAL

EXPLORING PERCEPTIONS AND PRACTICES OF INTENSIVE CARE UNIT NURSES WHEN SUPPORTING FAMILIES OF CRITICALLY ILL PATIENTS IN TWO HOSPITALS IN BLANTYRE, MALAWI

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EXPLORING PERCEPTIONS AND PRACTICES OF ICU NURSES WHEN SUPPORTING FAMILIES OF CRITICALLY ILL PATIENTS IN TWO HOSPITALS IN BLANYTRE, MALAWI

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 \mathbf{BY}

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MARCH, 2009

DECLARATION

I Wyness Tengeneza Gondwe Mulenga, declare that:

This research study is entirely the result of my own effort. It is being submitted for the degree of masters in Critical Care and Trauma Nursing at the University of KwaZulu-Natal, Durban, South Africa. It has never been submitted for any other degree purposes. All sources that I have used have been acknowledged by means of referencing.

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N Date 08. 64. 2009

DEDICATION

This work is dedicated to my daughter Olive and my son Hope.

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My sincere thanks go to the following:

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ABSTRACT

Aim: The aim of this study was to explore perceptions and practices of ICU nurses, when supporting families of critically ill patients, in two hospitals in Blantyre, Malawi.

Methodology: A descriptive qualitative approach was used to explore perceptions and practices of ICU nurses, when supporting families of critically ill patients. Simpson's Conceptual Framework was used to guide this study. Purposive sampling was done where five nurses from a public and five from a private hospital were interviewed until data saturation. Repeat interviews were conducted at two week intervals, for data depth and verification. Each interview lasted 25-40 minutes. All interviews were tape recorded and transcribed. Manual data analysis was used to identify themes and categories. Documents used for family support care were also reviewed.

Findings: The study revealed that nurses acknowledged that families experienced stress due to critical illness and ICU admission of their loved ones. The study also reiterated that families have psychological, social and spiritual needs, including the need for information, comfort and proximity to their loved ones. Nurses met the families' needs through empathy, dedication and commitment, inclusion of families in patient care and decision making and information giving to promote understanding and endurance during the stressful period. ICU nurses encountered some challenges when they provided support care to families, which included families' interference from wanting to be with their loved ones all the time, lack of clear policies to guide family support care, limited

time to attend to the relatives due to shortage of nurses and nurses' own stress, especially when they did not have enough information to answer questions from families, when communication was inadequate from physicians to families. In addition all participants did not have formal ICU training except "on the job" orientation, which was not enough to prepare them for family support care.

Recommendations: Recommendations have been suggested for improvements in nursing practice, nursing management, nursing education and future nursing research.

LIST OF ABBREVIATIONS

COMREC:

College of Medicine Research and Ethics Committee

Dr:

Doctor

ENM:

Enrolled Nurse Midwife

HIV:

Human Immune Virus

ICU:

Intensive Care Unit

MPH:

Mwaiwathu Private Hospital

NMT:

Nurse Midwife Technician

NT:

Nurse Technician

RNM:

Registered Nurse Midwife

UNIMA:

University of Malawi

URPC:

The University Research and Publication Committee

QECH:

Queen Elizabeth Central Hospital

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CHAPTER 1

INTRODUCTION

1.1 BACKGROUND INFORMATION TO THE STUDY

Critical illness may occur suddenly and unexpectedly and may usually end up with sudden and unexpected admission to intensive care unit (ICU). Critical illness and the admission to ICU are physically and emotionally stressful to families who usually accompany and look after their sick relatives during hospitalization (Pochard, Azoulay, Chevret, Lemaire, Hubert, Canoui, Grassin, Zittoun, le Gall, Dhainaut, Schlemmer, 2001; Johansson, Hildingh & Fridlund, 2002; Fox-Wasylyshyn, El-Masri & Williamson, 2005; Fox-Wasylyshyn & El-Masri, 2007).

The emergent admission happens without prior warning or opportunity for preparation, both emotionally and physically, for families of critically ill patients. Usually, there is little or no experience of such a situation, bringing confusion, shock, helplessness, uncertainty and changing roles and disruption of routines. This draws family members away from the patient, promoting separation and disconnection (Johansson, Hildingh & Fridlund, 2002; Medina, 2005). Critically ill patients are often incapable of making decisions regarding their own care due to the gravity of their condition, and families have to make such decisions on their behalf, as much as they are physically and emotionally stressed (Wasser, Pasquale, Matchett, Bryan & Pasquale, 2001).

The ICU traditional health care professional—patient relationship is often replaced by a health care professional—families relationship, due to the critical state of the patients (Hupcey, 1999). Families may find themselves as the primary care givers to their sick relatives before ICU admission, and as a result they facilitate communication between patients and health care professionals (Berwick & Kotagal, 2004). They are also able to provide feedback to nurses and physicians on behalf of the critically ill patients (Berwick & Kotagal, 2004; Guillianelli, Kelly, Skelskey, Gonzalez, Sharp, Turley & James, 2005).

Families accompanying patients admitted in ICU suddenly find themselves in a strange environment, where they do not know what to do and expect, and have to solely rely on the health professionals in ICU for support and information, to enable them cope with the stress (Leske, 2002; Fox-Wasylyshyn, El-Masri & Williamson, 2005; Fox-Wasylyshyn & El-Masri, 2007). The illness of the relative admitted in the ICU creates tension, anxiety and disequilibrium in families who need great support and care from the health care professionals (Johansson, Hildingh & Fridlund, 2002). In addition, families coping resources in such a state, are not readily mobilized and the focus of health care professionals is usually on the critically ill patients than on the families.

The sophistication of care, coupled with the high technology equipments, alarms and other gadgets for life support, fearful environment and the anxiety of the eventuality of the illness, are scary to patients and families (Williams, 2005; Todres, Fulbrook & Albarran, 2000). Similarly, Pochard, et al., (2001) reported that more than two thirds of the families who visited critically ill patients in ICUs suffered from symptoms of anxiety or depression, which

could prevent them from acting in the patients' best interest and could negatively impact on the patients' recovery.

A solution to the stated problem has been the introduction of family focused care in ICUs. Family support care is a method of care delivery that recognizes and respects the role of the families by assuming direct care giving roles and increased involvement during patients' hospitalization (Wright, 2007). Providing family support care begins by establishing a relationship that is mutually respectful, trusting, empathetic and collaborative with family members (Leske, 2002). Families need to be told on their first visit, that the unit has a family focus and new staff members should also be made aware of the unit's care philosophy which is family focused (Henneman & Cardin, 2002).

Nurses should also connect/link families with professional support from other disciplines including medicine, social work and pastoral care, whose expertise is needed for effective coping and complete family-focused care (Henneman & Cardin, 2002). Multidisciplinary family-focused care approach benefits patients, families and nurses by sharing the responsibilities to provide care (Henneman & Cardin, 2002). Henneman and Cardin, (2002) further indicates that in order to maintain consistent family support care, standard policies of care, proactive in meeting families' needs, should be established and followed by all nurses in ICU to prevent eruption of more serious issues of concern if not addressed (Henneman & Cardin, 2002). It is argued that for families to have the energy and capability to provide social support to the critically ill patients, they must receive adequate support and care themselves (King-Lee & Ling-Lau, 2003; Price, 2004).

However, nurses are faced with a lot of challenges, which include inadequate preparation to take care of critically ill patients and their families, little time for family support care due to shortage of nurses and stress of the presence of families in ICU. Nurses' knowledge of dealing with families in crisis may affect ICU nurses attitudes toward families of critically ill patients (Remonte, 1997). Working in ICU is intellectually challenging as the environment is different from the general wards (Farnell & Dawson, 2006). In addition, studies show that the basic nursing training programmes of most countries, do not meet the educational needs of nurses to care for families leaving them with a fear of the critical care environment (Farnell & Dawson, 2006). To enhance the care of patients and their families, nurses need to have specialized knowledge and skills.

The shortage of qualified ICU nurses, forces ICUs to recruit nurses who have no previous critical care experience, and offers them an orientation for knowledge acquisition, skill acquisition and socialization to critical care (O'Sullivan, 2002; Reising, 2002). The recommended ICU nurse to patient ratio is 1:1 (Nava, Confalonieri & Rampulla, 1998). As a result, critical care nurses need a lot of support to equip them with skills and knowledge required to care for patients and their families, but also strategies that will allow them to become socialized to the critical care environment (Farnell & Dawson, 2006). This will ensure that they feel supported, so that they will also be able to support the families adequately.

The amount of time available for nurses to deal with families may also affect family care (Remonte, 1997). Bed-side nurses are usually in short supply and as such, cannot adequately meet the needs of families and take care of patients all by themselves. The nurses find it

emotionally taxing to take care of the patients, due to the critical nature of the illness and, as such, they have little or no time and energy left for the families (Remonte, 1997). However, the nurses can still fulfill this role by mobilizing all non-nursing staff in ICU, including housekeepers, aides, volunteers and security guards, to assist with provision of nonmedical information, support and comfort to families (Appleyard, Gavaghan, Gonzalez, Ananin, Tyrell & Carroll, 2000).

Physical aspects of ICU are stressful, especially the amount and complexity of the equipment which is required for the high level of patient care. The nurses need to know how to use equipment (Farnell & Dawson, 2006). Families of critically ill patients are also constantly in attendance due to the critical nature of the illness. This nature of illness results in the nurse having less good news to share with the families. For many nurses, the presence of families acts as a source of stress (Henneman & Cardin, 2002). These challenges hinder the nurses' interaction with families.

In Malawi, 60% of free health care services are provided by the Ministry of Health and Population (MOHP), 25% by the religious missions, and 15% are provided by the private sector, for a fee (Department of Planning, 2004). Specialist care which includes ICU care is provided at the four tertiary hospitals in the country and at some private owned hospitals, which have specialist functions (WHO, 2006). Most public and private hospitals do not have ICUs in Malawi. Petients requiring ICU care from these hospitals are referred to the four tertiary hospitals and those who can afford to pay, obtain services from the private hospitals with ICU services. For patients who are referred to tertiary hospitals, they are usually accompanied by one or two family members to look after them. The families have to be at

the tertiary hospitals until patients are discharged from ICU. In Malawi, intensive care services are not well established due to lack of trained human and material resources. As such some patients requiring ICU services are referred outside the country especially, South Africa. However, plans are underway to have ICU care fully established in Malawi. A post registration programme for registered nurses is currently in the development phase which will lead to registration in intensive care nursing (Nurses and Midwives Council of Malawi, 2005).

1.2 PROBLEM STATEMENT

Critical illness and the admission to ICU are physically and emotionally stressful to families of critically ill patients (Pochard et al., 2001; Johansson, et al., 2002; Fox-Wasylyshyn et al., 2005). The emergent admission happens without prior warning, bringing confusion, shock, helplessness, uncertainty and changing roles and disruption of routines of families (Johansson, et al., 2002; Medina, 2005). Families have to act and make decisions on behalf of patients, as they are incapacitated due to the nature of illness. Yet the families' ability at this time is also affected by their own stress (Wasser, Pasquale, Matchett, Bryan & Pasquale, 2001).

Ideally, supporting families who are devastated by the admission of their loved ones in ICU, is an essential part of the responsibilities of health care professionals, in particular the nurses, who are more visible by virtue of their caring profession (Azoulay, Pochard, Chevret, Lemaire, Mokhtari, Le Gall, Dhainaut, Schlemmer, 2001; Remonte, 1997). Studies suggest that families, whose loved ones are admitted in ICU, have special needs that ought to be met,

which include the need for information, reassurance, comfort, communication, to be near their beloved ones, to trust health care professionals' ability, to be prepared for the consequences of the critical illness, to be aware of the patient's needs and reactions of families, and the need for ICU to provide emotional and social support (Henneman & Cardin, 2002; Chien, Chiu, Lai-Wah & Wan-Yim, 2006).

Although ICU nurses are in a position to help both the critically ill patients and their families, the patients are often the sole focus of the nurses' attention, due to the complexity of care which is essential for the patients' survival. Family support care then tends to be in competition with patient care, since nurses prioritize patient care, although they cannot give care to the patients without family involvement, since families contribute to the patients' recovery (Whyte, 1997). Nurses are critical, not only in the care of the patients in the ICU, but also in the care of the relatives. However, studies have established that nurses are the biggest barrier in the provision of support care to families (Chelsa & Stanard, 1997).

Studies on the support care of relatives of patients admitted in the ICU, have been done in the western countries, but there is limited information on the support care given to relatives of patients admitted in the ICU in Africa, and more so in Malawi, due to lack of published evidence. In Malawi, intensive care services are just emerging, as such nothing has been documented in literature concerning ICU care in general let alone, family support care in Malawi. Therefore nothing is known about ICU care and family support in Malawi. It is therefore against this background that the researcher conducted the study to better understand

nurses' perceptions and practices when supporting families of critically ill patients in ICU, using a qualitative study approach in two hospitals in Blantyre, Malawi.

1.3 PURPOSE OF STUDY

The purpose of this study was to explore perceptions and practices of ICU nurses when supporting families of critically ill patients in two hospitals in Blantyre, Malawi.

1.4 OBJECTIVES OF THE STUDY

- To identify nurses' perception of the needs of families of critically ill patients in ICU.
- To describe ICU nurses' practice of support care for the families of critically ill patients.
- To determine challenges encountered by ICU nurses when meeting the families' needs.
- To determine how ICU nurses are prepared for the role of family support care.

1.5 RESEARCH QUESTIONS

- What are ICU nurses perceptions of families' needs following ICU admission of critically ill patients?
- What are the practices of ICU nurses when supporting the families of critically ill patients?
- What challenges do nurses face when supporting the families of critically ill patients in ICU?
- How are ICU nurses prepared for the role of family support care?

1.6 SIGNIFICANCE OF STUDY

Bearing in mind that there are no major studies that are published on nursing support care of families in ICU in Malawi, the research findings may bring an awareness of the need to incorporate family support care in ICUs in Malawi. In addition, findings may be used to strengthen the existing programmmes which are targeting the support care of families. Findings may promote a favorable ICU environment for families, by developing reading materials for families and creating space for families' rest needs. Nurse Managers and other policy makers may use findings to draft policies and guidelines for family support care.

The study may also enable health professionals to become sensitive to the needs of the families of critically ill patients. The information from the research may be used as a baseline for quantitative studies to correlate families' reactions with nurses' behaviours or risk factors in Malawi, as well as elsewhere, since few quantitative studies have been done on the topic. The researcher also intends to publish the results in a peer reviewed journal to support evidence based practice.

1.7 OPERATIONAL DEFINITIONS

1.7.1 Critically Ill Patients

In this study, critically ill patients, means those patients that are admitted in the ICU and are on supportive treatments and close monitoring to prevent life threatening complications and restore health where possible.

1.7.2 Families

Families, in this study, refer to all who have a special relationship with the patient. These may include blood or psychosocial bonds, who may or may not live together, but those who visit the patients in ICU.

1.7.3 Family Support Care

Family support care, is care that recognizes and respects the role of families by establishing relationships with families, involving families in care, and having standard policies proactive in families' support care.

1.7.4 ICU Nurses

In this study, ICU nurses refers to any nurse, legally licensed to practice nursing and midwifery, by the Nurses and Midwives Council of Malawi and is allocated to work in ICU. These include registered nurses/midwives (RNM), enrolled nurses/midwives (ENM), nurse/midwife technicians (NMT) and nurse technicians (NT). In Malawi nurse/midwives have both general nursing and midwifery qualifications, while the nurse technicians have general nursing qualification only.

1.7.5 Intensive Care Unit (ICU)

In this study, ICU means a designated hospital area with specialized trained staff and equipment for the prevention of complications, continuous monitoring, treatment and care of

individuals with life threatening illnesses, injuries and complications from which recovery is possible.

1.7.6 Needs

Needs, in this study, means the things that the families require while in an ICU, in order to be comfortable while their loved ones are being treated.

1.7.7 Perceptions

Perceptions are a way of regarding, understanding, interpreting, experiencing, conceptualising or viewing something (Pearsall, Bailey & Elliot, 1999). In this study, perceptions means the process by which ICU nurses regard, understand, interpret, experience, or view family support care to families of critically ill patients in ICU.

1.7.8 Practices of ICU Nurses

Practices of ICU nurses, in this study, means the verbal and nonverbal interactions that the ICU nurses have with families.

1.8 COURSE OF THE STUDY

This study consists of five chapters, which will address aspects relevant to scientific inquiry as follows:

Chapter one, as has been seen, presents the problem and its background including the purpose, research questions, objectives, significance of the study and definition of terms.

In chapter two, literature, that supports the study, is examined and the gaps identified which are then investigated scientifically. The conceptual framework that guided the study is also presented.

Chapter three presents procedures which were followed to explore the perceptions and practices of ICU nurses when supporting families of critically ill patients in the two hospitals in Blantyre, Malawi. It includes the study design, study population, study setting, sample size, sampling methods, criteria for selection of sample, data collection instruments and academic rigor. Data management and analysis, ethical issues and plan for dissemination of results are also discussed.

Chapter four presents a descriptive analysis of the data according identified categories and major themes.

Finally chapter five examines the collected data relative to the literature on family support care in ICU. Recommendations are subsequently made relative to the findings and conclusions drawn.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

This review focuses on literature and previous studies on the ICU, effects of admission, family support care, needs of families as perceived by families and health care professionals, including nurses and challenges faced by nurses during implementation of family support care. Finally, the conceptual framework that is guiding this study is presented. However it should be noted that all literature reviewed, is on studies that have been done in the western countries, because there is limited information on the support care given to families of patients admitted in the ICUs in Africa, and more so in Malawi, due to lack of published evidence. In Malawi, intensive care services are not fully established, as such it is not known how families of critically ill patients are supported in ICU.

2.2 THE INTENSIVE CARE UNIT

ICU is a unit that uses technology to support patients, with teams of physicians, nurses and other members of the health care team, providing high quality care aimed at the recovery of the patients in their charge. It is important that this team works together for the benefit of the patients (Oberley & Hughes, 2001). In ICU, patients are often incapable of making decisions regarding their own care and therefore families are required to act in the interest of the patients, with regard to medical care decisions (Oberley & Hughes, 2001; Wasser, Pasquale, Matchett, Bryan & Pasquale, 2001). In addition to decision making, it has been established

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that patients, whose loved ones are at their bedside in ICUs, suffer fewer hallucinations (Granberg, Engberg & Lundberg, 1999).

Supporting families of patients in ICU, is a primary responsibility of ICU health care professionals and an important criterion in assessment of quality of care in ICU (Medina, 2005). Patients' families are called on to actively represent the patients and participate with healthcare staff in making crucial decisions about the patients' care, even though they may be experiencing emotional breakdown and anxiety (Henneman & Cardin, 2002). As patients recover and regain awareness, their families become their most important source of personal support and link to the healthcare team (Henneman & Cardin, 2002). Bucknall (2003); Söderström, Benzein and Saveman, (2003); Engström, (2006) described families as an important prerequisite resource for good nursing care in ICU because families provide information about their loved ones that only a very close relation can reveal.

2.3 EFFECTS OF ADMISSION TO ICU ON FAMILIES

Medina (2005) indicated that any illness, severe enough to require admission to ICU, is life threatening and can precipitate stress within the families. It is frightening for families to see their loved ones lying in ICU with tubes and other life support equipments on their bodies (Simpson 1997; Engstrom & Soderberg, 2004; Engström 2006). When loved ones fall critically ill, the situation becomes hard to understand, as everything that is happening seems unreal (Morse, 2000a; Morse, 2000b). The familiar body becomes frightening (Corbin, 2003) resulting in feelings of loss and changed identity, frightening and separating families from their loved ones.

Medina (2005) also observed that, although the stress may vary in intensity and duration, it has the ability to create a heavy emotional and psychological burden on families. The source of stress that families exhibit includes; fear of death, uncertain outcome, emotional turmoil, financial concerns, role changes and unfamiliar hospital environment (Medina, 2005). Families' high levels of stress may interfere with their ability to receive and comprehend information, maintain patterns of adequate functioning, use effective coping skills and provide positive support for each other as well as the patient (Leske, 2002).

The response of families to critical illness and psychological stress has a major implication for families and nurses (Medina 2005). Nurses must focus on family support care, where they must assess the needs of each family member and devise interventions specific to benefit them (Medina 2005). In addition, Azoulay, Pochard, Chevret, Lemaire, Mokhtari, Le Gall, Dhainaut and Schlemmer (2005) indicate that one of the major goals of family support care is to reduce the risk of stress reaction to the traumatic ICU environment, which if unabated, could lead to the risk of post traumatic stress disorder. Azoulay et al., (2005) demonstrated that families can exhibit Post Traumatic Stress Disorder more than four months after discharge from ICU or death. In a longitudinal study conducted in Israel, to assess stress related morbidity of families of critically ill patient after ICU discharge, clinically meaningful post traumatic stress reaction occurred in families 90 days after discharge from ICU (Bleich, Gelkopf & Solomon, 2003). The implication of admission of patients in ICU therefore is that nurses not only have the role of caring for critically ill patients, but also supporting families accompanying these patients. This concept of actively involving families in care of patients is referred to as family support care and is further discussed here below:

2.4 FAMILY SUPPORT CARE

Family support care is a method of care delivery that recognises and respects the role of families by assuming direct care giving roles and increased families' involvement during patients' hospitalisation (Wright, 2007). Providing family support care begins by establishing a relationship that is mutually respectful, trusting, empathetic and collaborative with families (Leske, 2002). Families need to be told on their first visit, that the unit has a family focus and new staff members should also be made aware of the unit's care philosophy, which is family support care (Henneman & Cardin, 2002). Managers should serve as role models, by participating in decisions related to family support care and promotion of family support care behaviours.

Nurses should also link families with professional support from other disciplines, including medicine, social work and pastoral care, whose expertise is needed for effective coping and complete family support care (Henneman & Cardin, 2002). Multidisciplinary family support care benefits patients, families and nurses by sharing responsibilities to provide family support (Henneman & Cardin, 2002). Henneman and Cardin, (2002) further indicate that in order to maintain consistent family support care, standard policies of care, proactive in meeting families' needs, should be established and followed by all nurses in ICU, to prevent eruption of issues if concerns are not addressed (Henneman & Cardin, 2002). It is argued that, for families to have the energy and capability to provide social support to critically ill patients, they must receive adequate support care themselves (King-Lee & Ling-Lau, 2003; Price, 2004). When families provide support to their loved ones it makes them feel good because they are helping, in addition to being near their loved ones (Eldredge, 2004), although not all

families feel comfortable to do so, as they are afraid to interfere with the tubes and other connections on the patients. Eldredge (2004) found that most spouses wanted to help in uncomplicated care only and left the complicated care for the nurses to deal with.

2.5 NEEDS OF THE FAMILIES IN THE ICU ACCORDING TO FAMILIES

Families' needs in the ICU have been extensively studied, which resulted in the development of the Critical Care Family Needs Inventory, (CCFNI). CCFNI is a questionnaire consisting of 45 items rated on 4 point Likert scales, which was developed in 1979, by Molter (Verhaeghe, Defloor, Van Zuuren, Duijnstee & Grypdonck, 2005). This questionnaire has been used in various studies since it was developed, although modifications of the original instruments have been done since then (Takman & Severinson, 2004; Azoulay et al., 2001). Azoulay et al., (2001), observes that there is consistency in the needs of family members using the CCFNI document as expressed by the families in various studies. The following are the needs of families of the patients admitted in the ICU.

2.5.1 Need to Receive Information

The need for information to families includes honesty in answering questions they may have, especially concerning the patient's progress (Lam & Beaurieu, 2004). The families have a great desire to access accurate information and knowledge about the progress of their loved ones. (Mendonca & Warren, 1998; Bijttebier, Vanoost, Delva, Ferdinande & Frans 2001; King-Lee & Ling-Lau, 2003).

Families want accurate information from doctors about the prognosis and precise treatment of patients and from nurses, the daily care of patients, reasons for particular treatments, ICU equipment and various disciplines involved in the management of care of their loved ones (Verhaeghe, Defloor, Van Zuuren, Duijnstee & Grypdonck, 2005). Families have a desire to be informed about any changes in the condition of the patient on time (Mendonca & Warren, 1998). Meeting this need lays the foundation for families' decision making and coaching patients, reduces families' anxiety and promotes sense of control (Leske, 2002; Engström, 2006; Verhaeghe, Vanzuuren Defloor, Duijnstee & Grypdonck, 2007). Hughes, Bryan and Robbins (2005) found that inadequate and inconsistent information from physicians, made families repeatedly ask nurses questions and at times nurses were blamed for not giving appropriate information. Knowledge about what is happening to the critically ill patients is essential in establishing a hopeful outlook and accepting the situation for both families and their loved ones (Kosco & Warren, 2000).

2.5.2 Need to Receive Assurance

Assurance from nurses includes making families feel that there is hope about the patients' outcome and recovery (Henneman & Cardin, 2002). The need for hope is important especially in sudden, unexpected and serious changes in the condition of patients, than in chronic illness (Mendonca & Warren, 1998). Families want to be assured that they will be involved in daily care of patients and be called from home to be with the patient should the condition deteriorate (Mendonca & Warren, 1998; Bijttebier et al., 2001). Meeting this need promotes confidence, security and freedom from doubt (Leske, 2002).

2.5.3 Need for Social Support and To Have Access to the Patient

Proximity of families to patients entails being able to access patients and being able to see patients regularly (Mendonca & Warren, 1998; Bijttebier et al., 2001; King-Lee & Ling-Lau, 2003). This can be enhanced by having flexible visiting hours, having telephone lines in ICU, where families can make enquiries to nurses about their patients, and waiting rooms close to ICU. Restricted visiting hours, lack of waiting rooms and telephones far away from the units interfere with the attempts of families to meet the need for social support and to have access to the patients (Takman & Severinson, 2004). ICU needs to invest in infrastructures that enhance comfort and support to families, such as telephones, television sets, comfortable waiting rooms and others. Meeting this need helps families to remain emotionally close and give support to patients while reducing anxiety, and augmenting families' resources to maintain strength for support (Leske, 2002). For recovering patients, seeing their loved ones near them shows that families are concerned, care about them, protect, need and love them (Bergbom & Askwall, 2000).

2.6 NEEDS OF FAMILIES ACCORDING TO HEALTH CARE PROFESSIONALS

Existing literature among nurses, on the needs of families and the CCFNI, suggest that nurses also perceive that families with patients in ICU have specific and unique needs. Although there are similarities between these needs, as perceived by nurses and families, research shows that nurses place emphasis on critical issues that relate to trust, preparing families for

consequences, to be aware of patients' reactions and to avail supportive resources for the families (Takman & Severinson, 2005). These needs are further discussed below:

2.6.1 Need To Trust Health Care Professionals' Ability

On comparing the perceptions of needs of significant others within ICU, among nurses and physicians in Norway and Sweden, most clinicians perceived that they would want families to trust health care providers with their loved ones, to be treated with kindness and to have one's wishes respected (Takman & Severinson, 2004; Takman & Severinson, 2005). Takman & Severinson, (2005) further suggested that because of the nature of nursing jobs such as shift arrangements, patients and their families could encounter different health care providers during their ICU admission which could compromise the trust and confidence they have in the staff and continuity of care. Families need therefore, to be assured that they can trust nurses with their patients, regardless of who is on duty. This could be enhanced by nurses giving up to date and satisfactory information on patients' current conditions (Takman & Severinson, 2005).

Moreover, trust can be achieved by health providers being attentive to families and showing sensitivity when informing and listening to them (Hupcey, Penrod, Morse, & Mitcham, 2001). Failure to provide consistent and satisfactory information and giving contradicting information to families has been attributed to cause depression, mistrust and anxiety (Pochard et al., 2001). Lack of consensus and consistency among the staff, on the provision of prognostic information, could lead to the families receiving conflicting information, thus exacerbating an already unstable situation and causing the breakdown of relationships

between nurses and families (Pochard et al., 2001; Henneman & Cardin, 2002). Attaining accurate information about the condition of patients is of utmost importance, since it enables the patients' families to make sense of what is happening with their loved ones (Takman & Severinson, 2005). It is also believed that the trust of health care providers is enhanced by their awareness of the influence they have on the emotional state of families and act in a sensitive manner towards them and focus their attention on meeting the perceived needs of families (Pochard et al., 2001).

2.6.2 The Need To Be Prepared For the Consequences of the Critical Illness

In a study to compare the perception of needs of significant others within ICU among nurses and physicians in Norway and Sweden, it was found that health care providers perceived that families needed to be prepared for the consequences of the patients' condition and treatment, as many families may have never experienced serious illness previously (Takman & Severinson, 2005). Health care providers perceived that families needed to be told that it is normal for families to experience a state of shock or crisis and to be prepared for any eventuality, if it appeared likely (Takman & Severinson, 2005).

Although clinicians should refrain from giving false hopes to their loved ones about the prognosis, there is a feeling among nurses that families would love to hear that there is hope for a better prognosis for their loved ones, which serves as a coping strategy to prevent feelings of despair (Engostrom & Soderberg, 2004). Other studies state that families should be exposed to situations that will make them develop a judgment of the prognosis of their loved ones (Takman & Severinson, 2005). Some of the strategies that have been thought

would work, were ensuring that families were present during resuscitation, as the experience could provide them with a sense of reality and confirmation that everything possible was being done for patients, and may facilitate the grieving process, should the patient die (Ardley, 2003).

2.6.3 Need To Be Aware Of the Patients' Needs and Reactions in Relation to Significant Others

The need for families to be aware of the patients' needs and their reactions involves family intimacy exemplified by the desire to talk, have bodily contact with and remain close to patients, although the situation can be restricted due to presence of other patients' families. In studies done in Sweden, Norway, Canada and Australia, families expressed the need for being involved in the day to day care of patients (Takman & Severinson, 2004; Takman & Severinson, 2005). Takman and Severinson (2005) suggest that nurses need to be considerate in the provision of care which is in the best interest of patients. Family intimacy is a concept which describes the involvement of families in the care of their loved ones in ICU, by allowing families to be present and participate in some aspects of the care of critically ill patients (Engström & Söderberg, 2004).

Hewitt (2002) suggested that families can be valuable resources, both in sustaining the patients' orientation and in helping to prevent the emergence of ICU syndrome. Hewitt (2002), in his study called 'psycho-affective disorders in ICU, found that former patients of both medical and surgical ICUs described that care and support provided by their families, was more important than the number of visitors they got. In addition, those patients who

survive ICU may still need continuous support at home, due to their critical illness (Adamson, Murgo, Boyle, Kerr, Crawford, & Elliott, 2004). This implies that families may get some important skills of taking care of patients while in ICU.

2.6.4 Need for ICU to provide supportive resources to families

Families that opt to stay in ICU require preparing themselves for hygiene, sleep and food (Takman & Severinson, 2004). Other needs included a safe car park, clear directions to the ICU, a quiet room for resting, television, bible and telephone (Simpson, 1997; Colville, Orr & Gracey, 2003). Takman and Severinson (2004) further indicated that ICUs should give families access to the social worker and chaplain, to support the families in a time of loneliness and grief. Formalised guidelines should be prepared for communication between social workers, nurses and physicians in order to provide families with accurate information during the critical phase (Takman & Severison, 2004). However Engström and Söderberg (2004); Engström (2006); Stubblefield and Murray, (2001) in their studies, established that families preferred friends, other family members and ICU staff as their first choice of support, rather than pastors or priests.

2.7 CHALLENGES FACED BY NURSES WHEN CARING FOR FAMILIES

2.7.1 Lack of Professional Knowledge

The nurses' knowledge of dealing with families in crisis may affect their attitudes toward families of critically ill patients (Remonte, 1997). Working in ICU is intellectually challenging

as the environment is different from the general wards (Farnell & Dawson, 2006). In addition, basic nursing training programmes of most countries do not meet the educational needs of nurses in order for them to be able to support families of critically ill patients in ICU, leaving them with a fear of the high technological and scary ICU environment (Farnell & Dawson, 2006). To enhance the care of patients and their families, nurses need to have specialized knowledge and skills. Less experienced and untrained nurses need to develop skills in physical caring for patients, prior to being ready for the emotional support of families of different cultural backgrounds, which makes them respond differently to admission of their loved ones (Beeby, 2000). Lack of formal ICU training makes nurses handle families inconsistently when their loved ones are ill (Hupcey, 1999; Engström, 2006). ICU nurses in Australia had problems meeting the needs of culturally different families, highlighting the need for nurses to have knowledge of different cultures, to ensure consistent and uniform family support care (Burr, 2001; Waters, 1999 & Pryzby, 2005).

The shortage of qualified ICU nurses forces ICUs to recruit nurses, who have no previous critical care nursing experience and offers them an orientation for knowledge acquisition, skill acquisition and socialization to critical care (O'Sullivan, 2002 & Reising, 2002). As a result, critical care nurses need a lot of support to equip them with the skills and knowledge required to care for patients and their families, but also strategies that will allow them to become socialized to the critical care milieu or environment (Farnell & Dawson, 2006). This will ensure that they feel supported so that they will also be able to support the families adequately. Hardicare (2003) also indicates that experience is gained with time.

2.7.2 Shortage of Nurses

The amount of time available for nurses to deal with families may also affect family support care (Remonte, 1997). Bed-side nurses are usually in shorter supply than the recommended ICU nurse to patient ratio of 1:1, as such they cannot adequately meet needs of families and take care of patients all by themselves (Nava, Confalonieri & Rampulla, 1998). In their study Hughes, Bryan and Robbins (2005) found that ICU nurses wished that one nurse took care of families while another one took care of the critically ill patients, especially when they had just arrived in the ICU. Due to shortage, the nurses find it taxing to take care of the critically ill patients, as such they have little or no time and energy left for family support care (Remonte, 1997).

However the nurses can still fulfill this role by mobilizing all the non-nursing staff in ICU including housekeepers, aides, volunteers and security guards to assist with the provision of non-nursing information, support and comfort to families (Appleyard, Gavaghan, Gonzalez, Ananin, Tyrell & Carroll, 2000).

2.7.3 Nurses' Stress Level

Physical aspects of ICU are stressful; especially the amount and complexity of the equipment which is required for the high level of patient care which nurses need to know how to use (Farnell & Dawson, 2006). Families of critically ill patients are also constantly in attendance, due to the critical nature of the illness. The nature of the illness results in nurses having less good news to share with the families. For many nurses, the presence of families, acts as a source of stress (Henneman & Cardin, 2002).

2.8 CONCEPTUAL FRAMEWORK

The conceptual framework on Exploring perceptions and practices of ICU nurses when supporting families of critically ill patients in two hospitals in Blantyre, Malawi has been derived from Simpson's framework, which examined the experiences of intensive care nurses caring for patients whom they did not believe were going to survive beyond critical care, using grounded theory. Simpson's conceptual framework illustrated the process by which nurses eliminated the barriers between the dying ICU patients and their families in intensive care (Figure 2.1). The title of the study was Reconnecting: the experiences of nurses caring for hopelessly ill patients in intensive care. This study yielded three core themes which are: family separation, trust and family reconnection. The core category was "reconnecting", which was the process by which nurses attempted to overcome the dehumanising aspects of dying in a technological environment (Simpson, 1997). The conceptual framework has been used in order to link the findings to the existing knowledge through concepts used in the framework in order to create a specific way of looking at family support in ICU. The framework helps to organize ideas (Brink, 2006). Family support care is an abstract phenomenon, so the conceptual framework helps to shape how it can be defined and operationalised so that research findings can be integrated (Polit, & Beck, 2004).

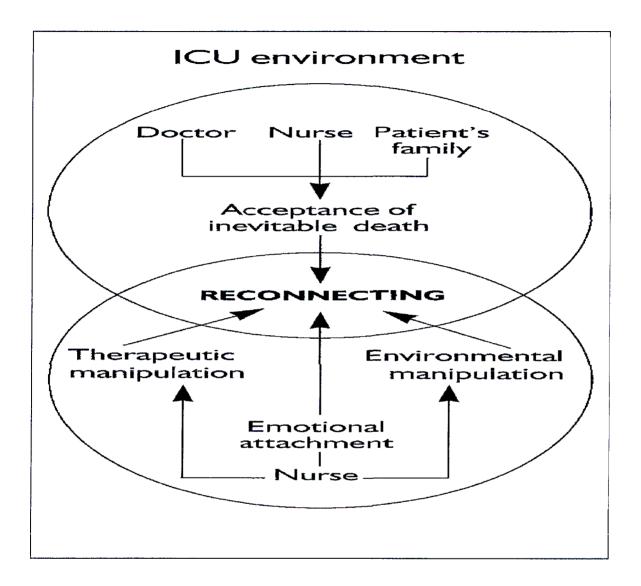


Figure 2.1: Simpson's Conceptual Framework.

2.8.1 Assumptions in Simpson's conceptual framework (Simpson, 1997)

- The critical appearance of patients brings about physical separation of the families from their loved ones.
- The critical care technological environment, within which is the critically ill patient and the family, acts as a physical barrier for families' reunion with their loved ones.

- The patients' suffering creates a psychological barrier and cause emotional stress to the families.
- Nurses and doctors can break the physical and psychological barriers created by the critical illness and the ICU environment to enable the families and their loved ones to reconnect. A nurse plays an integral role in the reconnection of the patients and their families by physical environmental manipulation, therapeutic manipulation and emotional support for families so that they develop trust and accept inevitability of death.
- In order for nurses to carry out the reconnection role, they require instructions regarding managing death in ICUs to enable as peaceful a death as possible, for the benefit of patients, families and nurses themselves.

2.8.2 Critique of Simpson's Conceptual Framework from the Researcher's Perspective

• Patient

The framework does not clearly indicate the position of the patients in the reconnection, since it has to be done between families and patients.

• Death vs. Critical Illness

The framework looked at reconnecting families and dying patients, though ICU is not a hospice for keeping dying patients, but rather for those whom recovery is generally possible.

• Other Members of Health Care Team

The position of other health care team members is not outlined. The ICU environment considered nurses and doctors as the only ICU team members. Normally there are others, like the clergy and social workers.

2.8.3 Application of Simpson's Conceptual Framework to The Study

The researcher has used the concepts that are used to describe the care of critically ill patients to describe the support care of the families of the critically ill patients to eliminate the physical and emotional barriers between the families and their critically ill loved ones in ICU. Although the concepts are similar, the researcher has given them different meanings to depict the interactions between the health care providers and the patients, as well as their families (Figure 2.2).

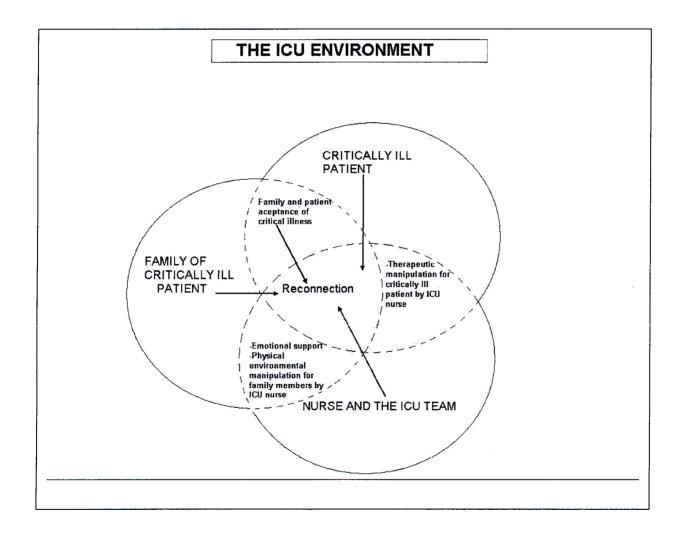


Figure 2.2: Application of Simpson's Conceptual Framework To The Study

Similar to the Simpson's framework, this study's framework has been based on the following assumptions:

• Critically Ill Patients

It holds that critically ill patients and their families are physically, spiritually and emotionally separated from one another, on account of the critical illness. The separation is further reinforced by the ICU environment, due to the scare that emanates from the high technological equipment needed to support patients, making the patients look more sick and miserable and families experience stress (Simpson, 1997).

• Family of Critically Ill Patients

Due to the nature of the illness, families of the critically ill patients take over the major decisions being made in the critical care unit for their beloved ones. The families need to feel comfortable with the clinical decisions made to treat their loved ones. Therefore, they must be in a position to believe that whatever is being done to the patients, is for the good of their loved ones. Nurses are agents of transmission of that trust. It is assumed that the trust that is developed between the nurses, families and the physician, develops when families are involved in patient care, decision making, and given all the information about patients clearly, enabling them to follow the prognostic decisions about their loved ones (Simpson, 1997).

The sense of trust is therefore a vital precondition to the families' feeling comfortable to take care of a critically ill patient. Conversely, autocratic decisions and disregard of family members' views, will lead to distrust (Simpson, 1997). This could be influenced further by linguistic or educational difficulties of the families (Simpson, 1997). Distrust makes families feel

uncomfortable to be involved in the care for the critically ill patients, further separating them from the patients.

The Nurse and ICU Team

The nurse and ICU team have a duty to remove the barriers between families and their loved ones, to promote reconnection. According to Simpson (1997), nurses are thought to play a big role among the ICU team in breaking these barriers by doing the following:

• Manipulating the Environment

This is where the nurses create an environment within which families can feel relaxed, and absorb the reality of events as well as facilitate healthy grieving and mourning. Part of the barrier is created by the physical environment of ICU (the machines, tubes and wires and constant noise) which scares families in getting close to the patient, fearing that they may interfere with the machines. Explanation on the equipment should be done for familiarisation. Other things that should be made accessible to the families include a safe car park, clear directions to the ICU, a quiet room for resting, television, bible and telephone (Simpson, 1997).

• Emotional Support

The patients' critical suffering causes families stress and depression, which can lead to the families' withdrawal physically or emotionally, from the situation, as it becomes too much to bear. The nurses need to recognise the symptoms of stress, such as withdrawal, and address them accordingly. The nurses are also expected to facilitate the access of the services of a chaplain, social worker and psychologist, to deal with the emotional aspects that families could be

suffering from (Simpson, 1997). Proper treatment of the patients will also promote good feelings in the families, and that their loved one's dignity is being maintained.

• Therapeutic Manipulation

Patient suffering causes a loss of dignity, which families find difficult to cope with, especially if it is felt that the patient will die. In these circumstances, families withdraw in order to allow the health care team to take over, thereby creating physical and psychological barriers which lead to more families' stress (Simpson, 1997). The nurses will ensure that the patients get the right treatment for recovery.

• Family and Patient Acceptance of Critical Illness and Reconnection

The focus of care in ICU, should be on the families and their loved ones, to promote reconnection. To reconnect, the nurses, being the most abundant health care professionals, should remove the barriers, by therapeutic manipulation through active treatment of the patient, to ensure that the patient is comfortable and cared for with dignity, physical environmental manipulation by explanation and orientation on the equipment, and the ICU environment for familiarisation and providing family emotional support, according to the identified needs (Simpson, 1997). This brings about acceptance and hope in the families for recovery of their loved ones, hence reconnection is realised and families actively participate in the care, since the barrier has been removed.

If the nurses do not manipulate the physical environment, the physical barriers to reconnection remain, as do psychological barriers, if patients are not comfortable, not cared for with dignity, as well as if the families are not getting any psychological support.

2.9 CONCLUSION

This chapter examined the literature and studies on the effects of admission of critically ill patients on families, family support care in ICU, families' needs and challenges faced by nurses in ICU, when providing the care to patients, which includes families. Admission of patients to ICU is a stressful experience for families, due to their critical conditions and a strange, scary ICU environment, causing disequilibrium in the family integrity.

Families of patients in ICU have been seen to have unique needs, which include the need for information, hope, reassurance, ability to remain close to the patient and social support, to trust health care professionals' ability, to be prepared for the consequences of the critical illness, to be aware of the patient's needs and reactions of families, and the need for ICU to provide supportive resources to the families.

The nurses' responsibility is to therapeutically care for patients and support families, so that both families' and patients' needs are met. By doing so, nurses facilitate a reconnection of families and their loved ones. However, nurses are not adequately prepared to take care of critically ill patients and their families. In addition, they have little time for family support care, due to the shortage of nurses, and for some nurses, the presence of families in ICU is stressful. This hinders their interaction with families.

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

This chapter describes procedures which were followed, in exploring the perceptions and practices of ICU nurses, when supporting families of critically ill patients in two hospitals in Blantyre, Malawi. It includes the study design, study population, study setting, sample size, sampling methods, criteria for selection of sample, data collection instruments and academic rigor. Data management and analysis, ethical issues and plan for dissemination of results are also discussed in the chapter.

3.2 RESEARCH APPROACH

A descriptive exploratory qualitative research approach was used to explore the perceptions and practices of ICU nurses when supporting families of critically ill patients. The qualitative research approach was used because it allowed the researcher to gain an understanding of support care, which would be difficult to quantify because of its subjective nature (Holloway & Wheeler, 1996; Brink, 2006). The researcher explored support care in an in-depth and holistic fashion, through the collection of narrative data from participants, using an exploratory approach (Polit & Beck, 2004). According to Brink (2006), exploratory approach involves the studying of subjects through extensive and prolonged engagement to develop patterns and relationships of meaning. This approach assisted the researcher to gain insight

into the perceptions and practices of ICU nurses when supporting families of critically ill patients.

3.3 STUDY POPULATION

The population included registered nurse/midwives, enrolled nurse/midwives, nurse/midwife technicians and nurse technicians who were working in ICUs of Queen Elizabeth Central Hospital (QECH), the largest referral public hospital and Mwaiwathu Private Hospital (MPH) the largest private hospital in Blantyre, Malawi. Although 25% of the health services in Malawi are provided by the religious missions, mission hospitals were left out because most of them are in the rural areas and do not have ICUs. The study population also included documents and reports used by OECH and MPH ICUs to promote family support care.

3.4 STUDY SETTING

The study was conducted at QECH and MPH in Blantyre, Malawi. Both are teaching hospitals for most Colleges of Nursing and Medicine in Blantyre city, located in the Southern region of Malawi. The two hospitals were purposively selected because they are considered model hospitals offering ICU services in Malawi and it was thought necessary to explore how ICU nurses at these model hospitals provide support care to families. Blantyre is the commercial capital city and main industrial center of Malawi, with a population of around 800,000 people.

QECH is the largest tertiary hospital in Malawi, with over 1000 beds and more than 1300 patients, at any given time. It is a government teaching and referral hospital that provides free

services to the population. It has a 4-bedded ICU which caters for all patients who need life support, including peadiatric and adult patients. The total nursing staff establishment in ICU, including day and night staff, in all categories, is seven.

MPH is the largest private hospital with 64 beds. It is a 15 minute drive from QECH, and the city centre. It is a hospital where, only those who can afford to pay, go for the services. The ICU of MPH has 4 beds, which admit paediatric and adult patients with varied conditions, as long as they need vital organs support or close monitoring. The total nursing staff establishment is five nurses, including day and night staff in all categories. The sites were chosen because the researcher works for the University of Malawi (UNIMA), Kamuzu College of Nursing, which uses the two facilities as clinical sites to train undergraduate nursing students. The facilities had the required population of ICU nurses which was ten, five from each of the two hospitals. Refer to figures 3.1 and 3.2 below for the study sites.

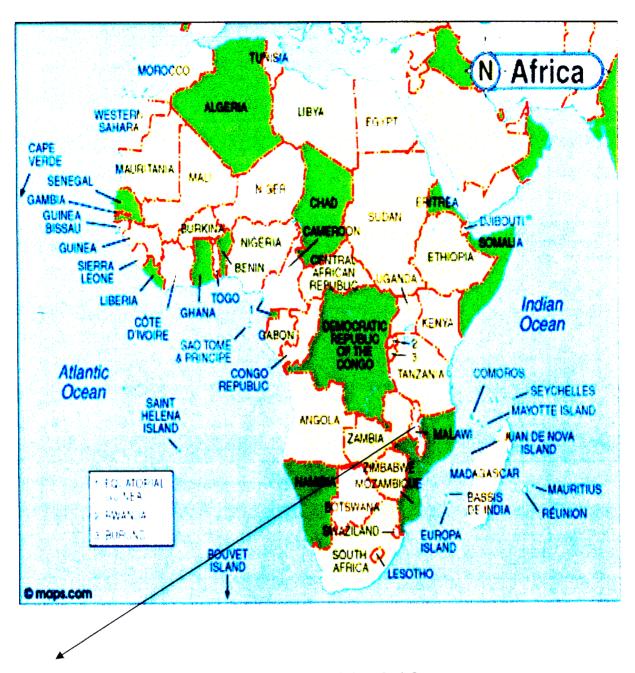


Figure 3.1: Map of Africa showing Malawi (copied from http://www.infoplease.com/atlas/africa.html)

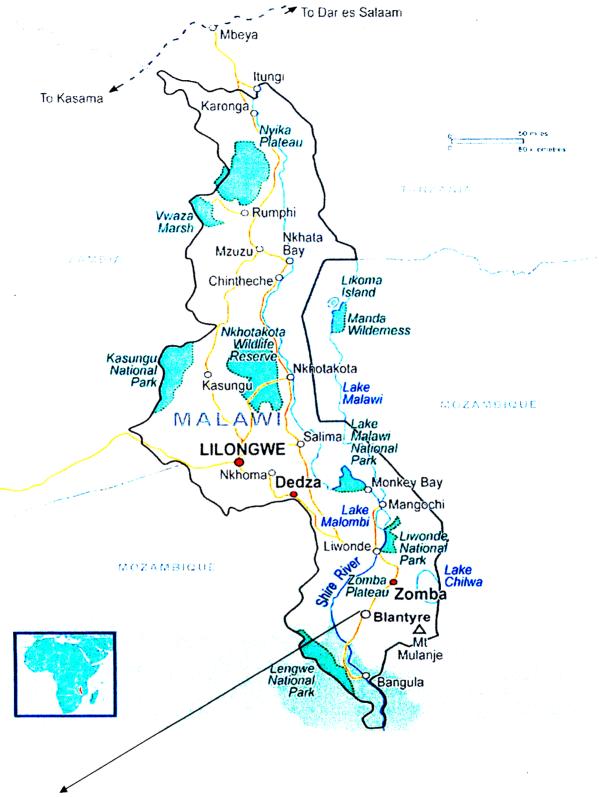


Figure 3.2: Map of Malawi showing Blantyre shown by the arrow, the site for the study (copied from http://www.aventure.co.uk/Map-of-Malawi.html)

3.5 SAMPLE SIZE

The researcher began by interviewing three nurses from each hospital. However, sampling continued until five nurses for each hospital were interviewed when data saturation was achieved. In qualitative studies, sample size is based on informational needs, where sampling is done to the point where no new information is obtained and redundancy is achieved (Gillis & Johnson, 2002; Polit & Beck, 2004).

3.6 SELECTION OF PARTICIPANTS

Purposive sampling was used to select study participants. A purposive sampling, also referred to as judgmental sampling, is a non probability sampling method which is based on judgment of the researcher regarding subjects that are especially knowledgeable about the phenomenon, so that they can be hand picked (Brink, 2006; Burns & Groove, 2001). The method was used, since the researcher wanted a sample of experts and key informants, with the desired characteristics. The researcher identified the unit managers of the ICUs of the two hospitals, whom she requested to avail their lists of all nurses under their departments, with their demographic information. Nurses meeting the inclusion criteria were selected and included in the sample.

3.7 CRITERIA FOR SELECTION

The criteria of the sample inclusion in the study, in both institutions, was that the participants be registered nurse/midwives, enrolled nurse/midwives, nurse/midwife technicians or nurse technicians; working in the ICU and must have worked for at least 6 months. They must also have given permission to participate.

3.8 DATA COLLECTION INSTRUMENTS AND PROCEDURES

An interview guide was administered by the researcher in English, since in Malawi the official language is English, and all categories of nurses are fluent with it. Individual in-depth interviews were used to collect data from the participants. Each interview lasted for 25-40 minutes. The interviews were tape recorded with permission for transcription verbatim later. Repeat interviews were done at 2 week intervals, for verification and data depth.

In addition to interviewing, document review of materials and policies used in management of families were examined, such as those for families' education and other communication media like, telephone and reports concerning families. This allowed for meaning and understanding to be established from various sources as they emerged, mutually enriching each method and providing a depth of understanding so as to converge an accurate representation of reality of the nature of family support care in ICU, that could not be achieved through the use of only one method (Burr, 1998; Polit & Beck, 2004).

Data were collected between March and April 2008. During the first day, after the permission was granted, the researcher visited the two hospitals to meet the people in charge of the two

units and to request access to the nurses participating in the study. Presentation of letters of permission to conduct the study in their hospitals, explanation of the purpose of the research and the process to be followed, was done. Purposive sampling was done so as to get the right mix of participants. Nurses meeting the criteria were selected and included in the sample. At QECH only five out of seven nurses met the criteria, while at MPH, all of the five nurses met the criteria.

On the second day, the researcher conducted a pilot study, a small-scale study before the main study at QECH ICU (Brink, 2006). The pilot study was conducted on two participants who met the criteria for the main study. The purpose of the pilot study was to test appropriateness and relevance of the interview guide, and to review documents used to provide family support care to elicit desired responses and make necessary adjustments before conducting the main study. Results from the pilot study formed part of the data, since they were found to be appropriate.

On the fourth day, the researcher embarked on an identification of the respondents who had been sampled purposefully. For those who were on duty, the researcher approached them and made appointments to meet and interview them at a convenient time. For those who were not on duty, appointments were made by telephone calls.

The researcher explained the purpose of the study, and also provided documents which had information about the study, with emphasis on voluntary participation. Due to problems with the availability of participants, the researcher interviewed participants from either centers on the same day, but had a maximum of two interviews per day.

Data collection and data analysis were done concurrently, enabling the researcher to redirect the study, in case new insights were developing (Brink, 2006). Transcription of the data commenced immediately after the first interview. Data analysis was done manually. Transcripts were coded, word for word, to give an initial coding scheme, which was examined to identify any repetitions. If repeated, codes were merged. Each description was read many times in order to make sense of the meaning of the whole. After initial coding and identification of themes, the researcher asked a more experienced qualitative researcher to verify the themes. The experienced researcher made his observations and suggestions. The researcher then worked on the suggestions in order to improve the quality of the data collected.

In addition to interviews, the researcher reviewed documents, related to family support care which included protocols, guidelines and information posters (Appendix 2: Checklist for document review).

3.9 ACADEMIC RIGOR

Academic rigor is the criteria used to judge reliability and validity or quality of qualitative research approaches, which are different from quantitative approaches (Polit & Beck, 2004). It is the degree to which one can rely on the concepts, methods and inference on study or tradition of inquiry as the basis of theorising and empirical research. It refers to confidence in truth of the data and quality of deserving to be believed and trusted (Polit & Beck, 2004). To guarantee academic rigor, data collection was done in a way that believability of the findings was enhanced. Academic rigor encompasses transferability, credibility, dependability, and confirmability which were all used in this study (Polit & Beck, 2004).

3.9.1 Transferability of the Study

Transferability refers to the extent to which the findings of one study can be applied to other situations, since findings of a qualitative study are specific to a small number of individuals (Polit & Beck, 2004; Shenton, 2004). Transferability is judged by the readers, after reading the detailed account of the study, in order to see whether the case can be transferred to other settings.

Sufficient thick description of the study is provided to allow readers to have a proper understanding of it, thereby enabling them to compare the instances of the phenomenon described in the research report, with those that they have seen emerge in their situations (Shenton, 2004). The description has included the hospitals taking part in the study and where they are based; type and number of participants involved; data collection methods; number and length of data collection sessions and period over which the data were collected (Polit & Beck, 2004; Shenton, 2004).

3.9.2 Credibility of the Study

Credibility of the study refers to the confidence in the truth of the data, and in the interpretation of that data by the researcher (Polit & Beck, 2004). Credibility can be enhanced by triangulation, member checking and thick description (Holloway & Wheeler, 1996; Polit & Beck, 2006). In this study, triangulation, member checking and thick description were all used to ensure credibility.

• Triangulation

Triangulation refers to the use of multiple references to draw conclusions about what constitutes the truth, in order to overcome bias and capture a more complete and contextualised portrait of phenomenon under study (Brink, 2006; Polit & Beck, 2004).

The researcher applied **method triangulation** to collect data, by interviewing and reviewing documents containing policies/guidelines on families' support care. These included those documents for families' education and other communication media like, telephone and reports concerning families. Method triangulation allowed for meaning and understanding to be established from various sources as they emerged, mutually enriching each method and providing a depth of understanding so as to converge an accurate representation of reality of the nature of family support care in ICU, that could not be achieved through the use of only one method (Burr, 1998; Polit & Beck, 2004). Refer to Appendix 2: Checklist for document review.

In addition, the researcher applied **time triangulation** by collecting data with the same participants at two week intervals, to determine the congruence of phenomenon across time (Polit & Beck, 2004).

Space triangulation was also applied by collecting data on the same phenomenon, in two sites; a public and a private hospital, in order to validate data by testing for cross-site consistency (Polit & Beck, 2004).

Finally, **person triangulation** was applied by collecting data from different cadres of nurses, in two institutions, with the aim of validating data through multiple perspectives on the phenomenon (Polit & Beck, 2004).

• Member Checking

Member checking is communication with study participants, regarding data analysis and conclusions of the study, for validation of the meanings according to them (Holloway & Wheeler 1996; Polit & Beck, 2004). In this study the researcher asked participants to provide their opinions on the data, to ensure that it was a true representation of their reactions.

• Thick Description of the Study.

Thick description of the study is where the researcher gives a detailed description of the interpretation of data that was collected, to include the complexities, the variabilities as well as the commonalities (Polit & Beck, 2006). To achieve thick description of the study, data analysis was done in such a way that it would represent the diversity of perspectives among the participants, leading to an interpretation that includes these variabilities under varying contexts or conditions. In addition the results and discussion sections provide a deep, rich and thorough description of the research setting and of the transactions and processes gathered during the inquiry. This provides sufficient information for judgment about the context under which the study was conducted.

To ensure further academic rigor, matching interview guide questions, document review checklist against study objectives and conceptual framework were done. Refer to Appendices 3 A & 3B.

3.9.3 Dependability

Dependability refers to the stability and the trackability of changes in the data over time and conditions (Gillis & Jackson, 2002; Polit & Beck, 2006). To assess dependability, the researcher determines the extent to which another investigator, with similar methodological training, rapport with the participants and knowledge of the field would make the same observations (Gillis & Jackson, 2002). This is done by an audit trail, in which the researcher documents all the raw data generated, including field notes and interview transcripts, methods and sources of data generation and analysis decisions (Polit & Beck, 2006). By reading the audit trail the other researcher should be able to arrive at comparable conclusions given the same setting (Gillis & Jackson, 2002).

In this study the researcher documented all the raw data that was generated, as well as the methods and sources for data generation, including data analysis methods, so that the supervisor and experienced qualitative colleague researchers could make an audit inquiry and draw the same conclusions as the researcher.

3.9.4 Confirmability

Confirmability refers to the degree to which study results and conclusions are derived from inquiry of participants and the study context, not from researcher biases (Polit & Beck, 2004). Confirmability is concerned with objectivity or neutrality of data so that two independent researchers would agree with the meanings emerging from the data (Gillis & Jackson, 2002). To assess it, an audit trail is used where the researcher must be explicit about

how personal biases, assumptions and values may have come into play in the study (Gillis & Jackson, 2002).

In addition, bracketing was employed whereby a qualitative researcher works towards recognising bias and controlling it by writing a description of everything he or she knows or believes about the topic of exploration and set aside (Brink & Wood, 1998). This bias could be manifested by the literature review. This is to ensure that all available perspectives of the phenomenon under study, are considered by deliberately seeing the other side of the arguments, thereby allowing the researcher to wander, to be confused and uncertain and to seek the opinion of the participants (Gillis & Jackson, 2002). The researcher therefore has described her preconceived ideas about the nurses' perceptions and practices of family support care, suspended and laid them aside. Refer to Appendix 12.

3.10 ETHICAL CONSIDERATIONS

3.10.1 Clearance by Ethics Committee

Ethical clearance was sought from the Ethics Committee of the University of KwaZulu-Natal (UKZN) after presenting, and approval of the proposal to the School of Nursing. Ethical clearance was also sought from the University of Malawi, Ethics committee -College of Medicine Research and Ethics Committee (COMREC) (Appendices 6 & 7).

3.10.2 Permission to Carry Out the Study

Permission was obtained from boards of management of QECH and MPH, before the commencement of the study. Permission was also sought from the managers of the two ICUs and from the individual ICU nurses to participate in the study. A written information document was presented to the participants enabling them to understand the study. The information document included the purpose of study, significance of study, benefits of the study, potential risks, duration, data collection procedures and ethical considerations. An informed consent form was signed by each participant who volunteered to take part in the study. Permission for tape recording before each interview was also sought. (Appendices 4, 5, 8 & 9).

3.10.3 Respect for Autonomy

The selection of the participants was done on a strictly voluntary basis. Participants had freedom of choice to participate or not to participate, and the right to withdraw at any time, if they so wished. Participants were made aware of this right through the information document.

3.10.4 Confidentiality and Anonymity

The data that was collected was treated with confidentiality and kept under lock and key. It was only accessible to the researcher and the research supervisor. The researcher interviewed the participants in a private and quiet place of their choice, in order to maintain privacy. A note was placed on the door informing people that an interview was in progress, in an attempt to prevent interruptions. Pseudo names were used so that whatever they said was not

connected to any real names. Maintaining anonymity was difficult, due to the interviewing process, but all the information given was not shared with anybody, except the research supervisor.

3.11 PLAN FOR DISSEMINATION OF RESULTS

The researcher will hold dissemination seminars to authorities in the Ministry of Health-Malawi, health professionals, including managers, nurses, doctors, and non-health professionals including housekeepers, patient attendants and security guards of QECH and MPH who assist with the provision of non-medical information to families in ICU. This will be done to promote knowledge and evidence based practice. Copies of the final report will be submitted to the University of KwaZulu-Natal Library in South Africa, and in Malawi, to the University of Malawi (UNIMA): the College of Medicine Research and Ethics Committee (COMREC), College of Medicine Library, The University Research and Publication Committee (URPC) and Kamuzu College of Nursing Library for reference. In addition the researcher plans to publish the study in a peer-reviewed journal for evidence based practice. Lastly the researcher will utilize local, regional, or international conferences or seminars/workshops to disseminate results in order to reach the majority.

3.12 CONCLUSION

In this chapter the process undertaken to conduct the study was presented in keeping with exploration as the chosen design. The chapter further described the process for selecting the sample, data collection and analysis for this study. Measures to meet the ethical requirements

for the study, including academic rigor were presented to avoid errors of conclusion and interpretation of the data.

CHAPTER 4

RESEARCH RESULTS

4.1 INTRODUCTION

This chapter presents the analysis of the data that was acquired from the study. The aim of the study was to explore perceptions and practices of ICU nurses, when caring for families with critically ill patients, at QECH and MPH in Blantyre, Malawi. The analysis is divided into demographic data and themes and categories of qualitative data.

Research results have been presented by intertwining data and interpretation, with direct quotes from participants, to illustrate important points. However, to maintain the participants' confidentiality and integrity of data, pseudo names have not been matched with the quotes, to prevent possibilities of identifying participants, as the sample was small. Another observation is that in Malawi, families are commonly referred to as guardians or relatives. During interviews therefore, the words guardians or relatives were used interchangeably to mean families of critically ill patients in ICU.

4.2 DEMOGRAPHIC DATA

Ten ICU nurses, who participated in the study, were aged between 26 and 46 years. All of them were females and they were confessing Christians. All did not have any formal intensive care qualification, only some orientation on the job, ranging from two days to one week, with only one having done the orientation for one year. This ICU orientation was

conducted by a qualified ICU nurse and by the anaesthetic department at MPH and QECH respectively.

Five of the nurses, who participated in the study, had qualifications as enrolled nurses and midwives, three were nurse-midwife technicians and one was a nurse technician. Only one was a registered nurse and midwife with a diploma in general nursing and a certificate in midwifery. The experience of the participants in the ICU, ranged from nine months to eleven years. The participants' demographic data has been summarised in table 4.1 below.

Table 4.1: Participants' Demographic Data

Number of	Work	Brief Remarks Concerning the Participants
Interviews	Experience in	
	ICU	
Two	Nine months	26 yrs, female, Christian, NMT, 1week ICU orientation
Two	Four years	39yrs, female, Christian, ENM, 1week ICU orientation
Two	One year	26 yrs, female, Christian, NT, 3days ICU orientation
Two	Four years	35yrs, female, Christian, ENM, 1 week ICU orientation
Two	Five years	43yrs, female, Christian, ENM, 1 week ICU orientation
Two	Eleven years	45yrs, female, Christian, RNM, 1 year ICU orientation
Two	Three years	46yrs, female, Christian, ENM, 3 days ICU orientation
Two	Two years	32yrs, female, Christian, NMT, 1 week ICU orientation
Two	Three years	31yrs, female, Christian, NMT, 2 days ICU orientation
Two	Two years	29yrs, female, Christian, ENM, 1 week ICU orientation
	Two	Two Nine months Two Four years Two One year Two Four years Two Five years Two Eleven years Two Three years Two Two years Two Three years

4.3 CATEGORISATION OF THEMES

From the transcribed interviews, several themes emerged, by looking at common narrations across the participants. Only themes relevant to the study objectives were grouped together to form categories, following the research objectives themselves (Simpson, 1997; Polit & Beck, 2004). These categories were the nurses' perceptions of needs of families of critically ill patients in ICU, ICU nurses' practice of support care for the families of critically ill patients, challenges encountered by ICU nurses when meeting families' needs and ICU nurses' preparation for patient care and family support care. Table 4.2 below illustrates the categorisation of themes.

Table 4.2: Categorisation of Themes

OBJECTIVES AS CATEGORIES	A. ICU Nurses' Perceptions Of Needs Of Families	B. ICU Nurses' Practice Of Support Care For Families	C. Challenges Encountered By ICU Nurses When Meeting Families' Needs	D. ICU Nurses' Preparation For Patient Care And Family Support Care
THEMES	want to know how the patient is doing	imagine what you would need to be done to you	perceived relatives	no qualification in ICU
	need psychological and		did not see the written policy	
	spiritual supportneed comfort	dedication and commitmentguardians' participation in	don't really have time to	
	want to sit next to the patient.	careguardians' decision making	attend to relativeswe too have stress	
		we permit them to stay	do not have anywhere to keep the families	
			we also do find problems	
			especially with the Jehovah's Witness	

4.4 PRESENTATION OF FINDINGS

4.4.1 CATEGORY A: ICU Nurses' Perceptions of Needs of Families

Theme 1: ...want to know how the patient is doing.

Most participants identified that families had a quest for information as a major need.

They indicated that families were anxious about the conditions of their loved ones:

"... What they require is information, concerning the condition of their patients if there is any improvement or a problem...".

However much as the information was of great need, it was noted that it was not always given promptly by doctors:

"...But most of the time, it is done when the patient's condition is really down...".

As a result, families were asking a lot of questions in an attempt to understand what was happening. This created a need for nurses to explain, now and again, what was happening with their loved ones, thereby reducing stress:

"...the main thing they need, is explanation now and again...".

Sometimes there was a limitation on how much information could be given by nurses due to institutional restrictions, especially at the private hospital:

"...our hospital policy, is that not anybody is allowed to explain the patient's condition to the relatives, except the doctor who is taking care of that patient...".

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Theme 2: ... need psychological and spiritual support.

Participants acknowledged that families were devastated, psychologically and spiritually, when their loved ones were admitted to ICU, as they were not sure whether their loved ones were going to recover or not:

"...they ask, whether the patient is going to survive or not...".

Families relied on their churches for spiritual support and encouragement:

"When the relatives want spiritual support, we allow them to bring the priest or pastor".

They felt that when the pastor prayed, something like a healing miracle would happen to their loved ones, or that their loved ones would be prepared to face a peaceful death, in case they died.

In addition, health care professionals, especially nurses and doctors, provided psychological support, although it was not always an easy thing to do:

"We also re- assure them, though sometimes it can be very difficult, especially when the patient is very sick and when the prognosis is poor".

Theme 3: ... need comfort

Most participants indicated that families needed comfort because they were stressed, due to the admission of their loved ones in ICU, and the lack of familiarity with its high technological environment and other critically ill patients. This caused uncertainty about the prognosis of patients and induced high levels of stress and anxiety in families:

"...they also need comfort, because they are stressed, when the patient is in ICU...".

To promote familiarisation to ICU environment and families' comfort, nurses orientated families to the physical environment:

"When relatives come for the first time, we orientate them to ICU and we explain to them, what we do..."

Apart from orienting families to the physical environment, they were also orientated to the equipment being used on their loved ones:

"... we have several equipment, so we explain to them, what those equipment are doing to their patients...".

Theme 4: ... want to sit next to the patient.

Most participants identified the need for proximity, where families wanted to be present during the course of illness of their loved ones:

"...most of them say, they want to stay close to the patient...".

They observed that families wanted to sit continuously in the unit, in order to be with their loved ones, especially during terminal illness. This was common at the private hospital. They would even suggest the discharge of their patients to the general wards, so that they could have uninterrupted time with their loved ones. In such cases nurses allowed families to visit their loved ones more frequently, since such patients were usually critically ill and were not even fit for discharge from ICU. It was felt that allowing families to visit more frequently relieved their anxieties:

"...we just arrange, so that they should be coming more in often...".

4.4.2 CATEGORY B: ICU Nurses' Practice of Support Care for Families

Theme 1: ... imagine what you would need to be done to you.

All ICU nurses who participated in the study did not have formal critical care training to guide their care towards families of critically ill patients. Most of the nurses gave the care that they would have wanted, had they had a family member in ICU. This made them less harsh and judgmental, but to be accommodative and humane when they interacted with families. Empathising was naturally expected of the nurses working in ICU:

"...you just put and picture yourself, how you would feel, if probably they never told you, what to do or how to do something."

By doing so, nurses became like relatives to the families:

"...we need to be like their relatives and they should look at us as one of their relatives...".

This made families feel that nurses were part of them, giving them more encouragement.

Theme 2: ... working in ICU needs dedication and commitment

All participants acknowledged that working in the ICU was trying. The ICU nurses were required to give their best to patients and their families. This called for dedication and commitment on the part of nurses:

"...you also have to be patient, to fellow staff and also to patients as well, because sometimes they are a bit stubborn, because they do not know what is going on to them and also to the guardians as well".

To be able to work in ICU requires a commitment and an overriding dedication to the interests of fellow human beings and society. When nurses, from general wards were asked to relieve shortage in ICU, they always refused due to the ICU environment being challenging and different from the general wards:

"... ICU is heavy, so people do not want to come and help...".

Theme 3: ... guardians' participation in the care

Participants differed in their practice when it came to allowing families to participate in the care of their loved ones. At the public hospital, where there was a critical shortage of nurses, families were allowed to participate in the care of patients when patients were about to be discharged from ICU, for continuity of care at the general wards and thereafter at home:

"...we do everything on our own, but when they go to the wards, with this shortage of staff, the nurse cannot manage to do everything for the patient, so some work needs to be done by the families and that is why we teach them...".

In addition, families' participation in care depended on the patients' condition. Families were not allowed to assist when patients were very sick, as they did not want them to disturb the patients in any way:

"...in ICU they are not involved in any care because patients are very sick and we do not want them to disturb some tubes and connections ...".

Families' participation in care also depended on the nurse on duty as some allowed them to participate in care, while others did not:

"...no, in ICU they are not involved in any care...".

To a great extent, families also influenced their participation in care, depending on their readiness to participate:

"... They shiver and you know when they enter in ICU, they have never seen those machines and the alarms, the patient is quiet and maybe they are not yet prepared that their relative is in that state. So we allow them so that they should get prepared psychologically...".

Theme 4: ... guardians' decision making

In most cases, patients in ICU are critically ill or sedated, and therefore, are unable to decide or give informed consent for themselves. Families therefore, automatically assumed the responsibility of decision making and consenting to the treatment of their loved ones. In the study, nurses worked hand in hand with families to make decisions regarding treatment:

"...In case the patient needs blood, we ask the guardian...".

Apart from consenting to treatments, families were also responsible for consenting to tests being done on their loved ones. Without their permission, such tests were not done:

"... we have to ask the guardian's permission to get blood from the patient to check for HIV...".

However, some families became over responsible in that they even demanded the patients to be treated in certain ways which they saw fit:

"...they think the patient needs transfusion so they demand us to tell the doctor ...".

Theme 5:... we permit them to stay ...

Although families wanted to stay near their loved ones during the course of their illness, there were no waiting rooms for families to use, in order to fulfill this need at either institution. However, families were allowed to stay near the hospital premises to ensure that they could visit their loved ones more frequently. At the public hospital, families were made to stay in the general wards, where their patients were initially admitted before ICU admission, or at a general waiting area, although it was very far from ICU:

"...we let them stay in the wards, where their patients were referred from...".

At the private hospital, some families waited in the common lounge by the reception or on the lawn near the main entrance, if they did not stay home:

"... Usually we tell them to sit in the lounge by the reception because it becomes very difficult for families to go home when they have got a very sick relative ...".

As much as they were allowed to use the lounge, it was not designed for that purpose. It was just an attempt to help the families to link up with their loved ones:

"... The lounge is not for families, but we permit them to stay there, according to the condition of the patient...".

4.4.3 CATEGORY C: Challenges Encountered by ICU Nurses When Meeting Families' Needs

Theme 1: ... perceived relatives' interference

Most ICU nurses indicated that some families interfered with the delivery of care, especially the educated and well off ones. These families refused to obey the rules of ICU, thereby frustrating the nurses. When nurses were busy helping patients, some families were interfering by visiting and then refusing to leave after visiting:

"... Especially these they come in and they do not want to go out...".

Other families were yelling and making absurd remarks at the nurses. Some even quarreled with the nurses:

"...your friend allowed us to stay here, so why are you not allowing us to stay? You are bad...".

In addition, despite nurses explaining to them what was happening with their loved ones, families kept on asking many questions which were seen to be time consuming for nurses. This behaviour interfered with the nurses' work because it meant nurses spending

a lot of time with families rather than the patients, who were a priority due to their critical conditions:

"...especially the...are used to getting first hand information, not from someone but us nurses.

Theme 2: ... did not see the written policy.

Participants in the two hospitals revealed that they lacked clear written policies on how to support families:

"... The time I came here, I was told that when you admit, you do this and that, so I assume it is the policy...".

However, both institutions had visitation times which were usually flexible, if patients were very sick, as their families were very anxious to wait for the next visiting hour:

"...the routine visiting hours are...but sometimes we are flexible depending on the patients' condition...".

Where there was a 'policy', it was seen as a restrictive tool rather than a facilitative tool to family support care:

"...our hospital policy is that not anybody is allowed to explain the patient's condition to the relatives except the doctor who is taking care of that patient...".

During document review it was also revealed that the institutions had visitation times clearly written and placed at the main entrances to ICUs, which were explained to all families as they came to see their loved ones. In addition, communication facilities like telephones, to call families in case they were needed in ICU were available. It was learnt from both institutions that apart from visitation times and telephone facilities, there were no other confirmed written guidelines on family support care. No notices or minutes of

meetings discussing families were available, nor information booklets on family support care for families' reference.

Theme 3:... don't really have time to attend to relatives

Participants in both institutions were overworked, due to the shortage of nurses, and therefore had no time for families. QECH had seven nurses while MPH had five nurses in total, to cater for day and night duty allocations, including unit managers. This resulted in a critical shortage of nurses for optimal patient care and family support care:

"...sometimes you are found to be alone on duty, you don't really have time to attend to the relatives because you are busy...".

This situation at times, caused emotional stress among nurses and forced them to behave in an unprofessional manner:

"....sometimes one loses temper just because of pressure of work...".

Theme 4: ...we too have stress...

Some participants indicated that they were stressed when they were interacting with family members:

"... We have problems because we ourselves too have stress...".

This mainly resulted when families were asking a lot of questions, which nurses could not always answer, due to lack of knowledge:

"...when they are around asking a lot of questions, sometimes you are not sure what to tell them...".

Theme 5: ... do not have anywhere to keep the families

Both institutions had no facilities to cater for the families' sleeping and resting, while their loved ones were admitted in ICU. QECH being a central and referral hospital, admitted patients from far and from rural areas, who were usually escorted by their families. The hospital had a general waiting area, but it was very far from ICU. As a result families with patients in ICU waited in the wards, where their patients were initially admitted before ICU admission. This was so that they could reach the families easily, in case they were needed urgently for decision making or information giving. Nurses therefore stressed the need for families to be available whenever they were needed, by telling them to always remain in their designated wards of initial admission.

"... they are always in the ward where the patient is coming from. If it is a female, surgical case...the guardian is always in 5B and sleeps there. If it is a male surgical patient, the guardian is in 5A, if it is pediatric patient, it is always in pediatric ward, if it is maternity mother, it is always in Chatinkha maternity unit. Whenever we want them, we always call the nurses in respective wards...".

Many of the families waited in the wards, but there was usually no specific room for them to use for resting purposes. Sometimes families were sent to the general hospital waiting area, to reduce congestion in the wards, and in the case when they were needed in ICU they were nowhere to be seen. Some families were getting lost as they were trying to relocate the ICU, especially at QECH, which has many corridors that look alike. This affected making processes and information transmission between ICU nurses and families:decision

"... If we want them, you find that there are no guardians in the wards...".

MPH also had no waiting room for families of patients in ICU. If there was need for families to stay near their loved ones, they waited in the common lounge by the reception or on the lawn near the main entrance. However, most of them stayed at home and were contacted by telephone in case they were needed, as they had transportation facilities,

unlike QECH, where most families were from rural areas and they had to remain in the hospital. Problems arose when the telephones were not working, and it took long for families to be contacted. At times patients died before the families' arrival and families complained about not being informed, in good time, by the nurses, to witness the last moments of their loved ones' lives:

"...when they go home they do not even know what is happening. When the patient has started gasping we have to check for phone numbers, call them, sometimes the lines are busy ...by the time we get through and they are coming here, patient is already gone. It then becomes difficult to explain to them on what was happening. Sometimes it happens that when they were going home they left the patient in a stable condition...".

Culturally, in Malawi, when a relation is sick, one or two family members are expected to stay near their loved ones, in case they are needed urgently, but this was not practical, as there was nowhere to keep them:

"... We understand that because it is ICU but sometimes according to our culture one or two relatives should be allowed to stay around somewhere outside...".

Theme 6: ...we also do find problems especially with the Jehovah's Witness...

Although the church provided spiritual support and encouragement to families during hospitalisation of a relation, at times it was a source of burden to patient care. Families had to follow church teachings when making decisions about certain treatments for their loved ones which were detrimental to patients' lives from the health care point of view:

"We also do find problems especially with the Jehovah Witness; they say they do not have blood transfusion...".

This created a dilemma amongst nurses because they knew, for example, that a blood transfusion could save the patients' lives, and that the consequence of the patient not receiving the blood transfusion, is death. The dilemma was more profound with minors,

who had not made informed decisions to join the church, and therefore parents or guardians had a major influence on whether or not to transfuse the minor:

"... we do have problems especially if it is a child, who has not chosen that religion.

4.4.4 CATEGORY D: ICU Nurses' Preparation for Patient Care and Family Support Care.

Theme 1: ... no qualification in ICU ...

All nurses did not have formal intensive care training to prepare them for patient care as well as family support care. They only had "on the job" orientation ranging from two days to one week, with only one having done the orientation for one year:

"...had a bit of orientation at QECH by visiting doctors and anesthetists which lasted for three days...".

In MPH this orientation was mainly done when a nurse was allocated to work in ICU:

"...after being allocated to work in ICU we had orientation to ICU by a qualified ICU nurse for one week...".

In both institutions, participants appreciated these orientations, but they felt that they were not adequate enough, resulting in sometimes experiencing problems when doing their work:

"... It was not really adequate but with time and experience we are coping up well although we have some problems...".

In addition, these orientations did not contain any specific content on family support care.

Their main focus was on patient care, use of ICU equipment and ICU procedures. As a result, the nurses used their knowledge from general nursing to support families:

"...No, the orientation did not include support care for the families. ...you just imagine what you would need to be done to you if you had a patient in the ICU from general knowledge...".

4.5 CONCLUSION

This chapter discussed the findings, according to the ICU nurses' demographic data, their perceptions of the needs of families of critically ill patients in ICU, their practice of support for the families of critically ill patients, challenges they encounter when meeting families' needs and their preparation for patient care and family support care. All participants did not have formal intensive care qualifications, except "on the job orientation, which was not adequate enough to prepare them for family support care. Their experience in ICU ranged from nine months to eleven years. The more years they worked, meant more experience and therefore knowledge to provide family support care. The nurses acknowledged that families of critically ill patients had needs, which required their interventions, by taking care of the critically ill patients and supporting their families. However, the ICU nurses encountered a lot of challenges to meet families' needs. These included relatives' perceived interference into patients' care, lack of clear policies to guide nurses on family support, lack of time to attend to relatives due to shortage of nurses, nurses' own stress, lack of waiting rooms to keep families, and ethical dilemma from some religious doctrines.

CHAPTER 5:

DISCUSSION, RECOMMENDATIONS AND LIMITATIONS OF THE STUDY

5.1 INTRODUCTION

In this chapter, findings of the study are discussed. The chapter also presents recommendations for improvement of family support care as suggested by the participants as well as the researcher and the limitations of the study.

5.2 DISCUSSION

The discussion is presented following the study objectives as a guide in order to match with the findings.

5.2.1 ICU Nurses' Perceptions Of Needs Of Families

From the findings, it is apparent that the families of patients admitted in ICU had needs. These included psychological, social and spiritual needs, including the need for information, comfort and proximity to their loved ones. These needs are also supported studies done by Mendonca & Warren, (1998); Bijttebier et al., (2001) and King-Lee & Ling-Lau, (2003). The critical suffering of loved ones causes stress in families, leading to separation of families and their loved ones hence creation of these needs.

In the study, families experienced stress due to sudden admission of loved ones to ICU. Receiving psychological and spiritual support from nurses and the priest or pastor respectively, relieved this stress. Both hospitals made arrangements for prayer services upon the request of families, since there were no hospital priests or pastors, nor chapels. This is in agreement with Engström (2006) who indicated that families had a vacuum that was generated from uncertainty of patients' recovery and that a priest was needed to talk to the families.

However contrary to Engström (2006); Stubblefield and Murray (2001); Engström and Söderberg (2004) established that families preferred friends, other family members and ICU staff as their first choice of support, rather than pastors or priests, which illustrates the importance of interaction between families and nurses and among families and friends themselves. The existence of psychologists and social workers was not confirmed in this study, but is supported by (Simpson, 1997; Takman & Severinson, 2004) to support families in time of loneliness and grief.

The fulfillment of family needs helped families to make decisions, or reach conclusions about the fate of their loved ones because they felt relaxed. These findings are similar to those by Bucknall (2003); Söderström, Benzein, & Saveman, (2003); Engström, (2006), who described families as an important prerequisite resource for good nursing care in ICU.

5.2.2 ICU Nurses' Practice of Support Care for Families

Family support care is a method of care delivery that recognises and respects the role of families by assuming direct care giving roles and increased families' involvement during patients' hospitalisation (Wright, 2007). Providing family support care begins by establishing a relationship that is mutually respectful, trusting, empathetic and collaborative with families (Leske, 2002).

In the study, ICU nurses supported families of critically ill patients by being empathetic, dedicated and committed in their duties. They also allowed guardians' participation in care and decision making guardians in addition to allowing them to stay near their loved ones despite not having waiting rooms for them. This is because nurses felt that families of critically ill patients were strangers in the fearful ICU environment, due to the high technology. The machines, tubes, wires and constant noise from monitors, prevented families from getting close to their loved ones for fear of interfering. To promote comfort and support, nurses orientated families to the equipment and physical environment. This is in agreement with Simpson (1997) who indicated that explanation on the equipment and environment should be done to families for familiarisation to promote comfort.

However, it was still difficult for some families to absorb the information, despite the orientation resulting in some families getting lost, especially at QECH, which has so many similar looking corridors. This resulted in some families not visiting their loved ones for the whole day especially those from the rural areas. Colville, Orr and Gracey, 2003, Takman and Severinson 2004, emphasise the need for clear directions to the ICU to

guide families. Explanations, orientations and support enabled families and their loved ones to understand and accept what was happening. This enabled families to actively participate in decision making and patient care. This is in agreement with Kosco and Warren, 2000 who found that knowledge, about what was happening to the critically ill patients, is essential in establishing a hopeful outlook and accepting the situation, for both the families and their loved ones.

However, in this study, nurses were not able to give information freely, due to restrictions, especially at the private hospital. Treating doctors were expected to give such information to families, but doctors were not always available, compared to the nurses who were always present, due to their caring profession. This made families ask nurses many questions in order to understand what was happening. This might be the reason nurses became emotional and lost their temper at times, due to the pressure from families in an attempt to understand what was happening.

This agrees with Hughes, Bryan and Robbins (2005) who found that the main reason families repeatedly asked questions was because the information they received was inconsistent. This was particularly true where physicians had not given families enough information. ICU nurses were sometimes blamed by families for not giving enough information, and this made nurses become stressed and aggressive (Hughes, Bryan & Robbins, 2005). Accurate, adequate and understandable information brings hope concerning the patients' outcome and promotes understanding of the patient's condition, and lays the foundation for decision making and participation in care by families (Engström, 2006; Verhaeghe, Defloor, Van Zuuren, Duijnstee & Grypdonck 2005).

However, delivering effective information raised a great challenge, due to time constraints resulting from the shortage of nurses and institutional restrictions, on who must give information to patients and their families, especially in the private hospital.

5.2.3 Challenges Encountered By ICU Nurses When Meeting Families' Needs

Findings showed that much as nurses tried to support families of critically ill patients, they did that with a lot of challenges. These challenges included lack of waiting rooms to keep the families, perceived family interference, lack of written policies to guide family support care, shortage of nurses to provide adequate support care to families, nurses' own stress, and churches' interference with patient care at times due to their doctrines, which restricted families in their decisions.

MPH previously had a waiting room close to the ICU, but it was closed, due to "abuse" by families, while QECH never had one specifically for ICU. "Abuse" of the waiting room was particularly noted amongst families of a certain race, who wanted to always remain in the waiting room, in order to visit their loved ones frequently, even when nurses were busy helping their loved ones. Nurses perceived such behaviours as "interfering" with their work hence the decision to close the waiting room at a private hospital, and, at time, not allow them in the ICU at a public hospital. This is in agreement with Hupcey (1999) who found that nurses varied in the way they handled families. Some nurses made families comfortable and developed relationships with them while others stayed in control and prevented them from interfering.

However the "perceived interference" might probably be due to cultural influences on the behaviours of families when their loved ones are ill. Engström (2006) found similar results where families from different cultures were problematic, due to diverse views on how to behave when their family members were critically ill. This can also be compared with Burr (2001) who found that ICU nurses in Australia had problems meeting the needs of culturally different families. The nurses were frustrated when they had difficulty understanding other cultures. Waters (1999) compared differences in families' expectations, across cultures of anticipated professional nursing support, expected during critical illness among Whites, Hispanics and African Americans. It was found that critical illness produced stress across cultures. This therefore highlights the need for nurses to have knowledge of different cultures to prevent culture from becoming an obstacle to family support care.

Proper family support care requires adequate nurses which was not the case in the study. A study by Hughes, Bryan and Robbins (2005) supports the need for adequate staffing for proper family support care. In their study, Hughes, Bryan and Robbins (2005) established that ICU nurses wished that one nurse took care of families, while another one took care of the critically ill patients, especially when they had just arrived in the ICU. At QECH and MPH ICUs, having a nurse look after the patient and another one take care of families would not be feasible due to the critical shortage of nurses.

Both hospitals lacked written policies to guide family support care. This might be the reason why each nurse handled families differently.

5.2.4 ICU Nurses' Preparation for Patient Care And Family Support Care

Experience and training status of nurses seemed to be a determinant in the ability to provide support to families. Beeby (2000) indicated that less experienced and untrained nurses needed to develop skills in physical caring for patients, prior to being ready for support of families. However through experience, nurses come to know patients and their families better (Hardicare, 2003). This was in congruence with findings of the present study, where some nurses indicated that the ICU orientation which they had was not really adequate, because they were experiencing some problems. However with time they gained experience and were coping with the situation. The nurses' knowledge of dealing with families in crisis may affect their attitudes toward families of critically ill patients because working in ICU is intellectually challenging as the environment is different from the general wards (Remonte, 1997; Farnell & Dawson, 2006). In the study none of the nurses had formal ICU training and probably this could be the reason for the nurses experiencing problems.

5.3 CONCLUSION

Analysis of the interviews revealed that families of critically ill patients experienced stress, due to the condition of their sick loved ones, and the scary ICU environment, which created needs in them. These included the need for information, psychological and spiritual support, comfort and proximity to their sick loved ones. Nurses had the potential to reduce families' stress by meeting these needs. This involved giving information for families' better understanding, empathizing and committing themselves to work under

pressure due to shortage, inclusion of families in patient care and decision making and allowing them to be present with and to be near their critically ill loved ones. Families' support varied among the nurses probably because of the lack of formal ICU training, which would ensure uniformity of some kind. The ICU orientations seemed not to have prepared nurses adequately for families' support.

Nurses encountered a lot of challenges when delivering family support care. These included perceived families' interference because families wanting to be with their loved ones all the time, lack of clear policies to guide family support care, limited time to attend to relatives due to shortage, nurses' own stress especially when they did not have enough information to answer questions from families, especially when communication was inadequate between physicians and families. Other challenges were the lack of waiting rooms to keep families, in order to fulfill the proximity needs, and churches' interference with patient care at times due to their doctrines, which restricted families in their decisions.

5.4 **RECOMMENDATIONS**

The findings in this study revealed that families have needs, which nurses managed, in different ways, under several challenges. The following recommendations from the nurses' and the researcher's perspective, are therefore made with implications to nursing practice, nursing management, nursing education and nursing research.

5.4.1 Recommendations for Nursing Practice

Because of the sudden onset of critical illness, families' anxiety cannot be prevented due to the uncertain outcome and unfamiliar ICU environment. There is a need for individual families' needs assessment upon admission to ensure a systematic plan of teaching which should be implemented by all ICU nurses whenever there is a new admission to ICU to meet their needs. An assessment of the family's previous experience with hospitals, especially ICUs, should also be taken into account as their previous experience affects their ability to cope with the current experience. This was also supported by Hughes, Bryan and Robbins (2005), who indicated that, recognising families' experience about ICU admission, may facilitate healthy interactions between the nurses and families.

In addition, the researcher also suggests the following recommendations, also supported by Leske (2002).

Adequate information that addresses the families' needs and concerns, should be given by ICU nurses, especially during the first days of hospitalisation. Information that families need should be anticipated and provided on a regular basis. Nurses should not wait for relatives to ask for information in order to provide it. This may include patients' condition, progress, treatment and equipment. It can include information booklets, attendance at bedside rounds, support groups and family support conferences. These promote families' understanding of the situation.

- In the study, despite nurses explaining to families what was happening with their loved ones, families kept on asking many questions, which were time consuming for nurses. It was perceived that families did not share the information given to them. As such, there is a need to identify a family spokesperson to receive information and relay that information to other family members resulting in a better understanding of the patients' condition.
- Flexible, individualized visitation should continue to facilitate the families' ability to cope with ICU hospitalization.
- Families, in both institutions, should be allowed to participate in the decision making and patient care of non technical tasks. The exclusion of families, during critical care hospitalization, intensifies their anxiety, stress and affects their functioning while their involvement in care alters stress responses.
- Families had different cultural, educational and religious backgrounds and dynamics, which affected their behaviour in ICU. Nurses therefore need to be sensitive to families' characteristics in order to respond accordingly, and to have knowledge of the different cultures, to prevent culture from becoming an obstacle to family support care.

5.4.2 Recommendations for Nursing Management

From management point of view, the researcher suggests the following actions in order to improve family support. These recommendations are also supported by Leske (2002).

- It was established that all institutions did not have waiting rooms, therefore families did not have a place to rest while they had patients in ICU. It was difficult for nurses to communicate easily with families where they were needed urgently, as they were not readily available. At the private hospital, families were usually made to wait at the reception, and at night they were asked to go home, while at a public hospital, they were made to wait in the general wards, where the patients were initially admitted before ICU admission, or stayed in the general waiting area which was far from the ICU. It became very difficult and uncomfortable for families to go home when they had a very sick relative. It was also difficult and sad for nurses to tell families to go home, as anything could happen to their patients during their absence.
 - Waiting rooms provide a comfortable environment for families to meet their basic needs and to rest. The hospitals should establish waiting rooms for families' rest because when the patients are very sick, families do not rest or sleep, even if they are sent home. They always think of their sick relatives. In the presence of waiting rooms, if patient's condition changes, families can be easily called in. This would facilitate understanding and appreciation of whatever was being done on the patient.
- Hospital nursing management need to be made aware of stressful situations under which ICU nurses function, and attempts should be made to support them as much as possible. Assess nurses' stress levels at regular basis and determine if they have special requests like transferring to another unit.

- Because nurses' focus on the care of patients in ICU, hospitals should enlist the services of a hospital chaplain, volunteers, family advocate and other dedicated ancillary staff to deal with families, as nurses are often too busy to attend to this task adequately. This would provide comfort measures to families. However, the challenge of this recommendation is that these people may not know the patients too well, from a health care point of view.
- During the study it was established that nurses from both institutions had no written policies to guide their practice of family support care. However, despite lack of policies at both institutions, MPH nurses felt that they lacked autonomy in the way they functioned in general with the doctors being the major players as opposed to QECH where nurses had some the autonomy when dealing with families of critically ill patients probably because it is a public hospital. As such, they were inconsistent in the way they delivered the care to patients and supported the families. This depended on the one on duty. Therefore there was a need to formulate policies for uniformity when delivering family support care.
- One of the challenges was the shortage of nurses to adequately provide care to critically ill patients, as well as to have time for families. There is a need therefore for more nurses to be deployed to ICU, as ICU is a very stressful area and it requires more staff, enabling them to cope.
- Many families may need a quiet, private space to get away and cry, therefore,
 there is a need for both institutions to have hospital prayer rooms or chapels to
 lessen their stress.

Another way to improve family support care, is to have suggestion boxes, with
papers and pencil for families to complete. This may also form part of the
families' needs assessment programme. A drop in complaint numbers, would
probably mean that improvements in family support care have been made.

5.4.3 Recommendations for Nursing Education

- It was established that nurses were not uniform in the way they executed family support. The probable reason was the lack of formal training and refresher courses. They all had an orientation, when joining ICU, which was not enough to equip them with adequate knowledge. It is therefore suggested that nurses should have continued in-service education as well as attaining formal ICU training for uniform practice of family support. Instituting formal staff education programmes and frequent in-service education in critical care would increase their knowledge base. Leske (2002) also supports this.
- In-service training for nurses, on stress management and individual professional counseling, should be made available.
- Nurse educators should be aware of importance of stress within nursing profession and nursing students need to be made aware of stress management as well as ways of recognising their own stress levels.

5.4.4 Recommendations for Nursing Research

- Within this study, ICU nurses articulated family needs, and suggested interventions to meet family needs, as necessary. Replication of this study in other ICU settings, from the families' point of view, to get first hand information from them and further qualitative research to explore perceptions and practices of ICU nurses when supporting families of critically ill patients is needed.
- Studies triangulating quantitative and qualitative methods would provide a more holistic understanding of perceptions and practices of ICU nurses when caring for families of critically ill patients.

5. 5 LIMITATIONS OF THE STUDY

The study employed purposive sampling, as such it was predominantly female. This may not be totally representative of the population of nurses, although there was no male nurse allocated to work in ICU at the time of the study. Another limitation of the study is its transferability, as the nurses were recruited from the general ICUs in the two hospitals. The results of the study therefore may be transferable only to nurses at general ICUs.

5.6 CONCLUSION

ICU nurses were aware of the effects of the admission of a relative to families, and that it created needs in the families, which required their interventions. Family support was stressful because nurses encountered a lot of challenges in the process. Recommendations

have been suggested for improvements in nursing practice, nursing management, nursing education and future nursing research. It is hoped that efforts may be made to address these issues for better family support care in ICU in the future.

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APPENDICES

7. Type of training

ΑF	PPENDIX	1: INTERVIEW	GUIDE		
Da	ite of Inte	erview <u>I</u> nte	erview No	_Name of hospita	al
Se	ection A:	Demographic D)ata		
1.	Age 20-	29 yrs	30-39	40-49	>50
2.	Gender	М	F		
3.	Religion	Christian	Muslim [Others	
4.	Basic Nur	sing Qualifications	}		
	•	Nurse Technician			
	•	Nurse/midwife tec	hnician		
	•	Enrolled Nurse/mi	dwife		
	•	Registered Nurse/r	nidwife		
5.	Work exp	erience in the ICU			
	•	6-12Months			
	•	13-36Months			
	•	37-60Months			
	•	>60Months			
6.	Qualificat	tion in ICU	YES	NO	

Hospital Based

University Based

Section B

- 1. Briefly narrate to me how your typical day is like in ICU? Probes:
 - What common cases do you regularly nurse?
 - Do you have families visiting or staying around?
- 2. Explain what you think are needs of families in ICU?
- 3. Describe your roles on family care?

Probes: How do you incorporate relatives in patient care;

- What is the hospital policy on care of relatives;
- What care do you provide to family members;
- How do you interact with relatives;
- What training did you receive on care for family;
- How does presence of relatives affect your care of patients in ICU;
- What do you like about presence of relatives;
- What don't you like about the presence of relatives;
- What barriers do you encounter when dealing with relatives;
- Do you have any nasty experience while dealing with family;
- Any case you vividly remember of patient relatives you interacted with;
- What challenges do you face in regard to caring for family members?)
- 4. Do you have any recommendations or suggestions to make to nurses towards caring for family members? If so which are these?

APPENDIX 2: DOCUMENT REVIEW CHECKLIST

Type Of Record	Availability	Compiled by	Maintained/utilized
1.Visitation Policy			
2 .Protocols and guidelines on			
family assessment/information			
checklist (at initial admission			
and during follow-up family	:		
visits)			
3. Incorporation of family-			
centered care into all			
appropriate standards and			
policies for the units (ICU			
mission statement and			
objectives)			
4. Minutes of meeting			
discussing family matters			
5. Notices on walls concerning			
family			
6.Circulars/information			
booklets on family			
8.Family-focused visiting policy			

(Henneman & Cardin, 2002: 15)

APPENDIX 3A: MATCHING RESEARCH OBJECTIVES, INTERVIEW GUIDE AND DOCUMENT REVIEW

Study Objectives	Interview Guide	Document	Review
		Checklist	
To identify nurses' perception of needs of families of critically ill patients in ICU	1, 2	1234567	
To describe ICU nurses' practices of care for families of critically ill patients	1, 3	1,2,3,4,5,6,7	
To identify challenges encountered by ICU nurses at QECH and MPH on meeting family needs	3, 4	1,2,3,4,5,6,7	
To determine how ICU nurses are prepared for role of family-support care.	3	1,2,3,4,5,6,7	

APPENDIX 3B: MATCHING CONCEPTUAL FRAMEWORK AND INTERVIEW GUIDE

Conceptual Item	Question
Environmental manipulation	1, 2, 3, 4
Emotional manipulation	1, 2, 3, 4
Therapeutic manipulation	1, 2, 3, 4

APPENDIX 4: INFORMATION DOCUMENT

Topic: Exploring perceptions and practices of ICU nurses when supporting families of critically ill patients in two hospitals in Blantyre, Malawi.

I am Wyness Tengeneza Gondwe Mulenga, a masters' student doing Critical Care and Trauma Nursing at the University of KwaZulu Natal in Durban, South Africa. In partial fulfillment of the masters program, I am required to complete a research project. I am interested in *exploring perceptions and practices of ICU nurses when supporting families of critically ill patients in two hospitals in Blantyre, Malawi*. The population will consist of nurses working in ICUs of Queen Elizabeth Central Hospital and Mwaiwathu private hospital and documents used to promote family support care in the two ICUs.

In ICU the traditional health care professional—patient relationship is often replaced by a health care professional—families relationship, due to the critical state of the patients. Caring for families therefore becomes an essential part of the responsibilities of a health care professional. Nurses, being the most visible health care professionals in ICU often assume the responsibility of maintaining this relationship and critically link/connect between the families and their critically ill patients during ICU admission. They are responsible for supporting families, including being aware of their unique stressors/needs, different ways of coping and help them cope as they suffer from uncertainty with the survival of their patients. It is against this background that the researcher wishes to conduct a study to better understand nurses' perceptions and practices when supporting families of critically ill patients in ICU.

The purpose of this study is to explore perceptions and practices of ICU nurses when supporting families of critically ill patients at Queen Elizabeth Central Hospital and Mwaiwathu private hospitals in Blantyre, Malawi.

I am therefore writing to ask you to participate in the study. The interview will last for 45-60 minutes and will be tape recorded for transcription. Should you need further

clarification, please do not hesitate to contact me or my supervisor on the contact details given below.

Your participation will be appreciated.

Thanks,

Wyness Tengeneza Gondwe Mulenga

Researcher's Contacts

Wyness Tengeneza Gondwe Mulenga Howard College Campus

School of Nursing

5th Floor, Desmond Clarence Building

4041 Durban, South Africa

+27 (0)786 705 406

Email: wynessgondwe@yahoo.com

Supervisor's Contacts

Professor B R Bhengu

Howard College Campus

School of Nursing

5th Floor, Desmond Clarence Building

4041 Durban, South Africa

+27 (031) 2607209

Email: bhengu2@ukzn.ac.za

APPENDIX 5: CONSENT DOCUMENT

STUDY TITLE: Exploring perceptions and practices of ICU nurses

when supporting families of critically ill patients in two hospitals in

Blantyre, Malawi

ETHICAL CLEARANCE NUMBER: HSS/0716/07

You may have attended presentations or heard about the above study. With regard to the

same, you are being asked to participate in the study because you are a nurse working in

the ICU. The researcher is interested in knowing your perceptions and role in support

care of families of critically ill patients in ICU. During the study you will be interviewed

and the interview will be tape recorded for transcription.

There are no individual benefits but the researcher hopes that information from this study

may identify opportunities for improvement in support and care of families in the ICU.

Your participation is voluntary and there will be no penalties involved if you choose not

to participate in the study.

You may contact the investigator by email at wynessgondwe@yahoo.com or at

Kamuzu College of Nursing, P.O. Box 415, Blantyre, Malawi on 01 873 623 or 08

873 848 any time if you have any question regarding the study.

You may also contact the Westville Campus Ethics Committee, Faculty of Health

Sciences, P/Bag X 54001, Durban, 4000 at +27 (031) 2607209 if you have any

questions about your rights as a research participant.

If you agree to participate you will append your signature as evidence of your acceptance

and be given a copy of the document.

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The research study including the above information has been explained verbally to me. I agree to be interviewed.

Signature of Participant	Date
Signature of Researcher	Date

Researcher's Contacts

Wyness Tengeneza Gondwe Mulenga Howard College Campus School of Nursing 5th Floor, Desmond Clarence Building 4041 Durban, South Africa +27 (0)786 705 406

Email: wynessgondwe@yahoo.com

Supervisor's Contacts

Professor B R Bhengu
Howard College Campus
School of Nursing
5th Floor, Desmond Clarence Building
4041 Durban, South Africa
+27 (031) 2607209
Email: bhengu2@ukzn.ac.za

APPENDIX 6: ETHICAL CLEARANCE -ETHICS COMMITTEE, UNIVERSITY OF KWAZULU-NATAL



RESEARCH OFFICE (GOVAN MBEKI CENTRE) WESTVILLE CAMPUS TELEPHONE NO.: 031 - 2603587 EMAIL: ximbap@ukzn.ac.za

28 FEBRUARY 2008

MRS. WT GONDWE (207514956) SCHOOL OF NURSING

Dear, Mrs. Gondwe

ETHICAL CLEARANCE: "EXPLORING PERCEPTIONS AND PRACTICES OF ICU NURSES WHEN CARING FOR FAMILIES OF CRITICALLY ILL PATIENTS IN MALAWI"

I wish to confirm that ethical clearance has been granted for the above project, subject to Supervisor's name and contact details being included on the informed consent document:

This approval is granted provisionally and the final clearance for this project will be given once the above conditions have been met. Your Ethical Clearance Number is HSS/0716/07

Kindly forward your response to the undersigned as soon as possible

Yours faithfully

Planba. MS. PHUMELELE XIMBA

cc. Supervisor (Prof. B Bhengu) cc. Mr. S Reddy

founding Computes: **** Edgewood

APPENDIX 7: ETHICAL CLEARANCE - COMREC, UNIVERSITY OF MALAWI



Principal

Prof. R.L. Broadhead, MBBS, FRCP, FRCPCH, DCH

Our Ref.:

Your Ref.: P.12/07/601

College of Medicine Private Bag 360 Chichiri Blantyre 3 Malawi Telephone: 677 245 677 291 Fax: 674 700 Telex: 43744

21st January, 2008

Mrs W.T. Gondwe C/o KCN Bt Campus P O Box 415 Blantyre

Dear Mrs Gondwe,

P.12/07/600 – Exploring perceptions and practices of intensive care nurses when caring for families of critically ill patients in Blantyre, Malawi.

I write to inform you that COMREC reviewed your proposal mentioned above which you submitted. I am pleased to inform you that your proposal was approved.

As you proceed with the implementation of your study we would like you to take note that all requirements by the college are followed as indicated on the attached page.

Sincerely,

Prof. E. Borgstein CHAIRMAN - COMREC

REQUIREMENTS FOR ALL COMREC APPROVED RESEARCH PROTOCOLS

- 1. Pay the research fees as required by College of Medicine for all approved studies.
- You should note that the follow-up committee will monitor the conduct of the approved protocol and any deviation from the approved protocol may result in your study being stopped.
- 3. You will provide an interim report in the course of the study and an end of study report.
- 4. You are required to obtain a continuation approval after 12 months.
- 5. All investigators must be fully registered with the Medical Council of Malawi.

APPENDIX 8.A: LETTER REQUESTING FOR PERMISSION TO CONDUCT THE STUDY -QECH

Wyness Tengeneza Gondwe Mulenga Kamuzu College of Nursing P.O. Box 415 Blantyre, Malawi 10th July, 2007

The Director, Queen Elizabeth Central Hospital P.O. Box 95 Blantyre, Malawi

Dear Sir/Madam,

Re: Permission To Conduct A Study On Exploring Perceptions and Practices Of ICU Nurses when Supporting Families Of Critically Ill Patients in Blantyre, Malawi

I am Wyness Tengeneza Gondwe Mulenga, Master Of Nursing Student in Critical Care and Trauma Nursing at University of KwaZulu Natal, Durban, South Africa. In partial fulfillment of the Masters Programme, I am required to complete a research project.

I hereby write to request permission to conduct a study titled above. The study will involve nurses working in ICU at Queen Elizabeth Central Hospital and Mwaiwathu Private Hospital. It will be conducted between December 2007 and January 2008.

The research has been approved by the ethics committee of the University of KwaZulu Natal, Faculty of Health Sciences. The study poses no risk of any kind to the participants.

Kindly receive copies of the ethical approval and the proposal for your perusal.

Thank you in advanced for your permission.

Yours Faithfully,

Wyness Tengeneza Gondwe Mulenga

CC: Professor B Bhengu, UKZN Ethics Committee, UKZN

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APPENDIX 8.B: LETTER GRANTING PERMISSION TO CONDUCT THE STUDY -QECH

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

All communications should be addressed to: The Hospital Director

Ref: QE/TR/11



In reply please quote No.

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

10th January, 2008

TO: Ms Wyness T. Gondwe, Kamuzu College of Nursing P.O. Box 415, BLANTYRE.

Dear Madam,

PERMISSION TO CONDUCT RESEARCH AT QECH INTENSIVE CARE UNIT (ICU)

With reference to your request for permission to conduct a study on "Exploring perceptions and practices of ICU nurses when caring for families of critically ill patients in Blantyre district Malawi"

I would like to inform you that we have no objection for you to conduct the mentioned study and will appreciate if a copy of your findings is shared with the hospital.

All the best in your studies

Yours Sincerely,

Dr. G. Msukwa

ACTING HOSPITAL DIRECTOR

APPENDIX 9A: LETTER REQUESTING FOR PERMISSION TO CONDUCT THE STUDY-MPH

Wyness Tengeneza Gondwe Mulenga Kamuzu College of Nursing

P.O. Box 415

Blantyre, Malawi

10th July, 2007

The Director, Mwaiwathu Private Hospital P.O. Box 3067 Blantyre, Malawi

Dear Sir/Madam,

Re: Permission to conduct a study on Exploring Perceptions and Practices Of ICU Nurses when Supporting Families Of Critically Ill Patients in Blantyre, Malawi

I am Wyness Tengeneza Gondwe Mulenga, Master of Nursing Student in Critical Care and Trauma Nursing at University of KwaZulu Natal, Durban, South Africa. In partial fulfillment of the Masters Programme, I am required to complete a research project.

I hereby write to request permission to conduct a study titled above. The study will involve nurses working in ICU at QECH and Mwaiwathu hospital. It will be conducted between December 2007 and January 2008.

The research has been approved by the ethics committee of the University of KwaZulu Natal, Faculty of Health Sciences. The study poses no risk of any kind to the participants.

Kindly receive copies of the ethical approval and the proposal for perusal.

Thank you in advanced for your permission.

Yours Faithfully,

Wyness Tengeneza Gondwe Mulenga

CC: Professor B Bhengu, UKZN Ethics Committee, UKZN

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APPENDIX 9 B: LETTER GRANTING PERMISSION TO CONDUCT THE STUDY-MPH



MWAIWATHU PRIVATE HOSPITAL LTD

: (265) 01 822 999 / 613 : (265) 01 834 989

: (265) 01 821 830 : (265) 01 821 190

Fax

E-mail: mdpa@mwaiwathuhospital.com

Old Chileka Road P.O. Box 3067 Blantyre Malawi

02nd January 2008

Wyness Tengeza Gondwe Kamuzu College of Nursing P.O Box 415 Blantyre MALAWI

Dear Madam

RE: PERMISSION TO CONDUCT A STUDY ON EXPLORING PERCEPTIONS AND PRACTICES OF ICU NURSES WHEN CARING FOR FAMILIES OF CRITICALLY ILL PATIENTS IN MALAWI

As per your request to conduct a study titled above, we wish to inform you that your request has been granted and you are welcome to conduct your study here between December 2007 and January 2008. Please feel free to ask us for any assistance and clarifications you might require during your study.

Thank you for the copies of approval and proposal for perusal.

Yours faithfully For Mwaiwathu Private Hospital

LEXA EVA PHOYA NURSING SERVICES MANAGER MWAIWATHU PRIVATE HOSPITAL OLD CHILEKA ROAD P.O. BOX 3067 BLANTYRE - MALAWI TEL: 01 822 999 - FAX: 01 821 190

Cc: Mwaiwathu Private Hospital

- Medical Director

题。ena

- Finance Manager
- Services Manager
- Human Resources Officer

APPENDIX 10: PROOFREADING LETTER FROM THE EDITOR

PROOFREADING by MARLENE

Cell: 082 466 0126

Date: 18 November 2008

This serves to confirm that I have proofread the dissertation for:-

Wyness Tengeneza Gondwe

My proofreading included:-

- Spelling
- Grammar and vocabulary
- Chapter and sub chapter numbering
- · Tables and figures
- General layout
- References

I have used "Track Changes" and "Inserted comments".

The completed work was emailed back to the student accordingly.

Yours sincerely

MARLENE SNELL

Ind feell.

APPENDIX 11: EXAMPLE OF A TRANSCRIBED INTERVIEW

Pseudo name: (Withheld for confidentiality)

11 April 2008 First Interview Hosp: (Withheld)

SECTION A

Researcher: Good morning once again. As I have already explained, I am Wyness Tengeneza Gondwe Mulenga. I am conducting a study, on perceptions and practices of ICU nurses when supporting families of critically ill patients in two hospitals in Blantyre, Malawi. You have been chosen as one of the participants, because you have been working in ICU for more than six months. I do not expect you to give me your real name. Just choose any name which you can be identified with, for recording purposes. It should not be your real name for confidentiality. So what name do you want to be identified with?

Respondent: Laugh.... Ok...uuuuh, Ok I will be (name withheld).

Researcher: Ooh (name withheld). Ok (name withheld), as I explained earlier after this interview, I will come again after 2 weeks for follow up. So now you will be (name withheld 1) and in the next interview, you will be (name withheld 2). In addition as I indicated earlier, you will be tape recorded for reference later, as I may not be able to write everything that you may say. So let me start by asking your demographic data unless if you have questions or need for clarification.

Respondent: No.

Researcher: Ok, Aah how old are you? Respondent: I am (age withheld) Years

Researcher: Ok, you are female

Respondent: Yes

Researcher: Eeh, religion Respondent: I am a Christian

Researcher: What is your basic nursing qualification?

Respondent: I have got (basic nursing qualification withheld)
Researcher: For how many years have you been working in ICU?
Respondent: I have been working in ICU for (withheld) years.

Researcher: Did you get any training in ICU?

Respondent: Ash I would say it was just a short training when they were opening ICU. There was Dr and Mrs. from South Africa. They provided some training but I

joined later when they had finished classroom work. It was on the job training

Researcher: It was for how long?

Respondent: It was for (withheld). Thereafter they left. Classroom training was for

(withheld) but then the practical continued for (withheld).

Researcher: Ok.

SECTION B

Researcher: So back to our family support care issue, can you briefly narrate to me how your day is like in ICU?

Respondent: Usually when I get to work, we do handovers but before handovers, we usually have prayers in the morning, then the night nurse hands over the daily duty nurses. After the handover, then we go to bed side of the patients, we assess the patient, just to find out how the patients are. If the patient is conscious we try to talk to him, even if the patient is unconscious, we try to assess just to have the real picture of how the patient is. And thereafter, we record our findings then after that, is when we start doing other activities. Then we expect the doctors, to come for ward rounds in the morning. If it is surgical patient, then is seen by the surgeon and if it is the medical patient, then usually is seen by the medical practitioner. But sometimes, the Medical Director himself, even if he is not a surgeon, is always interested to see any other cases.

Researcher: Do you have family members visiting in ICU?

Respondent: Yes. We do allow family members to visit the patients. The routine visiting Hours are, in the morning 6.30-7.30am, at noon from 12-1 o'clock, in the evening from 5.30pm-7.30pm. We allow 2 visitors per time. But sometimes, we can be flexible, depending on the patient's condition. Sometimes, the patient can be very sick and needs to be seen by the relatives at shorter intervals, sometimes because of the anxiety of the family members, we do allow then, because they can't wait that long, I mean waiting for the next visiting hour, so sometimes, we do allow them to come. They just allow us to work, but from time to time, they can ask for permission. We do allow them, to come and see their patients.

Researcher: But they don't stay around; they just come and visit?

Respondent: No, they don't stay around.

Researcher: From your experience, when those family members come to visit, do

you think they have any needs? **Respondent:** Yes, they do have

Researcher: What are their needs, or what do the express as their needs?

Respondent: Ok. Mostly, they want to know, why you have admitted the patient in ICU, unlike admitting the patient in any other ward, so you have to explain to them, why you have admitted the patient in ICU and they want to know, the problem with the patient, they want to know what you are actually, doing to help the patient. They also want to know the findings, so we also arrange times for them to meet the doctors, to explain to them. Because our hospital policy, is that not anybody is allowed to explain the patient's condition to the relatives, except the doctor who is taking care of that patient. So we can only explain other things like vitals signs, but not in details, but if they have questions we tell them that, they should ask the doctor. We encourage them to ask the doctor, when they have questions.

Researcher: So, basically, it is the information about the condition of their patient?

Respondent: Yes

Researcher: Apart from that, do they have any other needs?

Respondent: Yes. They also need to be re-assured, because mostly, they are very anxious, they look worried and they don't know what next is going to happen to the patient, so we also re-assure them though sometimes, it can be very difficult, especially when the patient is very sick and when the prognosis is poor. You think that may be the

patients is going to die and it can very difficult to re-assure somebody, when you know that the patient is going to die, and sometimes, they ask you a lot of questions, and it becomes very difficult to answer, depending on the condition of the patient. So they need to be re-assured where possible, and we try to re-assure them.

Researcher: So, need for re-assurance, need for information, any other need? **Respondent:** Sometimes, they also want to sit next to the patient, especially with terminal illness. We have had cases whereby, relatives have asked the doctors to discharge the patient from ICU to the general ward, because they want to sit next to the patient. Even though we do allow them time to come and see the patient, very often they still feel, they have to be there full time. Laugh....

Researcher: So, do you allow them?

Respondent: Sometimes, it depends on the doctor's assessment on the patient. When he feels like maybe something can be done, he just explains to them, that the patient needs to still stay in ICU and we just arrange that, they should be coming more in often. And when they come, we give them a chair to sit for maybe 10 minutes, and then allow them to go.

Researcher: When the family members visit, and you are giving certain care, like suctioning to the patient, do you allow them to participate in the care?

Respondent: Usually, we don't. Because, it depends on the procedure, you are doing. Most of them, are very scared especially, when you are suctioning, they feel that we are hurting the patient. So when doing such kind of procedures, we don't allow them. But sometimes, when we are turning the patient, or just cleaning the face if saliva was dripping, we allow them to do that.

Researcher: Have you ever tried allowed them, to remain when doing suctioning? **Respondent:** Laugh... I did that once because she was a nurse, it was the husband who was sick, so I felt that she knows what suctioning is. So I did once in her presence. But is unpleasant for them. She also (INCOMPREHENSIBLE)

Researcher: So, you mentioned that information giving basically, it is the doctor who does that, according the hospital's policy. Do you have that policy written?

Respondent: It should be somewhere, but I have not seen (INCOMPREHENSIBLE).

Researcher: But you were told, that the doctors should be doing that?

Respondent: Yes. For the policies, we have been revising the policies, because the initial ones, that we had, I think were copied from...... So we realized that some of them, were not tallying with the Malawian situation. So we are in the process of re-writing them.

Researcher: As an individual, do you like families to come and see their patients?

Respondent: Yes, it is good

Researcher: Why?

Respondent: They should see the condition of the patient, whether the patient is improving or deteriorating, at least they should be able to see that. But also when the patient is conscious, it also helps the patient to recover quickly.

Researcher: Is there anything that you don't like, about families visiting in ICU? **Respondent:** Yes. Especially the...... They want to come so many of them at once. They come in and they do not want to go out, and so they can cause a lot of stress to the patient. They will be many of them, around the patient's bed. So I don't like that.

Researcher: Why? I thought they are showing love to their patient?

Respondent: Yes, they are showing love, but it brings a lot of stress on the patient. But

also our room. When you think of ventilation, and then, there are so many people in the room, it is not nice at all.

Researcher: But are you affected yourself, with their presence, in case you want to give care, for example feeding, turning, does their presence affect your care to the patient?

Respondent: No, with some procedures like feeding the patient, sometimes, we do allow them because they are anxious, that their patient is not eating. We do allow them to see that their patient is eating. But with certain procedures, like taking blood specimen in tinny tinny babies, premature babies maybe born at 28 weeks, the mother can not stand that, and feels you are very cruel and so usually, I am not comfortable to do that, in their presence.

Researcher: Are there any barriers, that you come across, when you are trying to deal with family members, apart from the policy, which says the doctor is supposed to communicate to the family members. Is there anything else which may be, prohibits you from interacting with the family members?

Respondent: Yes. As I said, that we are supposed to be two nurses at least a shift, but sometimes you are found to be alone on duty. So you don't really have time to attend to the relatives, because you are busy, more so when you have more patients to attend to, so we do not have much time for them.

Researcher: Have you ever had any bad /nasty experience with families, when they come to visit. May be something, which you did not expect to happen?

Respondent: Not a very bad experience. But I remember one time, we had a patient. And then, she started to have a problem. Her level of consciousness, was going down. So I thought that may be she was going to hypoglycemia. So I took a glucometer and checked the blood sugar, and as I was doing that, I heard the family member talking with doctor (Dr).... (Doctor's name withheld for confidentiality) on the phone before I reported Myself, as a nurse on duty. Himself, as a guardian, phoned (Dr...). Then (Dr...) said, "can I talk to the nurse on duty". So I was busy attending to the patient, so I said I would come back to him, after attending to the patient. When I finished, I called (Dr...) and reported my findings. Anyway I didn't like, the fact that the relative called the doctor, before I reported my findings.

Researcher: Was he reporting about the findings of the glucose or what?

Respondent: He was just reporting that, his patient was not feeling okay. He didn't have any facts, no vital signs. And another time, we had an English lady who had a baby. This baby was on phototherapy. So we kept turning the baby, so that you that the phototherapy should be effective so she wasn't happy. She came to see the baby, found the baby in another position, came in another time, found the baby in another position. So, she called (Dr...) to say that these nurses are just turning the baby anyhow. And I am not happy, because they are going to remove the drip. So, (Dr...) called us and asked what we were doing with baby, because the mother was complaining about the turning. So, such kind of things do happen and they interfere with our work, and you are in a dilemma, because you are doing the right thing but the mother is not happy.

Researcher: May be she was not told the problem, and what you will be doing to the baby as treatment?

Respondent: No, we explained to her, but I think the main problem, was lack of trust. She didn't trust us much, because when **(Dr...)** explained to her later on, she became

comfortable. But she thought may be, we are just doing things, without knowledge. **Researcher:** You have mentioned of shortage of nurses, being one of the big problems regarding family care, and that you don't have time, and maybe you are alone against many patients; is there anything more which you can say is a challenge, towards providing proper family care?

Respondent: Yes. More especially, when the patient is very sick, you want to re-assure the family members, but there are times when you don't know what to say, in order to reassure them, mainly when the progress is poor or the patient is dying. That becomes a great challenge.

Researcher: In that case, what do you do?

Respondent: Laugh...If you know their background, sometimes for example if they are Christians and believe in God it can be easy because you can say something from the Bible and encourage them with the word of God but when you have got different religious background or somebody does not believe in God, it becomes difficult **Researcher:** Do you have any suggestions or recommendations to make, so that family care can be improved?

Respondent: I think things like, the research you are doing, can help to improve family care. And even researching from the family members, who had patients here, to hear from them what they expect from us, I think that can improve family care.

Researcher: Ok, that is encouraging to me. Thanks

Respondent: Yaah

Researcher: From the hospital point of view, do you think there is something, which could be done in order to improve?

Respondent: I think there isn't much, because for the visiting hours, as I have said, sometimes, we are flexible. We do allow them to come in, at any time. Again, initially, this room, was a waiting room for relatives of patients in ICU, but it was closed, because the room was being abused. We could have a lot people, with friends here, and it was difficult to control traffic on this corridor, because we have a theatre just next here. So, this was closed as a waiting room. Now, we tell them to sit on the reception. And at night, they are asked to go home. But it becomes very difficult for them to go home when they have got a very sick relative, Most of them, feel very uncomfortable to go home. So, sometimes they just sit around at the reception, the whole night. So, I feel if the hospital, can arrange or re-open this room, because sitting the whole night and then during the day, they don't have anywhere they can lie down at least to rest, I think they need to be considered. And more research, needs to be done as a unit. I think we should also have in-service education, so that, we nurses, should be doing uniform things.

Researcher: Those are very good observations and suggestions....

Respondent: I was surprised one time, I brought my neighbor at night. From casualty, I brought her to ICU here. The patient was put in bed, and the nurse on duty sat down, and started writing without explaining anything to the family members. I had to ask her to do it. I have discovered that some do it others don't. It is not uniform and I do not know if it is lack of knowledge or it is just negligence. So I think there is need for a in-service education to share some of the information for uniformity.

Researcher: Ok. Uuuuh do you have any question, because we have now come to the end of our interview?

Respondent: Ok. Are you going to furnish us with findings of your research?

Researcher: Definitely, I will have to do that. Actually, I will start analyzing data, and I will come to verify with you, to see if it is a true reflection of your views. After I finish compiling the report, I will send the copy of the report, and I might also come to give a verbal one. I think we will be working together onwards. Any more questions?

Respondent: No

Researcher: Ok. thank you very much. I will come again after 2 weeks as I explained.

Respondent: Thank you very much. We will appreciate that.

Researcher: Thank you.

APPENDIX 12: BRACKETING

Personal

The researcher has a fair understanding of the experiences of families of critically ill

patients, because of her own experience of nursing a critically ill relative. Patients come

from families. Patients' needs therefore do not exist in isolation, even in the ICU and

cannot be separated from those of their families, because of the bond that exists amongst

them right from home.

Professional

The researcher's work experience, as a nurse and as a critical care nursing student,

exposed her to what families go through when they have critically ill patients in ICU. My

experience is that, families of the critically ill patients, mostly want unrestricted access to

their loved ones, and often consider this, "their right" in addition to, receiving adequate

information about their patients. I observed that most often even when families were

told to go home or to the waiting area, most of them could not because they just wanted

to be close to their loved ones. In addition they continuously asked questions about their

loved ones because they felt insecure about the outcome of the illness. This drained all

their energy levels, creating a need for nurses to support families in order for them cope

with the situation.

However, the researcher observed that nurses limit family support care in ICU, because

their primary duty, is to the critically ill patients. This is due to the nature of the intensive

care environment, as there are many physical and technical aspects to care, which are

essential to the patient's safety.

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In addition, lack of time, knowledge, clear guidelines of family support care, shortage of nurses and fear of conflicting with doctors over information giving, prevented nurses from focusing on the needs of the families, and fully implementing family support care. The researcher feels that, novice nurses lack organizational, assessment, and technical skills and often have difficulty integrating the patients' families into the plan of care, with very unstable patients. They are also insecure and uncomfortable having families, at the bedside who could scrutinize their performance.

The researcher therefore, feels that in order for ICU nurses to be able to support families of critically ill patients well, they need to have the "know how", because ICU is different from other units. Therefore there is need for nurses working in ICU, to be trained in critical care nursing, in order to appreciate what families go through, when their loved ones are admitted in ICU, so that they can support families.

When nurses are charged with the care of critically ill patients, it is nearly impossible for them to meet the patients' needs, when they are constantly bombarded with questions and family needs. Nurses who are new to the critical care setting, need to concentrate on patients' assessment and what they are doing for the patients, and these frequent interruptions can lead to frustration. I know this is one of the reasons, many nurses have left the bedside in ICU, because the situation is too taxing, for them to cope.

Nurses can not be all things, to all involved, and still meet the patients' needs first. I feel that, much as there is need to seriously look at patients' and families' needs, there is also

need, to see how the bedside nurses can be supported, in order to meet these needs. Additionally, I feel that the critical care environment, is currently not set up, to accommodate families' constant presence at the bedside. There are concerns about privacy and confidentiality issues, frustration and resentment about family members being "in the way", which need to be addressed.