ASSESSMENT OF STRESS IN CAREGIVERS WITH CHILDREN ADMITTED IN CRITICAL CARE UNITS AT QUEEN ELIZABETH CENTRAL HOSPITAL, BLANTYRE, MALAWI

MSc. (Child Health Nursing) Thesis

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Declaration

I, Jester Jere, hereby declare that this thesis is a result of my own hard work and has not been presented for any other award at the University of Malawi, or any other university. Other people's work referenced has been duly acknowledged.

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Certificate of approval

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

Signature: _____ Date: _____

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Dedication

This thesis is dedicated to the Lord God Almighty for being my strongest pillar through many bumps in the journey and to my dear daughter Favour Glory Valeta for the inspiration.

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Abstract

Admission of a child to Critical Care Unit (CCU) is an unexpected and stressful event for the caregiver which may result in physical and mental exhaustion. If stress in caregivers goes unnoticed, they become emotionally traumatised and this affects their role in the parenting of a critically ill child. This was a descriptive cross-sectional study that utilised quantitative data collection and analysis approaches to describe stress experienced by caregivers of critically ill children admitted in CCU at Queen Elizabeth Central Hospital. Caregivers who had critically ill children admitted in various CCU in the paediatric department were recruited using convenience sampling technique. The researcher in person conducted interviews using a structured questionnaire to 385 caregivers who were 18 years of age and above. Data analysis was done with the aid of the Statistical Package for Social Science (SPSS) version 20. Descriptive and inferential statistics were used to present results of the study.

Results of the study revealed that the average level of stress in caregivers was 3.41. Appearance of the child was the most stressful element in CCUs while healthcare workers' conduct caused minimal stress to caregivers. Two components emerged from Principal component analysis (PCA) and these were stress related to child situation and stress related to healthcare workers. The findings also show that the level of stress in caregivers was significantly associated with the age of the caregiver and child and the nature of admission. Gender, residence, religion, education, ethnicity, prior admission, the gender of the child did not affect the level of stress. Healthcare workers require knowledge and skill in assessment of stressful situations in caregivers. Healthcare workers' support will assist caregivers to cope while fulfilling important caregiver roles that are therapeutic to the critically ill child.

Keywords: caregivers, stress, critical illness, critical care unit

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List of abbreviations and acronyms

A- PSS: PICU	:	Abbreviated Parent Stress Scale Paediatric Intensive Care unit:
CCU	:	Critical Care Unit
COMREC	:	College of Medicine Research and Ethics Committee
CPAP	:	Continuous Positive Airway Pressure
HDU	:	High Dependency Unit
FCC	:	Family Centred Care
ICU	:	Intensive Care Unit
KCN	:	Kamuzu College of Nursing
KCH	:	Kamuzu Central Hospital
KMO	:	Kaiser Meyer of Olkin
PICU	:	Paediatric Intensive Care Unit
PCA	:	Principal Component Analysis
NICU	:	Neonatal Intensive Care Unit
NRU	:	Nutrition Rehabilitation Unit
SPSS	:	Statistical package for social sciences
QECH	:	Queen Elizabeth Central Hospital

Operational definitions

Stress: Physical, mental, or emotional factor which leads to bodily or mental tension as a result of an individual's inability to cope with a particular situation or circumstance (Juneja et al., 2019). It is a feeling that is expressed due to increased demands beyond one's coping capabilities from interactions between the person and environment.

Caregiver: A person who provides direct care to children, elderly, or chronically ill (Merriam – Webster dictionary, n.d.). In this study, caregiver refers to any individual who is responsible for providing direct care and needs of the critically ill child regardless of gender or biological relationship while in the Critical Care Unit.

Caregiver stress: A caregiver's experience of bodily, mental, or emotional tension resulting from factors that tend to alter an existing equilibrium (Llanque et al., 2015).

Critical illness: Any immediate life-threatening disease or injury. It is an illness where a patient is suffering from severe failure of one or more vital organs such as the heart, lung, liver, or kidneys (Mallett et al., 2013).

Critical Care Unit: Hospital settings that are responsible for the provision of complex and advanced care or intensive medicine to patients with life-threatening health problems. The settings include Accidents and Emergency departments, theatre, High Dependency Units (HDU), and Intensive Care Unit (ICU).

Chapter One

Introduction and Background

Introduction

Admission of a child to the Critical Care Unit (CCU) is a difficult experience for both the child and caregiver (Majdalani et al., 2014). Caregivers are psychologically affected by the sudden severe illness of the child. They become hopeless and afraid of losing the child as a result of the seriousness of the condition. The strange critical care environment and the presence of various equipment connected to the child create fear and a feeling of hopelessness in caregivers. Family functions and roles become disorganised and disrupted. Colville et al. (2009) and Kanmani et al. (2019) emphasise that when a child is admitted to an Intensive Care Unit, caregivers face psychological and financial problems. They often compromise on the quality of life due to changes in daily routines and financial hardship which result from increased daily expenses and absenteeism from work.

In the CCU, caregivers are exposed to numerous factors such as physical, environmental, psychological, personal and social, that are likely to determine the magnitude of stress that caregivers of a critically ill child may experience (Gallegos, 2011; Musabirema et al., 2015). Miles and Carter, the original developers of the Paediatric Intensive Care Unit: Parent Stress Scale (PICU: PSS) suggest that caregivers' stress responses result from the interactions between the following factors: situation variables, personal characteristics, and environmental stressors (Gallegos, 2011). The source of stress appears to emanate from the sick child, caregiver, healthcare workers, and the critical care environment.

Depending on the severity of the condition, the sick children may need to be immediately separated from their caregivers for resuscitation and critical care intervention in

CCU. Children with critical illness often require various technologies, tubes, medications, and wires for care and monitoring. Caregivers are unable to provide for their children's basic needs, such as clothing, feeding, and comforting, because of the technological equipment which are connected to the sick child. Caregivers' inability to provide for their children's basic needs affect their roles and responsibilities in the care of a sick child in CCU. Caregivers are intimidated by the complex layout of the CCU environment and they go through a grieving process because of loss of their caregiving role and fear of losing a child (Roets et al., 2012). The physical separation of the caregiver and the child can cause significant stress in caregivers. Levels of stress in caregivers may be dependent on the severity of the condition of the child, situation surrounding the condition of the child, demographic variables of the caregiver and child.

The practise of paediatric critical care nursing must include psychosocial support of caregivers and their families to help them endure the stressful and unspeakable experience of a child's critical illness. Healthcare workers in CCU require knowledge and skill in the assessment of stressful situations to caregivers with critically ill children. Healthcare workers' support will assist caregivers to cope while fulfilling important roles that are therapeutic to their family and the critically ill child.

Background Information

Stress is defined as a physical, mental, or emotional factor which leads to bodily or mental tension and may arise when an individual is unable to cope with a particular situation (Juneja et al., 2019). The ability to deal with difficult situations varies tremendously from one person to another. Some individuals can handle stressful situations better than others taking into account the availability of resources. However, some individuals may reach a point

where they are unable to take in any more stress and this may lead to a series of stress response.

Critical care unit can be a highly stressful environment for the caregivers of critically ill children. There is a high burden of illness and patients with chronic or acute conditions are requiring intensive and immediate critical care. Intensive Care Society (2009) defines CCU as all units that are responsible for the provision of level 2 and level 3 of critical care to severely ill patients, for instance, the High Dependency Unit (HDU) and Intensive Care Unit (ICU) respectively. Increased numbers of children with life-threatening illnesses are being admitted to CCU for resuscitation and organ failure support. HDUs provide more detailed observation and interventions including support for a single failing organ system, post-operative care, and those patients stepping down from ICU. On the other hand, ICUs provide advanced care to critically ill patients who require support for multi-organ system failure.

Critical care is a multidisciplinary and inter-professional speciality dedicated to the comprehensive management of patients having, or at risk of developing, acute, life-threatening organ dysfunction (Marshall et al., 2017). The complexity of critical care is that it uses technologies that provide support for failing organ systems for instance the lungs, heart, and kidneys. More children with life-threatening conditions are now being managed in CCU in both developed and developing countries. Complexities in critical care and severity of illness create an environment that is quite stressful for caregivers.

There are great differences between critical care in rich and poor countries worldwide. In developed countries, the creation of advanced life support techniques has expanded treatment options for critically ill children. On the other hand, in developing and least developed countries provision of critical care services is extremely challenging because of many factors such as limitations in the existing infrastructure, high burden of diseases, lack of

material resources, and low numbers of healthcare workers trained in critical care (Murthy & Adhikari, 2013). Riviello et al. (2011) concur that critical care in a limited-resource country like Malawi is affected by lack of basic equipment, medications, and trained personnel as well as the late and severe presentation of disease secondary to poor access to appropriate health care.

There are only four Intensive Care Units (ICU) located in Mzuzu, Kamuzu, Zomba, and Queen Elizabeth Central Hospitals. These are tertiary government hospitals that receive critically ill patients from primary and secondary level health facilities. Mwaiwathu Private and Blantyre Adventist Hospitals also provide critical care services to adult and paediatric patients in the private sector. The general ICU at QECH has a standard bed capacity of four which caters for both critically ill adult and paediatric patients from all clinical sections. However, additional paediatric beds may be added in the unit for under-five children.

Tomlinson et al. (2013) in their study on the burden of surgical diseases on critical care services found that 34 out of 233 admissions were children aged 1-17 years at Kamuzu Central Hospital. Besides, at QECH ICU, 113 children aged 1-17 years compared to 258 adult patients were admitted between September 2013 to October 2014 (Prin et al., 2016). Previously before they opened Mercy James Centre for Paediatric Surgery and Intensive Care (MJC), few paediatric patients were admitted to ICU compared to adult patients because of limited space as only one bed was allocated for paediatric patients. It can be estimated that, at any given moment in time, 30 to 50 paediatric inpatients are critically ill (personal communication with Dr Q. Dube, Head of Department of paediatrics) as cited by Manda-Taylor et al. (2017). Most critically ill children were admitted to HDU which is a step-down unit from ICU. However, there is no data to qualify this statement because there was no separate register for the unit. According to a systematic review by Murthy et al. (2015), low-

income countries lack CCU beds and more than 50% of the countries lack any published data on CCU capacity.

The admission of the child to CCU may be one of the most stressful events of both the child and the caregiver (Oxley, 2015). Most of the admissions in CCU are unplanned due to life-threatening illnesses or accidents and arouse feelings of fear and helplessness in the caregiver (Gallegos, 2011). This is also reflected in the admissions which were done at KCH and QECH ICUs where children were admitted from the emergency department while some following major surgery. Surgical cases account for the majority of ICU admissions in Malawi (Tomlinson et al., 2013). Caregivers are tremendously affected by the severity and the unpredictability of the immediate health outcomes of their sick child.

Studies agree that there are several variables associated with caregivers' stress during childhood admission to CCU. Caregivers' stress can manifest in response to different stimuli for example personal characteristics, situational variables, and environmental factors. According to Gallegos (2011) and Musabirema et al. (2015) personal characteristics include social-demographic information describing personal attributes of both caregiver and child. It may also include an individual perception regarding illness. Situational variables are circumstances or situations that surround the admission of the child such as nature of admission, the severity of the illness, prior hospitalisation, and uncertainty of the outcome of the illness (Gallegos, 2011; Musabirema et al., 2015). Environmental stressors are the physical outlook of the critical care environment that includes the presence of acutely ill children attached to monitors and technical equipment with sudden alarming noise (Gallegos, 2011; Rodríguez-Rey & Alonso-Tapia, 2016). It also involves communication and behavioural patterns of healthcare workers in the unit. Situational variables, personal characteristics, and environmental stressors determine the level of stress a caregiver with a

child in CCU would experience. CCU stressors, individually or in combination, may interfere with the caregiver-child relationship and create extra difficulties for the couple and family (Chiejina et al., 2015).

Ramírez et al. (2018) described factors that cause stress to caregivers with critically ill children in CCU in four groups. Stressors were grouped into factors derived from the critically ill child, caregiver, environment, and the clinical team. Factors derived from the critically ill child are related to circumstances surrounding the childhood illness in addition to the presenting signs and symptoms. The severity of the condition changes the child's appearance and behaviour and these affect caregivers psychologically (Kumar & Avabratha, 2015; Musabirema et al., 2015; Pooni et al., 2013; Roets et al., 2012). The child may be unconscious, connected to life support equipment, and also under the influence of sedative medications (Oxley, 2015; Pooni et al., 2013).

The above interventions may distort the facial features of the child and affect child and caregiver interactions. The severity of the condition may alter the child's response to the caregiver. The child may not respond or may present with physiological body changes such as increased heart rate or blood pressure causing alarms on monitors to sound. The caregiver becomes anxious and hopeless that the familiar method of comfort is not effective on the child. Caregivers become psychologically affected because of their inability to protect the child from painful procedures as a result of the severity of the condition (Roets et al., 2012).

Factors derived from the environment include the presence of technological assistance in the execution of critical care. The technological equipment such as monitors, ventilators, oxygen concentrators, oxygen cylinders, bubble Continuous Positive Airway Pressure (bCPAP), and suction machines cause stress in caregivers. Literature shows that caregivers experienced stress due to unfamiliar sight and sounds in the ICU (Majdalani et al., 2014; Musabirema et

al., 2015; Roets et al., 2012). Other stressors in CCU environment may include unpleasant odour, lights, environmental noise such as alarms from monitors and other machines, crowded rooms with many critically ill children, and healthcare providers. Caregivers were also concerned about the open setting between patients and lack of space between beds which affects comfort (Majdalani et al., 2014).

Factors derived from the clinical team include bedside manners of healthcare professionals. In this study, bedside manner was defined as any nuances in body language, behaviour, and communication exhibited by healthcare workers during interactions with the critically ill child and their families and caused physical, mental or emotional tension in caregivers. The bedside manner of the healthcare workers often included the attitude, professionalism, and manner of care expressed by the nurses and doctors in the unit (Williams et al., 2018). Poor bedside manner for instance inappropriate healthcare workers' behaviour such as laughing, speaking loud, not introducing themselves and lack of attention or carelessness are stressors to caregivers. Caregivers receive information from both doctors and nurses. Most often healthcare workers do not introduce themselves and do not describe their roles to patients and their guardians. Gondwe et al. (2017) found that caregivers had difficulties differentiating nurses and doctors because healthcare workers may not have introduced themselves and may not have worn prescribed uniforms and identity cards. This may result in confusion, worry, and anxiety to the caregivers.

Factors derived from the clinical team may also include stressors related to communication problems between caregivers and healthcare professionals. Problems arise when explaining information in a way that caregivers do not understand, expressing contradictory opinions, talking too little or too fast, and using medical jargon. Shortages of nurses, congestion, and workload may also contribute to inadequate dissemination of

information by healthcare workers. Healthcare workers focus on providing physical treatments, and therefore educating family members may not be a priority. Lack of collaboration between doctors and nurses may also lead to a variation on the information about the condition and treatment plan of the patient therefore leaving the caregivers stressed and confused.

In most neonatal nurseries in Malawi, caregivers stay on a different ward and visit their children every 3 hours. When a neonate's condition deteriorates, healthcare workers must implement lifesaving procedures immediately and caregivers usually received information after commencing treatment. On the other hand, caregivers from the paediatric nursery ward received information before commencing treatment because they are always available in the unit. A study that was done by Gondwe et al. (2017) on experiences of caregivers of infants who have been on bCPAP at QECH, Malawi found that the caregivers who found their infants already commenced on bCPAP in the neonatal nursery were more stressed than their counterparts in the paediatric nursery. It is healthcare workers' responsibility to give adequate and timely information about the condition of critically ill children and the treatment plan to reduce stress in caregivers.

Caregivers are also affected by role alteration when their child is admitted in CCU. This is the main factor derived from the caregiver. There is role revision process where caregivers surrender their role as a caregiver of a healthy child and assume the role of a caregiver to a critically ill child (Gallegos, 2011; Kumar & Avabratha, 2015). Therefore, caregivers are stricken with grief for the loss of their previous role (Kumar & Avabratha, 2015). Caregivers no longer have control over the care of their children and need to accept that healthcare workers act in the best interest of their child. The high technological environment, ethical dilemmas, staff shortages, professional attitudes, and critical care

organisational culture may contribute to caregivers' lack or partial involvement in the decision-making process and provision of care to their child.

Each caregiver develops his or her own perceptions about the CCU experience determined by various factors that can influence the caregivers. Some caregivers, may view their situation as positive since their critically ill child is getting the care he or she needs, others may see it as negative when the child or healthcare worker is unable to meet their expectations or needs. Individuals' ability to deal with difficult situations depends on the nature and severity of stress, the psychological make-up of the individual, and the availability of the resources. Some caregivers may cope by using the environmental resources available to them such as the support of the healthcare workers, while others may use personal resources such as family, friends, or financial assets. Hence, the response to the stress of having a child in the CCU can therefore be the result of a complicated interaction of various variables or factors that can potentially be adaptive or maladaptive.

Caregivers' health and wellbeing are affected by the enormous psychological burden inflicted on them. The caregiver is at a greater risk of failure to cope with the critical illness of his or her child. They put aside personal commitments, family roles, physical needs, and daily routines while adapting to the needs of their critically ill children and CCU environment (Tsironi & Koulierakis, 2018). Lee et al. (2012) study results confirmed that the above elements left the caregiver feeling a lot of mental and physical exhaustion during hospitalisation of his/her child. Furthermore, Lee et al, found that caregivers may experience considerable emotional distress for instance being either very quiet or worried about a child's illness.

Colville et al. (2009) and Majdalani et al. (2014) explain that caregivers may present with anxiety, grief, acute stress, and post-traumatic stress disorder before and after discharge

from the CCU. Untreated stress in caregivers may also lead to a lack of trust of healthcare providers, inability to comply with hospital regulations and decisions, anger and hostility, and litigation (Karale et al., 2016). Caregivers need emotional support to help them adapt to the admission of the child to CCU. In this case, family-centred care (FCC) becomes a necessity because it provides a platform where both physical and emotional needs of the critically ill child and caregivers are addressed through principles of partnership, participation, and protection.

FCC is a model of care that involves planning, provision, and health evaluation that is conducted mutually by the partnership between healthcare provider, patient, and family (Balbino et al., 2016). FCC is an essential element of paediatric nursing practice because the family is central to the sick child. However, Roets et al. (2012) state that a gap exists in valuing FCC and its implementation in practice. A healthcare provider is inclined to be more focused on the child's physiological crisis and health, while the emotional needs of the caregivers are often neglected (Roets et al., 2012). Gondwe et al. (2011) identified challenges that critical care nurses face while meeting patients' families' needs at QECH in Malawi. The challenges include learning critical care through experience, lack of clear written policy on family support, inability to answer persistent questions from family members, and an increased workload due to staff shortages. The study found that inadequate critical care training, lack of preparedness to provide continued and persistent support and information to families and competing demands for the patient and family care affect nurses' support to the families. Therefore, the key nursing function is to assess the emotional state of the caregiver with a child admitted to CCU and to provide appropriate psychosocial support in such a challenging situation.

Problem Statement

Admission of a child to CCU is an unexpected and stressful event for the family. Caregivers experience personal-family, situational and environmental stressors (Kumar & Avabratha, 2015) all at once. Situational stress of the child's unplanned hospitalisation coupled with other stressors in the CCU environment and personal /family issues could increase stress in caregivers. Hospitalisation of critically ill children demands complex medical care that caregivers are unable to provide (Oxley, 2015) and this affects their caregiver role in child care and protection. The severity of the child's condition, alteration in the caregiver role, and the strange CCU environment disturb caregivers' emotional state.

An interpretive descriptive qualitative study that was done by Gundo et al. (2019) in two tertiary hospitals in Malawi found that nurses are unprepared to provide critical care in CCU because of lack of educational preparation, loss of nurses who gained experience in critical care to other departments as a result of the annual rotation, and lack of short courses on critical care. Healthcare workers in CCU may only attend to the physiological needs of the critically ill child neglecting the emotional state of the caregiver. A study that was done by Phiri et al. (2017) on Registered nurses' experiences on family involvement in the care of hospitalised children at a tertiary government hospital in Malawi, revealed that although registered nurses involve family members, its implementation was inconsistent and problematic. Tertiary hospitals need to involve families because they provide specialised care which may be a source of stress to the sick children and their caregivers.

A descriptive qualitative study that was done by Gondwe et al. (2017) on experiences of caregivers of infants who have been on bCPAP at QECH, Malawi found that caregivers were afraid, worried, and anxious that their children may die. Also, some caregivers described interruption of caregiver and infant interaction caused by bCPAP machine as a

major source of stress. If caregivers' stress in the CCU environment goes unnoticed, they may become traumatised psychologically. They may suffer psychological problems such as post-traumatic stress syndrome, anxiety attacks, depression for a long time even after their children are discharged from CCU as well as the hospital (Colville et al., 2009; Oxley, 2015). Masulani-Mwale et al. (2018) in their quantitative cross-sectional study on the prevalence of psychological distress among caregivers of children with intellectual disability in Malawi revealed that 41% of caregivers reported a level of psychological distress above the expected norm.

Healthcare professionals need to be aware of the stressors that affect caregivers when their child is admitted in CCU. Most studies that generated literature on caregiver stressors in CCU have been conducted in developed countries. It may be difficult to use literature found in developed countries to caregivers with children in CCU from developing countries or least developed countries because of differences in technological advancements, family background and support system, religious and cultural influences. Therefore, this study was conducted to identify stressful situations among Malawian caregivers when their children were admitted to CCU. The study also identified social and demographic factors that affect the level of stress in the caregiver in a limited resource country. Therefore, it is important to assess the most stressful situations and the level of stress caregivers experience when their children are admitted to CCU in Malawi.

Broad Objective

The aim of the study was to assess stress experienced by caregivers with critically ill children admitted to CCUs at QECH.

Specific Objective

1. To identify situations caregivers find stressful whilst in CCU environment.

2. To determine the strength of the correlation between variables that cause stress on A-PSS: PICU instrument.
3. To examine the relationship of child and caregiver demographic variables and the level of stress in the caregiver.
4. To examine the relationship of child clinical variables and the level of stress in the caregiver.

Significance of the Study

Intensive care nursing (ICN) is a specialist area of nursing that involves caring for patients who are suffering from life-threatening illnesses or injuries, while at the same time offering comfort and support to their family members (Beer et al., 2011). Critical care practice involves the provision of both physical care and psychological support to a critically ill child and his or her caregiver. Assessment of stress among caregivers with children admitted in CCU's is very important in the attainment of Family Centred Care concept. Healthcare workers need to understand factors that cause stress to caregivers in order to offer effective supportive interventions. Healthcare workers in CCU will be able to provide holistic FCC which attends to caregivers' needs in order to cope with stressful experiences during their children's illness. Hospital and unit managers will be able to make the necessary adjustment to meet caregivers' needs during their critically ill children's hospitalisation to CCU such as emphasis on FCC.

The findings of the study will assist in creating standard guidelines that will help healthcare providers prevent, or reduce stress in caregivers of children admitted to CCU. Healthcare workers' knowledge and skill in the assessment of stress and the provision of effective support interventions will assist in the provision of an environment with lower stress and greater caregivers' satisfaction with critical care. There is a relationship between stress

and general satisfaction. According to Tsironi and Kouleirakis (2018) increased caregivers' stress levels were found to lead to lower rates of satisfaction from the care provided.

Furthermore, the research-based evidence that has been generated will contribute to the body of knowledge in the health sector especially child health nursing by contributing to the scant literature on assessment of stress in caregivers. The study may act as a baseline for further research on assessment of stress to caregivers in order to improve child health services in critical care units. It will assist educators to identify possible gaps in the current nursing curriculum that need to be addressed in educational institutions.

Chapter Two

Literature review

Introduction

This chapter presents a review of the literature that was relevant to the topic of study. A literature review was conducted to generate knowledge and understanding of studies already done on the assessment of stress to caregivers with critically ill children in CCU. The literature search was done through various academic databases such as Pub Med, Open Access, World Health Organisation database (HINARI), ScienceDirect.com, and Google scholar in order to review what is known about situations that caregivers find stressful in CCU environment. A manual search from Kamuzu College of Nursing library was done where unpublished documents were accessed and reviewed.

Search queries that were used included: caregiver stress OR parental stress AND PICU admission, assessment of stress AND PICU environment, family caregivers AND CCU admission, Parental OR caregiver stressors AND PICU.

Literature shows that several variables or factors are associated with caregiver stress when a child is hospitalised in CCU. Many studies conducted in developed countries and few in developing countries found that stressors or factors that cause stress to caregivers in CCU include loss of caregiver's role, sight and alarming sound of monitors, change in child appearance, change in child's behaviour and emotions, poor healthcare workers' communication patterns, procedures done on the child, inappropriate healthcare workers behaviour, child's critical condition and uncertainty of outcome. This chapter is discussed under four subheadings derived from the list of factors presented above. The subheadings are as follows: - factors or stressors related to the critical care unit environment, the critically ill

child, healthcare workers, and caregivers. It also includes demographic factors of the caregiver and critically ill child associated with stress in caregivers.

Stressors related to the critical care unit environment

CCU environment differs in physical presentation and layout from other hospital settings. It is an environment intended for the care of seriously ill and unstable patients and its complexity is considered high because it is equipped with leading-edge technological and computerized appliances (Backes et al., 2015). In addition, it is where aggressive and invasive procedures are performed, the pace of activities is accelerated and the fight between life and death is ever-present. As technology continues to advance, a large number of critically ill children are being treated and kept alive in highly technical critical care environments.

CCU environment has the potential to exacerbate stress for caregivers of children admitted to the unit (Chiejina et al., 2015). The physical presentation of the CCU has been identified as a source of stress for caregivers. The environment is described in the context of technological advances as well as odour, alarms, light, environmental noise, and a large number of people in the unit (Ramírez et al., 2018). According to a study done by Majdalani et al. (2014) on the lived experiences of caregivers of children admitted to PICU in Lebanon, mothers found the CCU to be a new and strange environment. The presence of technological advances such as ventilators, oxygen concentrators, and cylinders, suction machines, monitors, bCPAP machines in CCU cause stress in caregivers. The presence of technological equipment, the constant sound of monitors, and the sudden noise of the alarms in CCU differ from that of the general paediatric or neonatal ward. The environment is perceived by them as an aggressive and threatening space because it evidences the risk of the patient dying (Barth et al., 2016).

Perceptions about the aggressive treatment in CCU vary but most caregivers fear injuries and eventually death of the child when treatment is initiated. In a different Malawian study, caregivers expressed fear and anxiety about using oxygen and cited this as a reason for refusing it because they had witnessed death of a patient on oxygen (Stevenson et al., 2012). There are misconceptions that oxygen delivering devices for instance oxygen concentrators or cylinders and nasal prongs, mask, bCPAP machines kill. A study that was done by Gondwe et al. (2017) revealed that participants reported fear when they observe their infants on bCPAP machines. They feared that their children may die or be hurt by the machine and expressed worry, disappointment, and anxiety.

Literature shows that caregivers experienced stress due to unfamiliar sight and sounds in the ICU (Majdalani et al., 2014; Musabirema et al., 2015; Roets et al., 2012). Musabirema et al. (2015) in their study on caregivers' perception of stress in NICU in Rwanda, found that sight and sound was the cause of moderate stress in caregivers with an average stress score of 2.7. A similar study that was done by Turner et al. (2015) in Australia identified that strange sight and sounds in NICU cause moderate stress in caregivers with an average score of 2.38. Musabirema et al. (2015) found that caregivers' perceived sudden monitor alarms to be more stressful with a stress score of 4.0 which differs from Turner et al. study that having a ventilator breath for the baby was more stressful with a stress score of 3.39. This concurs with a Malawian study that was done by Stevenson et al. (2012) on barriers to uptake of oxygen therapy in Malawi which revealed that participants found the appearance and noise from oxygen concentrators alarming and feared that healthcare workers wanted to kill their child when they placed nasal prongs into the child's nose.

Similarly, a study that was done in South Africa by Roets et al. (2012) found that environmental factors such as equipment and alarms were sources of stress to mothers in

PICU. In addition, caregivers can also become distressed from exposure to other paediatric patients' life-threatening conditions, traumatic treatment procedures, and death of another child (Ward-Begnoche, 2007). This is similar to the Malawian setup where there is overcrowding in CCU and critically ill children may share a bed. Caregivers become exposed to other critically ill children in the unit and even observe the dying of another child nearby. This may create fear and uncertainty about the sick child's outcome in the caregivers. Caregivers are bound to develop relationships with each other during the hospitalization of their critically ill child in critical care units. Lisanti et al. (2017) indicated that mothers' perceptions of interactions with other caregivers and families as stressful. This is so because they begin to have concern for other sick children as well as their own. On the other hand, a study that was done by Williams et al, (2018) revealed that communicating with other mothers was a factor that reportedly helped to alleviate some of the stressors of having a critically ill child in CCU. Several caregivers found comfort and support in talking with other caregivers going through a similar situation and being able to sympathise and empathise with each other which led to a reduction in their levels of stress.

According to a study by Tehrani et al. (2012), the most effective environmental stressor was unpleasant odors and the least one was concern about technological equipment in the unit. The hospital environment may sometimes be full of unpleasant odors as a result of medications with a strong smell, cleaning solutions, and poor sanitation. Additional stressors in the critical care environment may include crowded rooms, poor sanitation, and fear from the transmission of infections from other children to their child. Lisanti et al. (2017) in their study identified that lack of privacy for caregivers as well as the child as a result of crowded rooms and constant activities in the unit also affects caregivers psychologically. The study found out that most of the mothers admitted a sense of constant activity and feeling of

busyness while their infant was hospitalized in the CCU. The constant activity was stressful to some mothers while others appreciated that their child is being taken care of and it helped time to pass more quickly.

Stressors related to the critically ill child

When parents have their sick children in CCU, they develop unique characteristics influenced by their child's specific condition (Lim et al, 2017). The critically ill child's condition includes the seriousness of the diagnosis and prognosis, and the child's physical appearance and level of functioning. Critical illness exposes the child to highly invasive procedures, separation from families, other critically ill and dying children, altered levels of consciousness, elevations in light and noise levels, and multiple strangers providing sophisticated caretaking procedures. The critically ill child responds to the above factors differently and this affects the caregiver psychologically. In addition, the critical status of the child fluctuates during the period of hospitalisation. A study that was done by Lisanti et al (2017) revealed that children with critically ill conditions have a non-linear recovery and can experience a myriad of complications, causing the hospital experience to have many surprises for mothers and emotional ups and downs. In the above study, mothers become more stressed when the condition of the child was rotating from worse to better and then worsening again.

A change in the baby's appearance and behaviour as a result of the childhood disease affect caregivers psychologically. Caregivers are affected by the change in skin colour, body weakness, a weak cry, presence of wounds, and a change in their child's behaviour and emotions. They were used to seeing their child healthy and active and observing their child in an inactive state and helpless causes stress in caregivers. A quantitative study that was done by Musabirema et al. (2015) in Rwanda found that the change in baby's appearance and behaviour was the highest cause of caregivers' stress compared to the critical care unit

environment. Caregivers were more stressed when a baby stopped breathing (respiratory or cardiac arrest), followed by a baby who appeared weak and lethargic (Musabirema et al., 2015).

In another study in the United States, caregivers were unable to recognise their children due to intubation and sedation (Oxley, 2015) which changed their facial appearance. In addition, a study by Roets et al. (2012) on FCC in ICU in South Africa, showed that the change in child's appearance and behaviour were mentioned by 64.6% of 62 caregivers as stressors. The severity of the condition changes the child's appearance and behaviour. The child's appearance and response to the environment are different compared to the state he was before the illness hence caregivers become stressed.

Seriousness of the childhood disease may affect caregiver and child interactions. Oxley (2015) and Pooni et al., (2013) explain that children may be unconscious, connected to life support equipment, under the influence of sedative medications and these may affect a child's response to the caregiver. The child may respond inappropriately such as with confusion, pain, crying or whining, restlessness, anger, inability to cry, and sadness, or depression (Yacoub et al., 2012). The caregiver becomes anxious and hopeless that the familiar method of comfort is not effective on their child.

Severity of the condition of the child may lead to prolonged hospitalisation which is stressful to caregivers and their families. Hasanpour et al. (2017) state that stress in caregivers increases when there is prolonged hospitalisation of infants in the NICU since caregivers are treated as visitors. Similarly, a study that was done by Tsironi and Koulierakis (2018) on factors associated with caregivers' levels of stress in paediatric wards, found that caregivers whose children stayed in the hospital for more than two weeks were more stressed than

caregivers whose children were hospitalized for shorter periods. The longer the duration of hospitalisation in CCU the higher the level of stress in the caregiver.

Ramírez et al. (2018) in their quantitative study about caregiver stressors in PICU in Spain, caregiver's reported that it would be a great relief for them to be able to stay with their children during most of the procedures. However, literature shows that caregivers are affected psychologically when they observe their children undergoing so many procedures for treatment. A cross-sectional study by Yacoub et al. (2012) to test the reliability and the validity of the A-PSS: PICU in Jordan found that mothers were more stressed when they observed their child undergo different procedures. Invasive procedures and interventions generate an increased perception of stress in caregivers of critically ill children (Ramírez et al, 2018). Similarly, two studies that were done in India by Pooni et al. (2013) and Kumar and Avabratha (2015) on caregivers' stress in PICU found that caregivers felt stressed during procedures done on their children for example cannulation and blood sampling.

Many procedures and interventions are performed on critically ill children mostly at the bedside and caregivers observe while soothing the child. These procedures may include suctioning to clear the airway, obtaining a blood sample, suctioning endotracheal tubes, placing intravenous lines and central lines, performing lumber puncture, insertion of a nasal gastric tube, performing a lumber puncture, and drug administration. Witnessing a child undergo these can cause much stress in caregivers because invasive procedures and interventions are often painful or uncomfortable and children may become inconsolable to both the caregiver and healthcare worker. According to a cross-sectional and analytical study done by Sandhya (2019) on factors associated with stress among mothers of hospitalised children admitted through the emergency department, majority of caregivers experienced

increased levels of stress from observing their children being irritable 76.7% and in pain 73.3%.

Medical procedures and nursing interventions may be medically essential, however, they are inherently stressful and uncomfortable to the child and caregiver. This may be related to a lack of understanding or communication between the healthcare worker and caregiver. Caregiver uncertainty may decrease with information and it would be interesting to note whether caregivers' experiences of medical procedures and interventions would change if they were educated about and understood the reason behind the interventions.

Stressors related to healthcare workers

Stressors related to healthcare workers may include issues pertaining to professional behaviour and communication patterns. Bedside manner involves body language, behaviour, and communication exhibited by medical staff during interactions with patients and their families (Williams et al., 2018). Williams and colleagues further explain that the bedside manner of the healthcare worker often includes statements about the attitude, professionalism, and manner of care expressed by the nurses. Poor bedside manner is always noted as a stressor to the caregivers. Healthcare workers' communication patterns related factors of stress involve explanation about the illness from doctors or nurses, explanation by nursing staff or doctors about procedures for example finding a vein, and communication from doctors or nurses with child and caregivers on clinical ward rounds (Sandhya, 2019).

Caregivers have a desire to be kept informed about their child's condition regularly. Truth-telling to caregivers about the condition of the child, treatment options, progress to recovery, and the possibility of complications is paramount. Caregiver's communication difficulties with healthcare workers is a prominent stressor because caregivers are unable to understand the condition of their children and the progression of the illness. A mixed method

study done by Hagstrom (2016) on family stress in paediatric critical care found that the stress of not knowing or not being prepared for changes in the child's progression of illness was identified as a primary source of stress for caregivers. In addition, results of a quantitative study done by Musabirema et al. (2015) on caregivers' perceptions of stress in NICU show that 98% of caregivers perceived that healthcare workers were not sharing enough information about tests and procedures, 90.8% of caregivers felt that healthcare workers were not conversing with them frequently enough, and 81.6% of caregivers did not understand words used by healthcare workers during their conversation. This shows that unclear words or use of difficult medical terms, inadequate, and inconsistent information regarding the condition of the child could be a source of stress. Caregivers also reported particular dissatisfaction with providers' inappropriate body language and poor timing in giving information about the condition of the child (Colville et al., 2009).

Poor communication skills and inadequate interaction cause stress in caregivers with children admitted to CCU. A qualitative study that was done by Majdalani et al. (2014) on the lived experience of caregivers of children admitted to the paediatric intensive care unit in Lebanon reported that the use of the English language by the healthcare workers while talking to caregivers was a major concern and a hindering factor for proper communication. Furthermore, Majdalani reported that caregivers expressed the need for information in their own language in addition to supportive interaction with healthcare workers in helping them deal with stressors. In a study that was done by Roets et al. (2012) on family centred care in PICU, a total of 51 (82.3%) of mothers expressed that they wanted to share their feelings about their child's ICU admission with someone. Healthcare workers may find interacting and giving emotional support to caregivers extremely challenging in CCU because of lack of critical care training and increased workload resulting from shortage of staff (Gondwe et al.,

2011). Therefore, caregivers' inability to share their feelings and fears with someone in CCU will result in increased levels of stress, and caregivers may not have sufficient coping strategies.

Contrary, a cross-sectional study that was done by Barth et al. (2016) on stressors in relatives of patients admitted in ICU in Brazil found that scores for the stressors related to the nursing team and the ICU physician were lower. This highlights the trust placed on the CCU team, as well as on the information provided regarding the condition. Similarly, a cross-sectional study that was done by Yacoub et al. (2012) to test the reliability and the validity of the A-PSS: PICU in Jordan revealed that the least stressful dimension for the caregivers were related to communication patterns and behaviours of professional healthcare workers. In the study explained above, least stressful subscale items included the manner in which healthcare professionals interacted and communicated with family members during their stay in CCU. The findings may be explained by greater emphasis on FCC concept which is the centre of child health care even in critical care. Today's parents of hospitalised children are more informed and more involved in their child's care and decision making than the past.

Malawi's health system is understaffed and FCC becomes inevitable (Majamanda et al., 2015). Lack of adequate health care professionals has resulted in the shifting of other caring activities from the healthcare professionals to family members (Hoffman et al., 2012). Family members may assist with the provision of basic patient care like feeding, turning, bathing, and administration of oral medication. However, family members are not well prepared psychologically and are not provided with enough resources to use in the caring role and this brings anxiety to them (Hoffman et al., 2012). Hence the need to assess caregivers' stress during hospitalisation of their child in CCU.

Stressors related to caregiver role adjustment

Critical illness or injury of a child forces caregivers into a new and threatening world. Caregivers play an important role in their child's recovery and their ability to cope with stress of the critical illness or injury affects the quality of life of all family members. Admission of the critically ill child to CCU immediately changes the role of caregivers, from being responsible for the safety and care of their children to being completely reliant on healthcare worker to save their child's life. A caregiver becomes a spectator who is helpless and assumes the extremely challenging role of taking care of a critically ill child (Gallegos, 2011; Kumar & Avabratha, 2017). Caregivers may be unable or afraid to touch their child, as a result, there is physical and emotional separation. According to a quantitative study that was done by Musabirema et al. (2015 on caregivers' perception of stress in NICU, results show that caregivers 98% (n = 96), perceived that being separated from their babies was the most stressful challenge in CCU. In addition, a study that was done by Roets et al. (2012) on family centred care in paediatric intensive care unit in South Africa identified that almost 90% (n = 56) of mothers wanted to be involved in their child's care and 69% (n = 43) of them wanted to be even more involved than they were.

Caregivers are stricken with grief for the loss of their previous role. They no longer have control over care of their child and need to accept that health care professionals act in the best interest of their child. High technological environment, ethical dilemmas, staff shortages, professional attitudes, and critical care organisational culture may contribute to caregivers' lack or partial involvement in the decision making process and provision of care to their critically ill child. The lack of caregivers' involvement in their child care increases their level of stress even if they are present in the unit.

A prospective study that was done by Turner et al. (2015) in Australia identified that caregivers' role adjustments were the most stressful situation in the assessment of caregivers' stress and support in NICU. Similarly, a quantitative survey by Musabirema et al. (2015) on parents' perceptions of stress in NICU Rwanda found that caregiver role alteration was rated slightly more stressful than staff communication with an average stress score of 2.3 compared to 2.1 This study identified that lack of caregivers' participation in the care of their child such as not feeding or comforting the child as a result of technological equipment connected to the child contributed to increased levels of stress. Caregivers in the qualitative study that was done by Gondwe et al. (2017) described the disruption of caregiver–infant bonding caused by bCPAP treatment and nursery's visiting policy (every 3 hours) as major sources of stress. Oxygen delivery methods create a barrier between a mother and an infant such that mothers are afraid to hold their babies, are unable to see their babies' faces, and skin-to-skin contact is interrupted (Peeler, 2015).

A quantitative study that was done by Busse et al. (2013) on caregivers' responses to stress in NICU, found that alteration in the caregiving role was the largest source of stress in caregivers. Caregivers found it difficult to carry out parenting in the critical care setting as they may be afraid or lack knowledge and guidance on how to provide care to a critically ill child. Caregivers who accompany their hospitalised child put aside their personal commitments, family roles, physical needs, and daily routines while adapting to their critically ill child (Tsironi & Koulierakis, 2018). According to a prospective study that was done by Lee et al. (2012) on the impact on caregivers during hospitalization for acute diarrhea in young children, 23% and 21% of caregivers reported being extremely exhausted, 75% of caregivers experienced loss of sleep during hospitalization and 44% had their daily routines extremely disrupted. Therefore, there is an occurrence of anxiety, depression,

fatigue, and sleep disturbances among caregivers of critically ill children in critical care settings (Besse et al., 2012). It is therefore important that nurses offer assistance and support while clearly defining caregivers' roles and responsibilities in the care of a critically ill child.

Demographic factors of caregivers and the critically ill child.

Demographic characteristics such as age, gender, level of education, size of the family, and area of residence may affect the level of stress experienced by caregivers during their child's hospitalisation to CCU.

Several studies have found that the age of the caregiver is significantly associated with the level of stress caregivers may experience while in CCU. A prospective study that was done by Pooni et al. (2013) on caregivers' stress in PICU in India found that younger caregivers were more stressed compared to older caregivers. Results of the study show that out of 54 caregivers who were severely stressed, 67% of caregivers were ≤30 years of age compared to 33% who were older caregivers >30 years of age. Similarly, a quantitative study that was done by Gallego's (2010) on an examination of caregivers' stress in PICU, results show that the age of the caregiver was weakly negatively correlated with procedures done on the child $r = -.24$, $p<.01$, and alteration of caregiver role r = -.28, $p<.01$. This shows that younger caregivers perceived higher stress levels compared to older caregivers. Contrary to these findings, a study that was done by Musabirema et al. (2015) on caregivers' perceptions of stress in NICU, in Rwanda found that older caregivers' age groups reported increased stress levels when confronted with the poor appearance of their child $k = 13.6$, $p<.01$. Both India and Rwanda are developing countries; however, they have a diverse population, different cultural and religious practices hence young and older caregivers are presenting with contradicting stress levels.

Results of studies that were done by Pooni et al. (2013) and Patil. (2014) in India on caregivers' stress show that stress of caregivers was significantly higher if their child was a boy regardless of the severity of the condition. Culturally, parents and other elders place more value on the male child in India because of their future role as providers of their families including taking care of elders in the family. Similarly, in a study that was done by Mohamed and Mohamed. (2014) in Egypt on stress among mothers of hospitalized children, there was a statistically significant relationship between child gender and level of stress. Results show that male child evokes more stress in mothers than female child with $p = 0.000$. This finding can be a result of caregivers' cultural and religious values.

Female and male caregivers tend to differ in their levels of stress and what they find stressful. According to a study done by Pooni et al. (2013) on caregivers' stress in PICU in India, results show that mothers were significantly more stressed than fathers. The increased stress reported by female caregivers was associated with procedures done that were being performed on their child ($p = 0.0028$) and caregiver role alteration ($p = 0.0017$). In this study female caregivers were more stressed because naturally, they have the responsibility to take care of children whether sick or well hence creating a stronger bond, unlike fathers in India who are mainly providers and take less part in bringing up children. Similarly, increased stress experienced by mothers versus fathers in the factor of procedure and interventions could be because female caregivers usually stay longer with their children in the unit and are always available observing and participating in examinations, procedures, and interventions (Ramirez et al., 2017). However, this differs from other studies that found that gender does not seem to affect caregivers' stress levels (Tsironi & Koulierakis, 2018).

Education level also affects the level of stress experienced by caregivers with children admitted to CCU. A study done by Musabirema et al. (2015) found that caregivers with

primary-level school education reported significantly higher stress levels compared to university graduates in terms of sight and sound dimension. Similarly, a study that was done by Gallego's, (2010) on examination of stress in caregivers found that caregivers' education was weakly correlated with subscales of sight and sound $r = -.28, p<.01$ and procedures done on the critically ill child $r = -.40, p<.01$. The results indicate that caregivers with lower educational levels experience significantly higher stress levels than caregivers with higher education levels. It is relevant to note that university graduates may have a better understanding of the CCU environment than caregivers with primary or low education levels hence the difference in stress levels.

In most cases, our hospital setup refers serious cases from primary level or secondary to the tertiary level health care facility. Relocation to a new big hospital and environment affects caregivers financially and therefore increases the level of stress. According to Clark et al. (2017) and Argus et al. (2009) non-medical out-of-pocket expenses such as food, drink dependent care, travel, and incidental costs are unavoidable during hospitalisation. Argus et al. (2009) found that the major cost was related to food, transport, and accommodation in a study on financial cost for caregivers with a baby in the nursery. Diversely, caregivers also have the responsibility to take care of the people and other children left behind at home. The increased demand for their responsibilities affects caregivers financially which in turn affects their stress level. The results of the descriptive correctional study that was done by Lisanti, et al. (2017) showed that mothers with more than one child experienced higher stress response than did mothers with only the hospitalized infant. Caregivers who have other children may need additional support to cope with the hospitalization as they manage competing responsibilities of caring for children at home and watching over their sick child in CCU (Lisanti et al., 2017).

Caregivers experience a significant loss of income and financial difficulties due to absence from work or income-generating business because of their continual presence at the hospital. Findings from a study that was done by Lee et al. (2012) on the impact on caregivers during hospitalisation in Malaysia supported that the greatest cost incurred by caregivers from their own pockets were related to medical cost, followed by loss of income as a result of being unable to report to work and travelling cost. Caregivers have to spend most of their time with the child who is critically ill and also at the same time stay away from work while also fulfilling responsibilities for other children left at home. The situation brings extra financial burden and loss of productive hours (Shah et al., 2018). Caregivers with low socioeconomic status may potentially be more stressed while bringing in their efforts to share and balance responsibilities accordingly.

The majority of admissions in critical care settings are unplanned and do not allow caregivers to plan for sudden expenditures. The impact of non-medical out of pocket expenses is of particular concern to the caregivers. The impact of the financial burden on caregivers with low socio-economic status is often economically devastating and can diminish the quality of life such that caregivers may be forced to leave their child to return to work and resume other family caretaking needs (Clark et al., 2019). However, Kumar and Avabratha's (2015) study findings differ in that socioeconomic status, residential area, and age of the sick child did not affect the level of stress in caregivers. Similarly, (Pooni et al., 2013) found that type of family, income, education, number, and age of the sick child did not affect levels of stress in the caregivers.

Summary

The CCU is a busy and threatening environment that is full of critically ill children, advanced medical technology, bright light, and monitors with sudden high pitched alarms.

Stress in caregivers is normal and expected response to a child's critical illness. However, if the level of stress goes beyond the caregiver's coping capabilities and goes unnoticed, psychological trauma and problems may result even after the child is discharged from the hospital.

Several studies have identified the magnitude of stress in caregivers with children admitted in CCU. Most of the studies done on caregivers' stress in critical care units have been conducted in developed countries and a few in developing countries. The findings of studies from developed and other developing countries in Asia cannot be generalised and be applied for use in the Malawian critical care setting because of the differences in family background and preferences, technological advances, culture, and religious beliefs. Nevertheless, research on assessment of stress among caregivers with critically ill children in CCU in a diverse population is very limited and there is no data published in the Malawian context. Health care professionals in CCU must be competent in the assessment of caregivers' responses to their children's critical illness.

The emotional support of caregivers with critically ill children in CCU can reduce the occurrence of stress. However, in Malawi, studies regarding the assessment of caregivers' stress have not been conducted.

Chapter three

Methodology

Introduction

This chapter describes in detail the research process that was carried out to assess the level of stress in caregivers with children admitted to CCU. The chapter includes detailed information on study design, setting, population, inclusion and exclusion criteria, sample size and sampling strategy, data collection procedures and analysis, validity and reliability of the data collection tool, and ethical considerations.

Study Design

A cross-sectional design was used to examine caregivers' stress in CCU using the quantitative approach. A cross-sectional design describes the status of phenomena or relationships among phenomena that are captured during one data collection period (Polit & Beck, 2014). Quantitative research entails a formal, objective, systematic process in which numerical data is used to describe, examine the relationship, and determine the cause and effect interactions between variables (Burns & Grove, 2011). In this study, the design was used to describe stressful situations and examine the significant relationship between variables and caregivers' levels of stress. This cross-sectional descriptive study which is quantitative research in nature is suited for the positivist philosophy. The positivism paradigm emphasizes that observations and reasons are a means of understanding human behaviour. There is a systematic generation of knowledge through quantification which enhances the precision description of variables and understanding of the relationship among them.

Study setting

The study was conducted at Queen Elizabeth Central Hospital (QECH) which is located within Blantyre city in the southern region of Malawi. QECH provides tertiary health services and it is also a teaching institution for nursing, midwifery, and medical students from various colleges. The hospital was chosen as a setting for the study because it is a tertiary hospital where critically ill children with life-threatening conditions are admitted in critical care units. Complicated conditions are admitted as referral cases from secondary and primary level health facilities in various HDUs in the paediatric department. The paediatric department has four HDUs with the following bed capacity: Special Care Ward (SCW) 13, paediatric nursery HDU 10, Nutritional Rehabilitation Unit (NRU) four, and Chatinkha nursery. However, a bed in SPW and NRU HDUs can accommodate more than one patient as a result of a lack of space. Therefore, the bed capacity did not reflect the exact number of patients and there was no separate register for HDUs. The CCUs have the policy to permit one caregiver to stay with the child.

Study population

The study targeted caregivers who had a child admitted to a paediatric nursery, special care ward, and NRU HDUs, and ICU.

Sample size.

The formula for calculating sample size in prevalence studies by Lwanga and Lemeshow (1991) and Daniel (1999) was used to calculate the sample size (Naing et al., 2006) as below:

Estimated sample size (n) = $\frac{(z)^2 p\,(1-p)}{d^2}$

Statistic for the level of the confidence interval was set at 95%, so *z* value was 1.96 which also corresponded to the level of significance. Naing et al. (2006) explain that in many cases, estimated population prevalence is identified from previous studies and ranges from zero to one. The proportion of caregivers in HDUs who experience stress or not was known. Therefore, this proportion was estimated to be 50% in order to get a maximum sample size.

n = is the required sample size

Z = 1.96 (95% Confidence Interval)

p = is the estimated proportion of caregivers with stress or not which is set as a decimal at 0.5

d= is the level of precision which is set at 0.05 (allowable error of 5%)

$$\frac{(1.96)^2 \times 0.5(1-0.5)}{(0.05)^2}$$

$$\frac{3.8416 \times 0.25}{0.0025} = 384.16$$

385 caregivers

The sample size for caregivers with children admitted to HDUs was 385.

Sampling criteria

Convenience sampling was used to select and recruit eligible caregivers with children admitted to HDUs over a period of two months. Convenience sampling is the use of the most readily accessible persons or objects as subjects (LoBiondo-Wood & Haber, 2014). Caregivers with critically ill children admitted to various HDUs who were most readily available and willing to participate were recruited in the study. A convenience sample of 384 caregivers that met the inclusion criteria was reached.

Inclusion and exclusion criteria

a) Inclusion criteria

The inclusion criteria were:

- Caregivers who have children aged (1-17 years) admitted to the CCU and were willing to participate in the study.
- Caregivers who were 18 years of age and above.
- Caregivers who had children admitted to the CCU for more than 24 hours.
- Caregivers who were able to communicate in either English or Chichewa. These are the languages the researcher is fluent in.
- Caregivers who were recruited in another study and were allowed to be part of this study were included.

b) Exclusion criteria

The exclusion criteria were:

- Caregivers with children admitted to CCU but were not willing to participate.
- Caregivers below the age of 18 years of age.
- Caregivers with children admitted to CCU for less than 24 hours. According to Sandhya (2019), these already have high levels of stress.
- Caregivers who were fluent in other languages other than English or Chichewa.
- Caregivers who were recruited to a study and were not allowed to participate in another study

Data Collection tool

Data collection was done using a structured questionnaire that contained three parts. Literature review informed questions in the first and second part of the questionnaire. The first part collected the demographic variables of the caregiver and child. When caregivers have a child admitted in CCU, they bring with them their own unique socio-demographic characteristics and set of circumstances (Chiejina et al, 2015). Questions that were asked on demographic variables of the caregiver included age, gender, area of residence, education level, and ethnicity while only age and gender were enquired for the child.

In CCU, caregivers may also be influenced by specific situational conditions surrounding their critically ill children. According to Miles and Carter (1983), these conditions can include the severity of their child's diagnosis, the child's appearance and level of functioning, and the duration of their child's stay in the unit. The specific situational conditions have been put as clinical variables of the child and this informs the second part of the questionnaire. The questions that were asked to the caregivers involved the nature of admission, history of previous admission, and duration of stay in HDU while the severity of the condition and diagnosis of the child were collected from the patients' records.

The third part of the questionnaire is the Abbreviated Parental Stressor scale for the Paediatric Intensive Care Unit (A-PSS: PICU) which was developed by Rodríguez-Rey and Alonso-Tapia (2016). A-PSS: PICU contains environmental factors that can influence caregivers' unique reaction to having a child in the CCU might include difficulty in fulfilling their caregiving role, the medical equipment used for intervention, and the communication patterns and behaviour of the staff (Miles and Carter, 1983). A-PSS: PICU is a brief scale that contains seven items. The items on A-PSS: PICU included issues related to the child's appearance, sights and sounds, procedures done on the child, child's behaviour and emotions,

caregiver role alteration, healthcare workers' communication, and healthcare workers' behaviour. Caregivers rated sources of stress by using a five-point Likert scale from (or 0 not experienced), 1 (not stressful), 2, (minimally stressful), 3 (moderately stressful), 4(very stressful), and 5 (extremely stressful).

Permission to use the A-PSS: PICU instrument was granted by Rocío Rodríguez Rey (Appendix J). The questionnaire was developed in English and translated into Chichewa, which was the local language spoken by most people in the southern region. The researcher recruited one research assistant, a nurse, who was thoroughly oriented to the data collection tool for two days. On the first day, study objectives and participants' information were thoroughly explained. Emphasis was on ethical consideration in order to protect caregivers from harm that might result from their participation in the study. The assistant was urged to respect the participants' right to confidentiality, privacy, self-determination, withdraw from the study, fair treatment, and protection from any harm. Caregivers who voluntarily accepted to participate in the study signed a consent form before data collection. On the second day, demonstrations and observation of data collection were done so that the same standard is followed for both the researcher and research assistant.

Pretesting data collection tool

The structured questionnaire was pretested on 10 caregivers who had children admitted to Chatinkha nursery HDU at QECH. Pretesting is a method of checking that questions work as intended and are understood by those individuals who are likely to respond to them (Hilton, 2017). The questionnaire was pretested in order to test the accuracy and reliability of the questionnaire. Pretesting helps to identify ambiguous questions, incorrect or difficult words, unanswerable questions, sequencing of questions, and an estimate of the time it takes to complete questions. Pretesting also ensures the feasibility of the study. The pre-

test was conducted after approval of the proposal by the College of Medicine Research and Ethics Committee (COMREC) and the authorities for the hospital. Chatinkha nursery HDU was chosen because of its common characteristics with other HDUs in the Paediatric department and offers similar critical care services to the chosen study settings. The results showed that some questions were not clear and therefore pretesting assisted in refining the questionnaire so that questions were feasible and suitable for the study. Hence, some questions were deleted from the tool whilst others were just rephrased.

Data collection

The Hospital Director and the Head of the Paediatric department granted permission to conduct the study at QECH (Appendix E, F, G, H). Caregivers with critically ill children admitted in the CCU were approached and assessed to determine if they meet the inclusion criteria of the study or not. Caregivers who met the inclusion criteria were met individually and given all the information about the study (Appendix A, C). Participants who were readily available and willing to participate signed or put a thumbprint on a consent form (Appendix B, D). A structured questionnaire was used as a tool for the data collection on caregivers with children admitted to CCU in the Paediatric department at QECH (Appendix K, L). A private room, which was the treatment room situated within the ward was used to collect data from participants in the units in order to promote privacy.

The researcher and the research assistant in person administered the questionnaire to the participants because some of the participants were not able to read and write. The researchers physically met each participant, and read out the questionnaire items to them, and ticked their responses. This promoted a higher response rate and participants' understanding of the information and questions about the study since they had different education levels.

The researcher approximately took 20 – 30 minutes to administer the questionnaire to the participants. Data collection was done from July 2018 – December 2018.

The questionnaires were given numbers from 1 to 385 during data collection based on the number of participants in the study. The questionnaires were also coded as Q1 to Q385 for easy identification of the questionnaires, confidentiality, and anonymity of the caregivers.

Data Management and Analysis

The questionnaires were checked for completeness and accuracy of responses immediately after data collection. The completed questionnaires were locked up in a drawer that was only accessed by the researcher in readiness for data entry. The coded data was later on transferred from the questionnaire using Microsoft excel onto the researcher's laptop and was kept safe and secured by using a secret username and password. Data was only accessed by the researcher, research supervisor, and statistician as they were directly involved in the study. Data were cleaned by running frequencies that identify out of range responses and missing data.

Data were analysed using software for Statistical Package for Social Science (SPSS) version 20. Descriptive statistics such as frequency, percentages, means, and standard deviation were used to present the data in a meaningful way. Categorical variables are presented in tables using frequency distributions (both absolute and relative frequencies). The variables of the caregiver include; age, gender, residence, education, religion, ethnicity while those of the child are age and gender. The clinical variables of the child include nature of admission, history of previous admission, duration of admission in the CCU, the severity of the illness, and diagnosis of the child.

Descriptive statistics such as mean, range, and standard deviation also described stressful situations in caregivers while in CCU. According to a study that was done by

Rodriguez- Rey and Alonso-Tapia (2016) the developers of A-PSS: PICU recommended that calculation of group means for the items and total scale determines the greatest sources of stress among the caregivers. A high mean score signifies that the variable is the most stressful item to the caregiver in the CCU. To explore relationships among variables, factor analysis using principal component analysis and linear regression analysis was conducted.

Factor analysis using Principle Component Analysis (PCA) of A-PSS: PICU with seven items was conducted on a sample of 385 parents. PCA was conducted in order to restructure data by reducing the number of variables that measure stress levels. This is done by determining the inter-item corrections among original variables on A-PSS: PICU and results in useful components that reflect a large proportion of the information present in the original data set. Data were screened by examining descriptive statistics and inter-item correlations and all variables appeared normally and partially distributed. Kaiser Meyer of Olkin (KMO) measure of sampling adequacy was 0.6. The KMO value indicates that it was marginal, indicating that data were suitable for principal component analysis. Bartlett's test of Sphericity identifies statistical significance of the correlation matrix. The test found an associated p-value of <0.001 indicating sufficient correlation between variables, therefore, to proceed with the analysis.

Association between the level of caregiver stress and demographic variables of the caregiver, child, and clinical variables was also tested using linear regression. Linear regression is a statistical procedure applied to a data set to define and quantify the relationship between the considered variables. It calculates the value of a dependent variable from an independent variable. In this case, independent variables were demographic variables of both caregiver and child while the dependent variable was the level of stress in caregivers.

The cut-off point for the level of significance was set at $p<0.005$. Data was also presented in bar charts and pie charts.

Validity

Validity is the quality of the research project and reflects the extent to which the claims can be believed (Woodrow, 2014). It is the degree to which the questionnaire measures what it is supposed to measure (Polit & Beck, 2014). Content and construct validity were ensured through a comprehensive literature review before the formulation of the questionnaire. This also ensured that the questionnaire had adequate questions addressing the research phenomena.

The approach of forward and backward translation developed by Sousa and Rojjanasrirat (2011) was used to translate, adapt, and validate the questionnaire before use in the study. The approach includes:

- Forward translation of the questionnaire into Chichewa language by two independent translators with health care background and fluent in both English and Chichewa.
- The two questionnaires translated into Chichewa were compared separately as well as with the original English version.
- Blind backward translation of the initial Chichewa version of the instrument was done by two other independent translators.
- The two questionnaires translated back into English were compared separately as well as with the original English version.
- Any discrepancies regarding cultural meaning, construction of sentences, items, or response format were resolved.

The questionnaire was reviewed by two supervisors and COMREC before data collection in order to ensure its validity. The questionnaire was also pre-tested before data collection. Informed decisions and amendments on the questionnaire were made where necessary basing on the feedback from the supervisors and results from the pre-test to improve the effectiveness of each question and ensure content validity**.**

Reliability

Reliability refers to the consistency of research results on an instrument (Woodrow, 2014). It is the ability of an instrument to produce the same research results when used by a different investigator in a different study setting and sample. The questionnaire was pre-tested on participants with similar characteristics to study participants and amendments were done where necessary to ensure its reliability before data collection. The pre-test evaluates the instructions, response format, and items of the instrument for clarity (Sousa & Rojjanasrirat, 2011). Reliability is more concerned with accuracy or precision in the measurement an instrument provides (Grinnell & Unrau, 2011). According to a quantitative study that was done by Rodríguez-Rey and Alonso-Tapia (2016) on the development of a screening measure of stress for caregivers of children hospitalised in PICU, identified that A-PSS: PICU was reliable and the internal consistency was 0.76. In addition, the research assistant was trained on the instrument and data collection in order to get the same type of data.

Ethical Considerations

Ethical issues that protected the welfare of caregivers with children admitted in CCU were considered throughout the study. To ensure that caregivers' rights and interests have been considered, the study was approved by the College of Medicine Research and Ethics Committee (COMREC) before data collection (Appendix I). Permission to conduct the study

at QECH was obtained from the Director of the Hospital and the Head of the Paediatric department (Appendix E, F, G, H). The principal aim was to ensure that the participants of this study were protected from harm that might result from their participation (Hugman et al., 2011). Respect for the human rights of the participants was emphasised. To achieve that, the following were observed: the right to self-determination, obtaining informed consent, maintaining privacy, ensuring confidentiality, fair treatment, and protection from any harm.

Informed consent

An information letter was read to all caregivers by the researcher and research assistant in Chichewa. Participants were given information on the aim of the study, duration of the interviews, data collection methods and procedures, benefits or risks of the study as well as the relevance of the research study to the participants, health professionals, and the nation (Appendix A and C). Participants signed or put their thumbprint on a consent form to show their willingness to be recruited in the study (Appendix B and D).

Confidentiality

Participants were also assured of confidentiality and anonymity through the use of code numbers and not names in the questionnaire during data collection. In addition, they were informed on how data would be used and that confidential records were only accessible by the research team.

Privacy.

Participants were also informed that it is their right to withhold any sensitive information or issues they are not comfortable to share during data collection that could put them in an awkward situation. Data collection was done in a private room for the privacy of the participants.

The right to withdraw from the study.

Participants were informed that they were free to withdraw at any stage, stop the interview, or not to answer questions whenever they felt like. It was emphasised that the refusal to participate in the study would not affect their access to health care services.

The risk of participating in this study.

Participants were informed that there was no physical pain or discomfort associated with participating in this study. However, if participants experienced any emotional tension as a result of some unpleasant memories or experiences regarding the admission of their child in CCU, the researcher would use her counselling skills and assist them appropriately or refer them to trained counsellors for psychosocial support. In addition, they were also given the researcher's contact numbers for clarification. For all complaints concerning the violation of their human rights, the participants were asked to send such complaints to the Secretariat of the College of Medicine Research and Ethics Committee.

Summary

This was a cross-sectional descriptive study that used quantitative data collection method and analysis approaches. The study was conducted in CCU in the paediatric department at QECH in Blantyre. Caregivers who were above 18 years of age and had critically ill children admitted to various HDU for more than 24 hours were recruited. 385 caregivers were recruited using convenience sampling method. A structured questionnaire was used for data collection. The researcher and research assistant administered the questionnaire to the caregivers in a private room for approximately 30 minutes. Data analysis was done using SPSS version 20. Descriptive and inferential statistics were used to present data in a meaningful way. The content of the questionnaire was reviewed and pretesting was done to

ensure the validity and reliability of the data collection tool. Ethical considerations were applied throughout the process of the study.

Chapter Four

Presentation of results

Introduction

This chapter presents the results of a study whose main objective was to examine the stress experienced by caregivers with children admitted to CCU at QECH. The results are presented in three sections: demographic variables of the caregiver and child, situations caregivers find stressful in CCU, the relationship of parent demographic, child demographic, clinical variables, and level of parental stress.

Three hundred and eighty-five (386) caregivers whose children were admitted in CCU were approached, given all the information about the study, and asked to participate in the study. Three hundred and eighty-five (385) willingly consented to participate in the study representing a 99.7% response rate.

Demographic variables of study participants.

Demographic variables of caregivers.

Demographic variables show characteristics of caregivers that were recruited in the study. Caregivers' characteristics include: gender, age, area of residence, religion, education level, ethnicity, and number of children in the family (Table 1).

The majority, 95.6% (n= 368) of the caregivers were female. The age of caregivers varied from 19-79 years with most, 39.7 % (n = 153), aged <25 years and 35.3% (n = 136) between 26 – 35 years. The mean age was 29.98 years with a standard deviation of 9.279. Most, 72.1% (n = 277), of caregivers came from the urban area which is within Blantyre city limits and some district towns. Majority, 90.9% (n = 350), of the caregivers were Christians. Just above half, 51% (n = 196) of the caregivers attended primary education and 34.5%

(n=132) reached secondary education. The population of caregivers was dominated by the Lomwe tribe at 30.4% (n=117).

Table 1
Demographic variables of caregivers

Variable	Category	Frequency (n)	Percentage
Gender			
	Female	368	95.6
	Male	17	4.4
Age			
	<25 years	153	39.7
	26 – 35 years	136	35.3
	36 – 45 years	75	19.5
	>46 years	21	5.5
Residence			
	Urban	261	67.8
	Rural	124	32.2
Religion			
	Christians	350	90.9
	Muslims	35	9.1
Education			
	Tertiary	17	4.4
	Secondary	133	34.5
	Primary	196	50.9
	No education	39	10.1
Ethnicity			
	Chewa	80	20.8
	Yao	65	16.9
	Lomwe	117	30.4
	Sena	28	7.3
	Ngoni	81	21.0
	Tumbuka	14	3.6
Number of children	1	102	26.5
	2 – 4	214	55.6
	≥5	69	17.9

Child demographic and clinical variables

Demographic variables for the children were gender and age (Figure 1 and 2) while clinical variables included: nature of admission, history of previous admission, the severity of the illness, diagnosis of the child, and duration of admission in the CCU (Table 2).

Most, 59.2% (n=228), of children were male. The age varied from 1week to 17 years with the majority, 52.7% (n=203), below one year. The mean age was 36.01months with a standard deviation of 50. 492 months. Eighty-three percent (n=320) of the admissions were emergency cases compared to 16.9% (n=65) which were planned. The study results further show it was the first CCU admission for 67% (n=258) of the children while the rest had a history of prior admission. While in CCU, 98% (n=377) were oxygenated. Cardiovascular 34% (n=131) and respiratory 33.5% (n=129) conditions were most prevalent diagnoses among the patients. Duration of stay in the CCU varied from 2 to 16 days with a mean of 3.55 days, mode 2 days, and a standard deviation of 2.543.

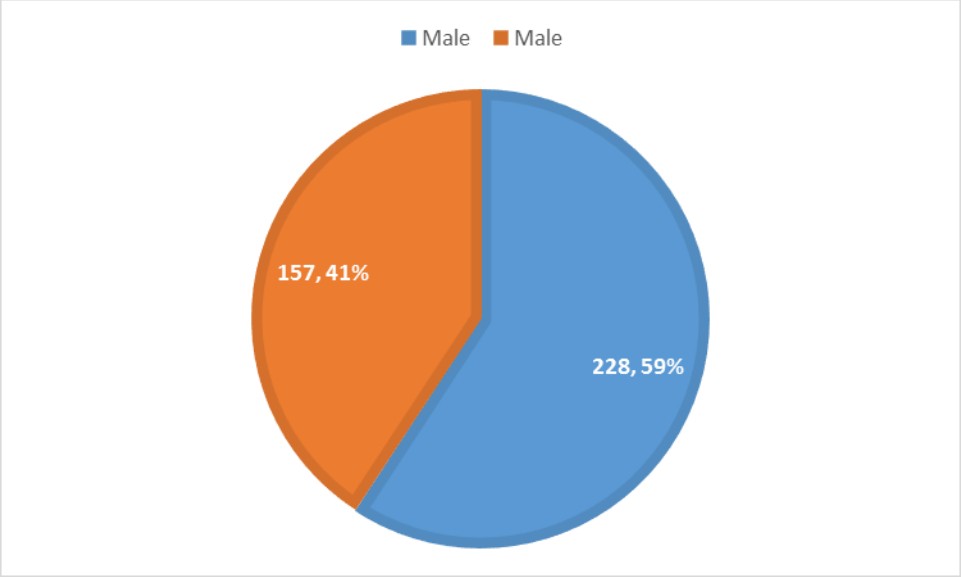

Figure 1. Gender of the critically ill child

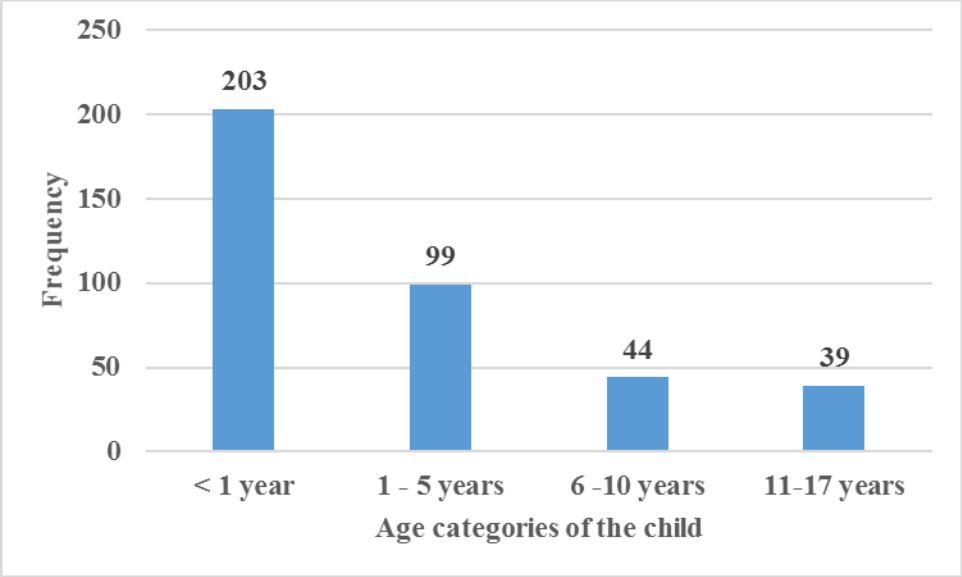

Figure 2. Age categories of the critically ill child

Table 2
Clinical Variables of the Critically Ill Child

Variable		Frequency (n)	Percentage
Nature of Admission	Emergency	320	83.1
	Planned	65	16.9
CCU Admission	1st	258	67
	>1	127	33
Severity of the illness	Intubated	1	0.3
	Oxygenated (nasal prongs/mask)	211	54.8
	Shock, Oxygenated	94	24.4
	Unconscious, Oxygenated	72	18.8
	Post-surgery	6	1.6
Diagnosis	Respiratory conditions	129	33.5
	Cardiovascular & blood disorders	131	34.0
	Neurologic conditions	59	15.3
	Gastrointestinal conditions	34	8.8
	Renal and metabolic disorders	23	6.0
	Musculoskeletal conditions	9	2.3
Length of Admission	2-3 days	285	74.0
	4-7 days	59	15.3
	> 7 days	41	10.7

Levels of stress among caregivers

Results of the study reveal that among 385 caregivers, 53.8% (n=207) were moderately stressed while 37.1% (n=143) were severely stressed and 0.5% (n=2) did not experience stress with the hospitalisation of their child in CCU (Figure 3).

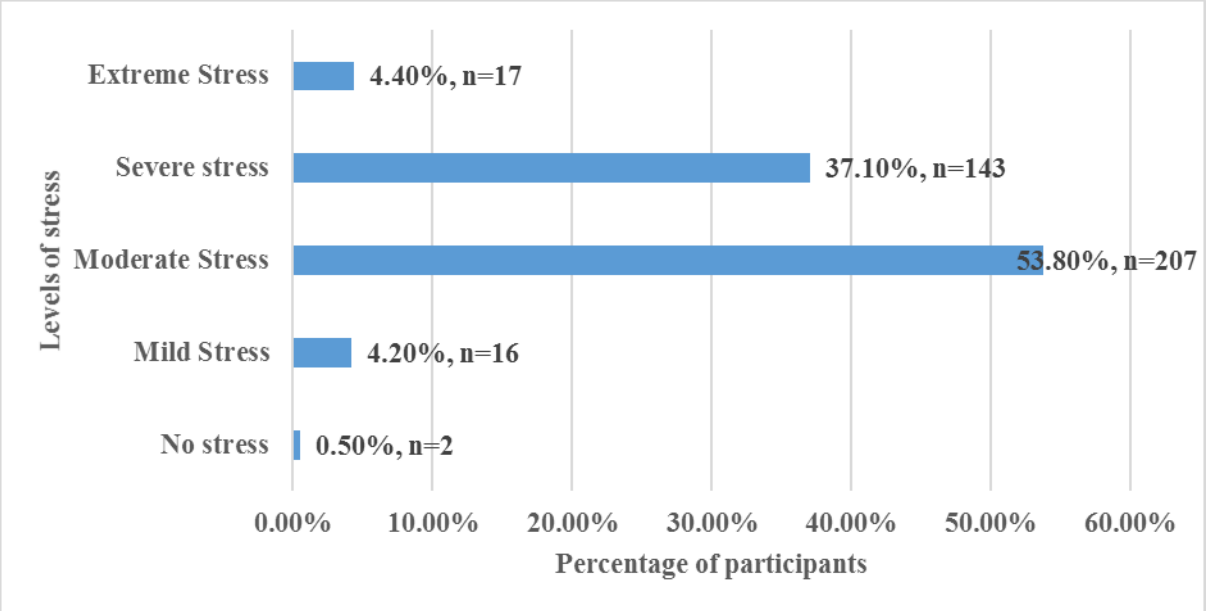

Figure 3. Levels of stress among caregivers in CCU

Stressful situations in the Critical Care Unit

Caregiver stressors were identified using the PSS: PICU that comprises of seven items as follows: Appearance of the child, sounds of monitors and other machines in CCU, medical procedures conducted on the child, caregiver role alteration, child's behaviour and emotions as a result of illness, healthcare workers' behaviour while caring for the critically ill child, healthcare workers' communication to caregivers regarding child's illness and treatment. Caregivers were rating potential sources of stress by using a Likert scale from 0 entailing "not experienced" 1 "not stressful" 2 "minimally stressful" 3 "moderately stressful" 4 "very stressful" to 5 entailing "extremely stressful".

In all seven items, an average mean stress score of 3.41 was found among the elements. Results indicate the presence of moderate stress in caregivers. The appearance of the child and caregiver role alteration has higher mean scores of 4.17 and 4.09 respectively indicating that they were the greatest source of stress to the caregivers while in CCU. Healthcare workers' conduct while caring for the child was found to be the least significant source of caregiver stress as shown by a mean score of 2 (Table 3).

Table 3
Mean scores, Ranges and Standard Deviations of A-PSS: PICU

Item	**N**	**%of caregivers who experienced that stressor**	**Range**	**Mean**	**SD**
Appearance of the child	385	100	1-5	4.17	1.00
The sound of monitors and other machines in CCU	385	100	1-5	3.24	1.38
Procedures done on child	385	100	1-5	3.36	1.42
Caregiver role alteration	385	100	1-5	4.09	1.06
Child behaviour and emotions	385	100	1-5	3.90	1.16
Healthcare workers behaviour while caring for the child	331	85.17	1-5	2.07	1.26
Healthcare workers communication to caregivers about child illness and treatment	356	92.47	1-5	3.04	1.48
A-PSS: PICU total	385		1-5	3.41	0.59

Principal component analysis

Principal component analysis was done to reduce the number of variables from a large number of interrelated variables while retaining as much information as possible. Eigenvalues show the importance of each of the six principal components. Only the first three (appearance of the critically child, sounds, and other noises from monitors and other equipment, caregivers' role adjustment) have eigenvalues of over 1.00, and together these accounted for

55.88% of the total variability in the data. This led to the conclusion that a three-factor solution was probably adequate **(**Table 4**).**

Table 4
Total Variance Explained

Components	Extraction sum of squared loadings		
	Total	% of variance	Cumulative %
1	1.772	25.321	25.321
2	1.076	15.365	40.686
3	1.063	15.193	**55.879**

The significance level of correction of above 0.5 was determined to identify the original variables that are strongly correlated with the principal components. Higher values closer to 1 indicate that the original variable can be fully explained by the principal component while low values closer to 0 indicate the variable cannot be predicted or does not share many relationships with the component in the data set. Table 5 shows correlations between the principal components and the original variables on the PSS: PICU and larger correlations are in boldface. There is a zero correlation between the components.

The first principal component was strongly correlated with four of the original variables on the A-PSS: PICU. The four original variables include sound of monitors and other machines in CCU, procedures done on the child, caregiver role alteration, child's behaviour, and emotions as a result of illness and are all related to the condition of the critically ill child in CCU. This indicates that level of caregivers' stress related to the child's condition increases with the sound of the monitors and other machines, procedures done on the child, caregiver role alteration, and change in child's behaviour and emotions.

The second component is correlated with healthcare workers' behaviour in CCU and healthcare workers' communication patterns. The second component is more related to the relationship between healthcare workers and caregivers in CCU. The principal component increases with a decrease in healthcare workers' good behaviour and an increase in communication patterns between healthcare workers and caregivers. This indicates that levels of caregiver stress related to the relationship between healthcare workers and caregivers increase with healthcare workers' misconduct and communication between healthcare workers and caregivers.

Table 5

Correlations between Principal Components and Original Variables

	Component loading		
	1	2	3
The appearance of the child as a result of illness	.399	.264	-.401
The sounds of the monitors and other machines in the Critical Care Unit	**.664**	.070	.427
Procedures done on the child	**.661**	.073	.480
Caregiver role alteration	**.602**	-.267	-.398
Childs behaviour as a result of illness	**.585**	.124	-.431
Healthcare workers' behaviour in the Critical Care Unit	.172	**-.546**	.320
Communication between the caregiver and healthcare worker about child illness	-.023	**.781**	.209

Extraction Method: Principal Component Analysis. (3 components extracted.)

Relationship of caregiver demographic, child demographic, and clinical variables to stress levels of the caregiver.

The study also aimed to find the relationship of caregivers', child's, and clinical variables and stress level of the caregiver. Regression analysis was done using linear regression. Linear regression is often used to describe relationships between two variables or among several variables through statistical estimation (Kumari & Yadav, 2018).
The cut-off point for the level of significance was $p < .05$.

Demographic variables of the caregiver and caregiver stress

The results show that there was a significant relationship between the age of the caregiver and the level of stress in caregivers related to procedures done on the child in CCU (Table 6). As the age of the caregiver increases with 1 year, caregivers' level of stress decreases by -0.25, 95% confidence interval (-.040 - -0.10), $p = .001$. The results reveal that young caregivers experienced high levels of stress when observing procedures done on the child such as insertion of tubes, injection of medication, suctioning, and others.

Table *6*

Relationship of Caregivers' Demographic variables and Level of Stress

Independent variable	Dependent variable	Regression coefficient	Standard error	P value	95% Confidence interval
Age of the parent	The appearance of the child	0.352	0.006	0.554	-0.008, 0.554
	Sound from monitors	-0.098	0.008	0.055	-0.029, 0.000
	Procedures done of the child	-0.165	0.008	0.001*	-0.040, -.010
	Caregiver role alteration	-.015	0.006	0.772	-0.013, 0.010
	Child behaviour and emotions	-.015	0.006	0.765	-0.014, 0.011
	Staff behaviour	-.015	0.007	0.765	-0.016, 0.012
	Staff communication patterns	-0.085	0.008	0.095	-0.002, 0.029
Gender	The appearance of the child	0.001	0.249	0.992	-0.488, 0.493
	Sound from monitors	-0.028	0.342	0.588	-0.859, 0.487
	Procedures done of the child	-0.081	0.352	0.114	-1.248, 0.134
	Caregiver role alteration	0.052	0.264	0.304	-0.247, 0.790
	Child behaviour and emotions	0.041	0.287	0.425	-0.335,0.793
	Staff behaviour	0.032	0.312	0.529	-0.809, 0.416
	Staff communication patterns	0.037	0.367	0.471	-0.456, 0.985
Residence	The appearance of the child	0.041	0.110	0.421	-0.127, 0.304
	Sound from monitors	-0.074	0.150	0.148	-0.513, 0.077
	Procedures done of the child	0.007	0.155	0.886	-0.283, 0.327
	Caregiver role alteration	0.002	0.116	0.967	-0.224, 0.233
	Child behaviour and emotions	0.085	0.126	0.098	-0.038, 0.456
	Staff behaviour	-0.003	0.137	0.952	-0.278, 0.261
	Staff communication patterns	0.143	0.160	0.005	0.136, 0.764
Education	The appearance of the child	0.052	0.071	0.312	-0.068, 0.213
	Sound from monitors	0.048	0.098	0.347	-0.100, 0.285
	Procedures done of the child	-0.073	0.101	0.154	-0.343, 0.054
	Caregiver role alteration	-0.007	0.076	0.892	-0.159, 0.139
	Child behaviour and emotions	0.003	0.082	0.953	-0.167, 0.157
	Staff behaviour	0.032	0.089	0.534	-0.120, 0.231
	Staff communication patterns	0.020	0.105	0.689	-0.165, 0.249
Number of children	The appearance of the child	-0.037	0.028	0.467	-0.076, 0.033
	Sound from monitors	-0.018	0.039	0.731	-0.089. 0.063
	Procedures done of the child	-0.142	0.039	0.005	-0.188, -0.033
	Caregiver role alteration	0.049	0.030	0.341	-0.087, 0.030
	Child behaviour and emotions	-0.087	0.032	0.089	-0.118, 0.008
	Staff behaviour	0.044	0.035	0.390	-0.039, 0.099
	Staff communication patterns	0.038	0.114	0.454	-0.139, 0.309

Demographic variables of the child and caregiver stress

The study aimed to find the relationship between the age of the child and gender with levels of stress in the caregiver. Findings show that level of stress in the caregiver was significantly associated with the age of the child (Table 7).

A significant association was found between levels of stress in caregivers and the age of the child in relation to healthcare workers' communication with caregivers about the child's illness and treatment. An increase in the age of the child by one month increases the level of stress in caregivers by 0.004 with a 95% confidence interval of 0.001- 0,0007. The regression model was significant with a $p = .004$. This shows that caregivers with critically ill older children felt that healthcare workers' communication about the diagnosis and treatment of their child was very stressful.

Table 7

Relationship of Child Demographic Variables and Level of Stress in Caregivers

Independent variable	Dependent variable	Regression coefficient	Standard error	P value	95% Confidence interval
Age of the child	The appearance of the child	-0.055	0.001	0.282	-0.003, 0.001
	Sound from monitors	0.099	0.001	0.053	-0.005, 0.000
	Procedures done of the child	-0.128	0.001	0.012	-0.006, 0.001
	Caregiver role alteration	-0.040	0.001	0.431	-0.003, 0.001
	Child behaviour and emotions	-0.004	0.001	0.940	-0.001, 0.002
	Staff behaviour	0.082	0.001	0.109	0.000, 0.005
	Staff communication patterns	0.147	0.001	0.004*	0.001, 0.007
Gender	Appearance of the child	0.062	0.104	0.228	-0.330, 0.079
	Sound from monitors	0.023	0.143	0.646	-0.216, 0.347
	Procedures done of the child	0.053	0.147	0.303	-0.442, 0.138
	Caregiver role alteration	-0.061	0.110	0.230	-0.349, 0.084
	Child behaviour and emotions	-0.045	0.120	0.375	-0.342, 0.129
	Staff behaviour	-0.021	0.130	0.681	-0.310, 0.203
	Staff communication patterns	-0.030	0.153	0.552	-0.393, 0.210

Clinical variables of the child and caregiver stress

The study results show that stress in caregivers was significantly associated with the nature of admission and duration of stay in the CCU when confronted with various items on the PSS (Table 8). The nature of admission was significantly associated with stress-related to a child's behaviour and emotions. The results show that emergency admission was significantly associated with a decrease in caregivers' levels of stress by -.566 with a 95% confidence interval of -0.870, -0.262. The regression model significant with a $p = 0.000$. Caregivers felt that their child's behaviour and emotions on admission in the CCU was not very stressful despite being an emergent case.

Table 8

Relationship of Child Clinical Variables and Level of Stress in Caregivers

Independent variable	Dependent variable	Regression coefficient	Standard error	P value	95% Confidence interval
Nature of admission	The appearance of the child	-0.142	0.199	0.005	-0.952, -0.169
	Sound from monitors	-0.041	0.171	0.421	-0.474, 0.198
	Procedures done of the child	-0.184	0.155	0.000*	-0.870, -0.262
	Caregiver role alteration	-0.084	0.144	0.098	-0.523, 0.045
	Child behaviour and emotions	0.050	0.193	0.332	-0.192, 0.567
	Staff behaviour	0.012	0.188	0.816	-0.325, 0.413
	Staff communication patterns	-0.032	0.137	0.526	-0.356, 0.182
Duration of hospitalisation	The appearance of the child	0.127	0.020	0.012	0.011, 0.090
	Sound from monitors	0.064	0.105	0.209	-0.075, 0.339
	Procedures done of the child	0.079	0.108	0.121	-0.045, 0.381
	Caregiver role alteration	0.025	0.081	0.625	-0.120, 0.200
	Child behaviour and emotions	0.035	0.088	0.497	-0.114, 0.234
	Staff behaviour	0.103	0.096	0.044	-0.005, 0.381
	Staff communication patterns	0.013	0.030	0.795	-0.051, 0.066

Summary

This chapter has presented and analysed the findings of the study. Among demographic variables, the majority of 95.6% of caregivers were female. The age range of the caregivers varied from 19-79 years old with most, 39.7%, aged <25. Among them, 72.1% came from the urban area and the majority 90.9 % were Christians. The findings of the study suggest that caregivers experience stress while their child is hospitalised in CCU. Among 385 caregivers, 53.8% (n=207) of caregivers were moderately stressed, 37.1% (n=143) were in severe stress, approximately 4% of the caregivers were either in extreme or mild stress and less than 1% of caregivers were not stressed. Appearance of the child and caregivers' role alteration were the most stressful elements in CCUs while healthcare workers' behaviour and communication patterns caused minimal stress to caregivers.

Using principal component analysis for reduction of the number of variables, the sound of monitors and other equipment, procedure being done on the child, caregiver role alteration, and child behaviour and emotions in CCU can be related or fully explained by component loading number one whereby stress is related to child's situation in CCU. In addition, healthcare workers' behaviour and communication patterns can be related to component loading number two whereby stress is related to difficulty in the interpersonal relationship with CCU staff. Furthermore, the study findings have shown that higher stress scores were negatively related to the age of the caregiver where younger caregivers experience more stress when they observe their children undergoing different procedures and interventions. The findings also show that the level of stress in caregivers was significantly associated with the age of the child and the nature of admission. Gender, residence, religion, education, ethnicity, prior admission, and gender of the child did not have any significant associations with the level of stress in caregivers.

Chapter five

Discussion of the result of the study

Introduction

This chapter presents a discussion of the results of the study whose aim was to examine caregiver stress experienced in paediatric CCU at QECH. The chapter also includes limitations of the study, recommendations, and areas for further research. The discussion is focused on study objectives which were: to find situations that were stressful to caregivers while their child is admitted in the CCU, to find the relationship between variables on A-PSS: PICU, to find the relationship between caregiver stress and caregiver demographic variables, to find the relationship between caregiver stress and child demographic variables and to find the relationship between caregiver stress and child clinical variables.

The results from this study suggest that caregivers experience stress while their child is admitted in CCU. The results further show that caregiver stress is associated with a number of caregivers' demographic, child demographic, and child clinical variables. The results of the study add to the literature on studies that found that caregivers experience stress when their child is admitted in CCU. The results support other international, regional, and national findings of previous studies on caregiver stress.

Demographic data and the level of stress

Results of the study show that 53.8% (n=207) of caregivers were moderately stressed, 37.1% (n=143) were in severe stress, approximately 4% of the caregivers were either in extreme or mild stress and less than 1% of caregivers were not stressed. Similar to these findings Patil. (2014) assessed the level of stress and coping strategies of mothers whose babies were admitted in the NICU and the study revealed that out of 40 mothers, 28 (70%) of mothers had moderate stress and 12 (30%) of mothers were having severe stress and nobody

was in mild stress. Contrary to these findings a study that was conducted in Nepal by Sandhya (2019) revealed that almost half of the caregivers 46.7% (n=42) had extremely severe stress and 21.1 % (n=19) had severe stress during hospitalization of their child. Levels of stress in caregivers may vary due to differences in geographical location, social, and demographic factors. Kumar and Avabratha (2015) explained that findings may differ because of family preferences and healthcare workers' delivery of critical care may be affected by regional, religious, and cultural influences.

The results show that both male and female caregivers experience stress when they have their children admitted to CCU. However, there may be a bias in the findings because of the differences in sample size as the majority, 95.6% of the caregivers were female and 4.4% were male which could have been due to the community's social and cultural norms regarding the total female involvement in parenting and care of the children. Similarly, looking at Yocoub et al. (2012) sample size, majority 83.1% were mothers while 15.1% were fathers, and 1.7% grandparents to the sick child. One explanation could be related to the fact that the majority of fathers both in Malawi and Jordan are occupied with their work to provide for their families and had less experience in caring for the sick child, and usually, mothers are more involved in the care of the critically ill child. Although there were few male caregivers in the study, this trend may be changing and healthcare providers must be prepared to communicate effectively with male caregivers of critically ill children as they are also being involved in child care.

Stressful situations in CCU

In this study an A-PSS: PICU instrument was used to examine stress experienced by caregivers in CCU where mean scores were used to calculate the level of stress on the seven items. The total mean stress score was 3.41. The results of this study show significant stress

in caregivers of children admitted in CCU. This is supported by results of studies that were done in India by Kumar and Avabratha. (2017) and Pooni et al. (2013) on levels of stress in caregivers that show significant stress in caregivers when their children are admitted in CCU. The studies found a total mean stress score of 3 and 3.5 respectively. Children's admission to CCU is highly stressful for caregivers because they are not mentally prepared. The atmosphere of CCU is filled with highly stressful situations such as technological equipment, the critical condition of the child, and in addition the caregiver is expected to make critical decisions about child care, therefore rendering the environment stressful.

Using the mean stress score of each item on the A-PSS: PICU, caregivers identified the following situations to be most stressful in the CCU: the appearance of the child and caregiver role alteration, child behaviour and emotions, procedures done on the child, and sound of monitors and other machines. The results indicate that caregivers were more stressed with the appearance of the child and the alteration of their roles in the CCU. Lisanti et al (2017) examined the stressors and stress response of mothers during their infant's admission to a paediatric cardiac intensive care unit and infant appearance and behaviour was the highest-rated source of stress. This is consistent with a study done in Rwanda by Musabirema et al. (2015) which also found that the appearance of the child was the most stressful source of stress in the NICU. Studies done in India by Kumar and Avabratha (2015) and Pooni et al. (2013) also found that caregivers were more stressed with the way their child appeared. However, Rodríguez-Rey and Alonso-Tapia (2016) observed that the appearance of the child was one of the most prevalent stressors in PICU but caregiver role alteration was found to be the most stressful event experienced by 50% of the caregivers.

The signs and symptoms of critical illness coupled with the complex and aggressive critical care treatment contribute to the distorted appearance of the child. Caregivers may

have problems to show affection and interact with their child, therefore, they are unable to fulfil their role in the CCU. According to a study that was done by Gondwe et al. (2017) on experiences of caregivers of infants who have been on bCPAP at QECH, caregivers reported that the tubing on bCPAP machines prevented contact between them and their children. Critical illness may bring about physical separation between the caregiver and the child leading to significant stress to caregivers. In the CCU infants may appear blue or in respiratory distress and may be separated from their caregivers because they need resuscitative measures and various technologies, tubes, medications, and wires for care and monitoring (Lisanti et al., 2017). Caregivers may be unable to provide for their critically ill child basic needs, such as clothing, feeding, diaper change, and comforting, altering the sense of caring role with the child.

The severity of the child's illness appears to be a significant stressor to the caregivers. In this study, results showed that above 90% of the critically ill children were oxygenated and one was intubated indicating that their conditions were severe. A qualitative study that was done by Peeler et al. (2015) on experiences of caregivers of hospitalised infants requiring oxygen therapy, revealed that caregivers felt isolated from their child when the latter was receiving a headbox oxygen which acted as a physical barrier that limited their involvement in child care. Caregivers further reported that they were unable to hold their child and this increased their stress levels. Likewise, Pooni et al. (2013) study results indicated that caregivers of intubated children were more distressed than caregivers of non-intubated children because they are also unable to participate in the provision of basic care to their sick children due to the seriousness of the condition. When healthcare workers take over care of critically ill children, caregivers are unsure how they can get involved and productively participate in their child's care.

Yacoub et al. (2012) study results acknowledge that alteration in the caregiver-child relationship was more stressful than the physical aspects (sight and sound, procedures done on the child, healthcare workers' behaviour, and communication). This demonstrates that it is more difficult for caregivers to adjust to the alteration in their traditional roles and responsibilities than adapting to the physical environment of the CCU. Gondwe et al. (2017) study results found that caregivers were less anxious when they were able to undertake caregiving roles such as feeding, changing nappies, turning the baby, tepid sponging, and reporting any problem to nurses. The support, encouragement, and reassurance from healthcare workers and significant others for instance family members could help caregivers to reduce stress, accept treatment, and cope well with the situation.

It was observed that healthcare workers' communication patterns and behaviour while caring for the critically ill child was the least significant cause of stress to the caregiver in CCU. These results concur with the study that was done by Yacoub et al. (2012) on Jordanian caregivers' stress during child admission to PICU which found that professional staff communication and behaviour were the least stressful items in the unit. Similarly, Pooni et al. (2013) found that most caregivers were satisfied with healthcare workers' behaviour. A descriptive correlational study by Hasanpour et al. (2017) on Iranian healthcare workers and parent communication identified that appropriate communication between caregivers and healthcare workers was related to significantly lower caregiver stress scores. In as much as Family Centred Care (FCC) is concerned, caregivers are more informed and involved in the care of their sick child hence healthcare workers' communication and behaviour was the least stressful. In addition, good communication about the child's critical condition and treatment portray the provision of quality child health care despite the presence of inadequate conduct of health personnel. Sometimes caregivers may recognise that healthcare workers hold the

responsibility of their child care and recovery as such may not be able to rate them accordingly on communication and behaviour conduct (Yacoub et al., 2012).

Although healthcare workers' communications pattern was one of the least stressful elements in this study, a study that was done by Tehrani et al. (2012) found that the most influential stressors on this element were inadequate explanation about medical procedures such as inserting intravenous lines and the responsibility of monitoring intravenous fluids and medication by caregivers. In relation to the above results, Sandhya. (2019) found that hospital staff related factors of the low level of stress were due to responsibility caregivers got from healthcare workers for monitoring intravenous fluids and oral medications and was seen in 53.3% of the caregivers. Similarly, 48.9% of caregivers had a low level of stress due to inadequate communication of doctors/nurses with the child and caregivers on rounds, procedures, and interventions. Caregivers are always passionate about taking care of their child whether sick or not and giving partial responsibility of child care to them can improve their mood that can lead to low levels of stress relating to healthcare workers' communication patterns.

Contrary to this, a study by Gondwe et al (2017) found that the caregivers in the neonatal nursery who found their infants already commenced on bCPAP without being informed were more stressed than their counterparts in the paediatric nursery who are always available in the unit. In Malawi, caregivers in neonatal nursey visit their children every 2 or 3 hours and when the condition deteriorates, caregivers usually are informed after commencing bCPAP. It is the responsibility of healthcare workers to give adequate information where possible, before any treatment, to reduce stress. Most participants acknowledged that the information given helped understand their infant's condition and bCPAP (Gondwe et al, 2017).

Two components emerged from the principal component analysis. The first component was stress related to the condition of the child and the second one was stress related to caregivers' situation with healthcare workers. The sound of monitors and other machines in the unit and procedures done on the child were strongly correlated with stress-related to the condition of the child. Healthcare workers' communication was strongly correlated with stress related to the relationship between healthcare workers and caregivers in CCU. The first component related to child condition in CCU comprised technological equipment found in the unit, procedures done on the child, caregiver role alteration, and child behaviour and emotions. These according to Rodríguez-Rey and Alonso-Tapia (2016) may have a longer-term impact on the health of the child as well as the mental health of the caregiver. On the other hand, the second component about stress related to the relationship between healthcare workers and caregivers has only two variables and was the least significant cause of stress to caregivers according to this study and literature. Rodríguez-Rey and Alonso-Tapia (2016) explained that although difficulties in the relationship with CCU staff can be a source of stress, the stress can be temporary and can disappear once the child is discharged.

Relationship between caregiver stress and caregiver demographic, child demographic and child clinical variables

The age of the caregiver was significantly associated with procedures done on the child and healthcare workers' communication with caregivers. The results show that young caregivers experienced high levels of stress when observing procedures being done on the child such as insertion of tubes, injection of medication, suctioning, and others. Nursing interventions may be medically essential, at the same time making a child uncomfortable and be inherently stressful for caregivers who are observing and soothing the child. This may be

related to a lack of understanding or communication between the healthcare worker and caregiver.

Gallegos (2011) also identified that caregiver age was weakly negatively correlated with procedures done which means that as caregivers grow older, the stress associated with their child receiving procedures and the alteration of caregiver role decreases. Similarly, studies that were done by Kumar and Avabratha. (2015) and Rodríguez-Rey and Alonso-Tapia. (2016) also identified that younger caregivers were more stressed than older caregivers irrespective of illness and clinical status. The explanation could be that as caregivers age, they may have had the opportunity to pursue additional education through experience from prior hospitalization which may assist them in understanding the reason for the various procedures and their role change. Contrary to these results, a study that was done by Turner at al. (2015) identified that older caregivers rated high-stress scores factors related to sight and sound of the CCU environment.

The results show that 26.5% of the caregivers had one child and this could mean that they were young and first-time mothers. Parenthood is a complicated period for first-time female caregivers and is characterised by low confidence, symptoms of depression, and high stress which improve over time for the majority of caregivers (Kristensen et al., 2018). However, the transition may be affected if the child becomes critically ill and admitted in CCU. Caregivers who were young first-time mothers may have had difficulties to cope with the extra responsibility of caring for a sick infant in CCU leading to increased levels of stress. First-time mothers need extra guidance and reassurance concerning their child's condition and treatment.

The age of the child was significantly associated with caregivers' stress when related to healthcare workers' communication patterns. Caregivers with older children experience

more stress in the CCU. However, there have been no comparable studies similar to this result. Contradictory to this result, a study by Ramirez et al. (2018) found that with the younger age of the child, there is a greater perception of stress in caregivers regarding the appearance of the child, procedures, and interventions done on the child, and caregivers' role alteration. In the same vein, Rodríguez-Rey and Alonso-Tapia. (2016) found that high-stress score was negatively correlated with the age of the critically ill child. This means that caregivers with younger children experienced more stress compared with caregivers with older children.

The nature of admission was significantly associated with stress-related to the factor of the critically ill child. Caregivers felt that their child's behaviour and emotions as well as the appearance of the child in the CCU were not very stressful despite being an emergent case. Previous observations have shown that planned admissions are associated with less stress in caregivers (Pooni et al., 2013). However, the results of this study tend to differ in that caregivers who had planned admissions were greatly stressed with the change in their child's behaviour and emotions, and appearance of the child compared to caregivers who had emergency admission. Mostly children who had a planned admission were scheduled for a major surgical operation so caregivers were more stressed with the change of behaviour and emotions as well as the appearance of their child following surgery. In the immediate post-operative period, infants who had a major surgical procedure require complex critical care that is often reflected by their critical appearance and change in behavior and emotions (Lisanti et al, 2017). Mostly, caregivers' basic parenting tasks for the children such as clothing, feeding, diaper change, and holding the child are paused during this critical care admission.

According to findings of the study that was done by Ramirez et al. (2018) regarding the type of admission whether programmed or emergency, two stressors were identified with a greater impact on the aspect of the appearance of the child and procedures and interventions which increased in those caregivers whose children were hospitalised on a planned basis. This could be explained by considering that children involved in the study that was done by Ramirez and colleagues were hospitalized for a cardiological reason, often as a consequence of performing cardiac surgery, which although is programmed, in most cases, becomes a great emotional burden due to the eventual severity of the condition.

Limitations of the study

The main limitation of the study was the use of a convenience sampling technique where any caregiver who met the inclusion criteria was likely included in the sample. A convenience sample can lead to under-representation or over-representation of particular groups within the sample (Gravetter & Forzano, 2011) and therefore can result in selection bias. Since the sample was not chosen at random, the inherent bias in convenience sampling meant that the sample was unlikely to be the representative of caregivers that were studied. This undermines the ability to make generalisations of the result of the study from the sample to the population of caregivers with critically ill children in CCU.

In addition, voluntary response samples also led to selection bias because they over-sample people with strong opinions and under-sample people who do not care much about the topic of the survey. Caregivers who volunteered for the survey may pose different characteristics than the average individual in the study population. In the same vein, the use of one tertiary referral hospital in Blantyre led to over-representation of caregivers from the southern region of Malawi. It would be more powerful and reflective to have different hospitals from multiple regions in Malawi that would better represent a general population of

caregivers with children in the CCU. The study also recruited caregivers whose children were admitted in HDUs only since there were no children admitted in ICU. It is important to have ICU from different hospitals so that comparisons can be made on the results since the outlook of the ICU and HDU differ.

Another limitation of the study was the use of a self-reporting instrument in identifying stressful situations in CCU. Self-reported data are limited by the fact that the data rarely can be independently verified and are affected by self-reporting bias. According to Althubaiti (2016), self-reported data are often argued to be unreliable and threatened by self-reporting bias which may arise from social desirability and recall bias. Social desirability bias is the tendency to underreport socially undesirable attitudes and behaviours and to over-report more desirable attributes in order to fit into the situation or maintain a positive self-concept (Latkin et al., 2017). Recall bias contains several potential sources of bias for instance selective memory is where caregivers may or may not remember experiences that occurred at some point in the past, telescoping involves caregivers recalling previous CCU admission as if it occurred at another time, attribution involves caregivers assigning positive experiences to one's own means but negative experiences to external forces and exaggeration is where caregivers may present some experiences as more significant than is suggested from other data. Therefore, the validity constraints of self-reported data may have affected the results through either under or over-reporting.

Implication to nursing practice

The knowledge gained from this study adds to a limited body of knowledge regarding stressors experienced by caregivers during their child's critical illness. This study provides knowledge that assists healthcare providers to have a better understanding of the stressors that caregivers experience during their child's hospitalization in the CCU. The study results

show that there is significant stress among caregivers of children with critical illness in CCU. Healthcare workers need to provide caregivers with the necessary information, support, and tools to empower them to care for their child during the CCU experience. According to Beer et al. (2011) critical care nursing is defined as a specialist area of nursing that involves caring for patients who are suffering from life-threatening illnesses or injuries, while at the same time offering comfort and support to their family members.

The results of the study also show that the appearance of the child and caregiver role alteration were was the most stressful situations to the caregivers when their children were admitted in the CCU and are consistent with the results of previous studies. The seriousness of the condition coupled with aggressive treatment of a critical condition affects the appearance of the child. Caregivers are afraid and unable to provide basic caregivers' roles and responsibilities to the child. These findings may be useful in strategizing targeted measures to assist in facilitating caregivers' coping in CCU. The targeted interventions may involve teaching caregivers about the physical environment of the CCU, various equipment commonly used in the unit, the child's appearance, child's potential behavioural, and emotional reactions. Healthcare workers need to assist caregivers in dealing with their changed caregiver role and responsibilities by explaining to them how they can help their sick child.

Literature reported that planned admission was associated with lower stress in caregivers. However, this is not the case with the current study where it was found that planned admission was also associated with an increased level of stress. Healthcare workers should be aware of the fact that caregivers with planned admission experience an increased level of stress while in CCU. Although the study found that most of the caregivers were female, healthcare providers must be prepared to communicate effectively with male

caregivers of critically ill children because both male and female caregivers equally experience significant stress while in CCU. In addition, there is a need to raise awareness of the likelihood of gender differences in stress responses between male and female caregivers.

Recommendations of the study

Nursing practice

The results of the study indicate that there is a significant amount of stress in caregivers of critically ill children in CCU. Therefore, there is a need for psychosocial interventions to help manage stress in caregivers. Psychosocial interventions are non-pharmacological activities, techniques, and strategies that target psychological, social, and environmental factors intending to improve health functioning and wellbeing. According to a meta-analysis by Doupnik et al. (2017) on coping support intervention outcomes during acute pediatric hospitalizations, there is evidence that psychosocial interventions can improve caregivers' emotional outcomes. In particular, the meta-analyses showed that coping support interventions for instance relaxation technics such as yoga, distraction using music therapy, education on knowledge and skill for management of anxiety and stress to caregivers through counselling, education on coping strategies through videos, and training healthcare workers on empathetic communication to promote caregiver's emotional expression are effective for improving caregivers' anxiety and stress symptom burden. In a meta-analysis, combined intervention effects significantly reduced stress and anxiety but not depression. Healthcare workers' knowledge and skill in the assessment of stress and provision of effective psychosocial interventions will assist in the provision of an environment with lower stress and greater caregivers' satisfaction with critical care.

Understanding caregivers' most stressful experiences in CCU will help healthcare workers to fully embrace the FCC approach that encourages caregivers to get involved and

participate in their child care. According to the clinical trial that was done by Arshadi Bostanabad et al. (2017) which was aimed to investigate the effect of family-centred intervention in NICU on mothers' anxiety, the family-centred care was effective in reducing the anxiety of the mothers of premature infants hospitalized in the NICU. Following the intervention, the obtained results indicated a statistically significant difference between the two groups so that a considerable reduction in the mothers' anxiety was observed in the intervention compared to the control group. Caregivers are always passionate about taking care of their children and shared responsibility of child care between healthcare providers and caregivers can improve their mood that can lead to low levels of stress. This will help in fulfilling their parenting roles that are therapeutic to the critically ill child while adapting to the stressful atmosphere.

It was difficult to find data on the capacity of HDUs because they had no separate register in the units. Reliable published data on the availability of critical care services in low-income regions is limited (Murthy et al., 2015). There is a need for a database of critical care units' information and resources in order to evaluate health system performance and assist in the development of various related health policies such as the provision of comfort and support to caregivers with children admitted in CCU to reduce stress.

Nursing education

Nurse educators must upgrade the concept of stress and its management in the nursing curriculum (Patil, 2014). CCU environment is highly technological, requiring nurses to have a broad knowledge base and a high level of decision-making skills as they care for patients and their families who are in vulnerable circumstances. Provision of in-service critical care education and mentorship, the arrangement of workshops and conferences that will help healthcare workers in CCU to adopt new psychosocial interventions to prevent, minimize, or

manage stress of caregivers. Lack of experience and inadequate education and training of CCU nurses were identified as major barriers to providing support to caregivers (Gondwe et al, 2011).

Nursing Research

Better understanding of caregivers' experiences of hospitalisation to CCU will provide researchers with a background for conducting intervention research. Intervention studies will help in the development of research-based knowledge and practice on the reduction of caregiver stress. Quality nursing interventions are dependent on a better understanding of caregivers' stress and may improve caregivers' ability to positively cope with the situation.

Further Research

Recommendations for further research have been made. First, a mixed method study can be conducted to identify stressful situations as well as explore caregivers' experiences when their child is admitted in CCU. Furthermore, in this current study, data was collected once and stress response may change as the duration of admission in the CCU progresses. A longitudinal study can be conducted where data is collected at different times depending on the progress of the hospitalisation of the child in CCU. This might further describe and clarify caregivers' experiences and responses to stressful events during child's hospitalisation in CCU.

Conclusion

The purpose of this descriptive cross-sectional study was to examine stress and describe stressful situations experienced by caregivers with critically ill children in CCU. The study results show that there was significant stress among caregivers who had their children admitted to CCU. It was observed that caregivers rated the appearance of the critically ill

child and alteration of the roles of the caregivers as the most stressful issues of their CCU experience. However, professional staff communication and behaviour were found to be less stressful situations to the caregivers. Male and female caregivers equally experience stress while in CCU; however, they ranked the stressful situations differently. Age of the caregiver, age of the child, and nature of admission were significantly associated with caregivers' stress.

This study contributes to both our fundamental knowledge here in Malawi and to the growing research base on specific sources of stress that caregivers experience during their child's critical care hospitalization. The study results help to understand caregivers' stress in a critical care setting that is essential in effective planning for quality nursing interventions. Therefore, healthcare workers must be aware of caregivers' stressful conditions and provide psychological support through family centred care. On-going education of caregivers about the CCU environment is recommended to help improve their psychological wellbeing.

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Appendices

Appendix A: Participants information sheet

Study title: Assessment of stress in caregivers with children admitted in CCU at Queen Elizabeth Central Hospital.

Investigators: Jester Jere (Kamuzu College of Nursing),

Associate professor D. Jere (Kamuzu College of Nursing)

Mrs M. Simbota (Kamuzu College of Nursing)

Contact details for principal investigator: Jester Jere, University of Malawi, Kamuzu College of Nursing, P.O. Box 415, Blantyre. Email: jjere@kcn.unima.mw. Cell: +265999698340 or +265881762377.

Study Sponsor: Elma Philanthropies Foundation.

Dear Madam/Sir,

I am Jester Jere, and I am pursuing a Masters' Degree in Child Health nursing at Kamuzu College of Nursing. As part of my studies, am conducting a research project on "Assessment of stress in caregivers with children admitted in CCU at QECH". The aim of the research study is to identify stressful situations and levels of stress in caregivers during hospitalisation of their children in CCU. The aim of this letter is to request your participation in this study. I have asked you to participate in this research because I would like to understand what is most stressful to caregivers with children admitted in CCU.

Your participation in the study will require you to answer questions asked by the researcher from a questionnaire. This will take approximately 30 minutes in a private room, at the time suitable and convenient for you with no disturbances. There is no physical pain or

discomfort in joining the study, however, if you may experience uncomfortable feelings or emotional tension due to some memories while being interviewed, immediately inform the investigator who will help you appropriately by offering psychological support.

There are no costs or payments or any other direct benefits in participating in the study, however, study findings will be used to understand the presence of stress in caregivers with children in CCU. Therefore, supportive interventions or programmes will be developed in order to help caregivers cope with this changeling situation. Your personal information and your child's information will be kept confidential. They will only be accessed by the researcher and other people involved in the study. The study findings will not identify you in anyway. However, the study findings will be shared with individuals involved in this study such as my research supervisors, the hospital staff, and other individuals.

Your participation in this study is optional. You may choose not to participate in the research or withdraw at any time during the study. Your decision will not affect the care of your child in the CCU. You will be required to sign a consent form or put your thumbprint on the space that will be provided if you agree to participate in the study. This will indicate your voluntary willingness to answer the questionnaire.

The study and its proceedings have been approved by COMREC and QECH hospital authorities. For any questions or further information about the study and your rights you may contact the researcher at +265999698340 or +265881762377 or raise your concerns at COMREC Secretariat, P/Bag 360, Chichiri, Blantyre 3, Telephone number 01 989 766.

Thanks for taking your time to read and understand this information.

Appendix B: Participants consent form

Study title: Assessment of stress in caregivers with children admitted in CCU at Queen Elizabeth Central Hospital.

Investigators: Jester Jere (Kamuzu College of nursing)

Associate professor D. Jere (Kamuzu College of Nursing)

Mrs M. Simbota (Kamuzu College of Nursing)

Contact details for principal investigator: Jester Jere, University of Malawi, Kamuzu College of Nursing, and P.O Box 415, Blantyre. Email: jjere@kcn.unima.mw. Cell: +265999698340 or +265881762377.

Study Sponsor: Elma Philanthropies Foundation

Voluntary consent to participate in the study

I am making a voluntary decision to participate in the study described above. I have read and I understand all the information about the study. I understand the purpose of the study, its proceedings, and the time required for me to fill the questionnaire. I have been informed about my rights such as confidentiality of my personal information that will be given. It will only be accessed by the individual directly linked with the study.

I understand there is no cost or payment or any other benefits for taking part in the study, however, the study results will be used to understand the most stressful situation and level of stress to caregivers with children admitted to CCU. I understand that the study findings will also be used to develop supportive interventions and programmes for the caregiver to cope with the admission of their child to CCU. I have been given the opportunity to ask questions about the study. I understand I will not experience any physical

pain or discomfort, however, if I feel an uncomfortable or emotional strain, I will be helped appropriately by the researcher.

I have the knowledge of where to complain when my rights have been violated. I understand that participation in the study is voluntary and I can withdraw from the study any time without being penalised.

I willingly agree to participate in the study (name) _____

Participants' signature _____ Date_____

Participants thumb (if illiterate) _____Date_____

Witness signature (if illiterate) _____Date_____

Researchers' signature _____ Date_____

Appendix C: Kalata ya chidziwitso chakafukufuku mu chichewa

Mutu wa kafukufuku: Kuyeza chiphinjo kwa makolo omwe anaawo agonekegwa ku malo kwa ana odwalika kwambiri ku Queen Elizabeth Central Hospital

Opangitsa kafukufuku: Jester Jere (Kamuzu College of Nursing)

Associate professor D. Jere (Kamuzu College of Nursing)

Mrs M. Simbota (Kamuzu College of Nursing)

Mwini kafukufuku: Jester Jere, Kamuzu College of Nursing, P.O Box 415, Blantyre. Cell: 0999698340 or 0881762377, email: jjere@kcn.unima.mw .

Opeleka thandizo lopangira kafukufuku: Elma Philanthropies Foundation

Okondedwa Mayi kapena Bambo,

Ine dzina langa ndi Jester Jere, ophunzira wa ku sukulu ya ukachenjede ya Kamuzu Koleji ndipo ndikupitiliza maphunziro anga a unamwino wa ana. Ngati mbali ya maphunziro anga, ndikupanga kafukufuku amene mutu wake uli “Kuyeza chiphinjo kwa makolo omwe anaawo agonekedwa ku malo kwa ana odwalika kwambiri ku Queen Elizabeth Central Hospital”. Cholinga cha kafukufukuyi ndikuyeza chiphinjo kwa makolo omwe ali ndi mwana ku malo kwa ana odwalika kwambiri. Ndalemba kalatayi kukupemphani kuti mutengepo mbali mukafukufukuyi.

Mukavomereza kutengapo mbali, mukuyenera kuyankha mafunso omwe mutafunsidwe ndi opanga kafukufukuyi. Kuyankha mafunso kukutengerani mphindi zosapitilira makumi atatu, pamalo a chinsinsi kuti anthu ena asamve nawo komanso musasokonezedwe. Dziwaninso kuti palibe vuto lirilonse limene mutalipeze chifukwa

chotenga mbali mukafukufukuyi ndipo mukadzakumana ndi vuto lirilonse musadzazengeleze kudziwitsa opangitsa kafukufukuyi.

Dziwaninso kuti palibe phindu lirilonse limene mutapeze potenga nawo mbali mu kafukufukuyi koma mayankho anu adzathandiza kupeza njira zochepesera kapena kuletsa chiphinjo kwa makolo omwe ali ndi mwana kumalo kwa a ana odwalika kwambiri. Muli ndi ufulu odziwa zotsatira za kafukufukuyi ngati mungakonde kutero. Mayankho anu onse akhala a chinsinsi komanso adzawerengedwa ndi okhawo okhuzidwa ndi kafukufuku ameneyi. Palibenso amene ataziwe kuti mwayankha mafunso akafukufukuyi chifukwa muzagwiritsa ntchito nambala m'malo mwa dzina lanu.

Dziwani kuti simukukakamizidwa kutenga mbali mukafukufukuyi ndipo mutha kusankha kuvomera kapena ayi komanso ndinu ololedwa kutuluka mukafukufukuyi nthawi iliyonse mungafune. Simukhala ndi mulandu uliwonse mukatero komanso chisankho chanu sichisokoneza chithandizo chimene mwana wanu akuyenera kulandira pachipatala pano munjira iliyonse. Ngati mwavomera kutenga mbali mukafukufukuyi, mukupemphedwa kuti musayine kapena kudinda ndi chala chanu pa fomu la chivomelezo limene mutapatsidwe ngati chidzindikiro choti mwavomera kutenga mbali mukafukufukuyi mosakakamizidwa.

Kafukufuku ameneyi wavomelezedwa ndi komiti imene imayang'anira za kafukufuku yotchedwa College of Medicine Research and Ethics Committee (COMREC) komanso ndi oyang'anira chipatala cha boma la Queens Elizabeth Central Hospital. Ngati mungafune kudziwa zambiri zokhuzana ndi kafukufukuyi komanso za ufulu wanu ndinu omasuka kufunsa mafunso pogwilitsa ntchito manambala awa: +265999698340 or +265881762377 kapena kupelekanso mafunso ndi madandaulo anu ku komiti iyi: COMREC Secretariat, P/Bag 360, Chichiri, Blantyre 3, ndipo nambala yawo ya telefoni ndi iyi: 01 989 766.

Zikomo kwambiri popeleka nthawi yanu kuwerenga ndiku mvetsestsa kalatayi.

Appendix D: Chivomelezo chotenga nawo mbali

Mutu wa kafukufuku: Kuyeza chiphinjo kwa makolo omwe anaawo agonekedwa kumalo kwa ana odwalika kwambiri ku Queen Elizabeth Central Hospital.

Opangitsa kafukufuku: Jester Jere (Kamuzu College of Nursing)

Associate professor D. Jere (Kamuzu College of Nursing)

Mrs M. Simbota (Kamuzu College of Nursing)

Mwini kafukufuku: Jester Jere, Kamuzu College of Nursing, P.O Box 415, Blantyre. Cell: 0999698340 or 0881762377, email: jjere@kcn.unima.mw

Opeleka thandizo lopangira kafukufuku: Elma Philanthropies Foundation

Ndikupanga chiganizo chotenga nawo mbali mu kafukufuku omwe wa fotokozedwa mwamba mwa kalatayi. Ndawerenga komanso ndamvesetsa za uthenga wa kafukufukuyu. Ndamvesetsanso cholinga chaka fukufuku, ndondomeko yake komanso nthawi yomwe itadzanditengere kuyankha mafunso ndikavomeraza kutenga nawo mbali. Ndamvetsetsa kuti mayankho anga ndi achinsinsi, adzawerengedwa ndi anthu okhawo okhudzidwa ndi kafukufuku ameneyu.

Ndamvesetsa kuti palibe phindu lomwe nditapeze ndikatenga nawo mbali mu kafukufukuyi, koma zotsatira zake zidzathandiza kumvetsa zinthu zomwe zimapagitsa makolo kuphinjika mwana wawo akagonekedwa kumalo kwa ana odwalika kwambiri. Zotsatira zizagwiritsidwanso ntchito yopangira chithandizo cha makolowa kuti asakhale ophinjika kwambiri. Ndapatsidwa mpata ofunsa mafunso okhudzana ndikafukufukuyu.

Ndikudziwa kuti palibe vuto lirilonse lodziwika limene nditakumane nalo mukafukufukuyi. Ndadziwitsidwanso kumene ndingathe kupeleka madandaulo anga

ndikakumana ndi vuto lirilonse lokhudza kafukufukuyi. Ndikudziwa kuti sindine okakamizidwa kutenga mbali mukafukufukuyi komanso kuti nditha kusiya kutenga nawo mbali mukafukufukuyi nthawi ina iliyonse popanda mlandu uliwonse.

Mosakakamizidwa, ndikuvomera kutenga mbali mukafukufukuyi.

Sayini ya otenga mbali mukafukufuku: _____

Tsiku: _____

Chidindo cha chala chaotenga mbali mukafukufuku (ngati saakutha kulemba) _____

Tsiku_____

Sayini ya mboni _____

Tsiku: _____

Sayini ya opangitsa kafukufuku: _____

Tsiku: _____

Appendix E: Permission seeking letter to Queen Elizabeth Central Hospital

Kamuzu College of Nursing

P.O Box 415,

Blantyre.

The Director,

Queen Elizabeth Central Hospital,

P.O Box 95,

Blantyre,

30th March, 2017.

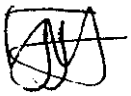
Dear Sir/Madam**,**

REQUEST FOR YOUR PERMISSION TO CONDUCT A STUDY AT QUEEN ELIZABETH CENTRAL HOSPITAL

I am Jester Jere, a Master of Science in Child Health nursing year two student at Kamuzu College of Nursing. As part of the academic requirement for the award of a Master's degree, I am required to conduct a research study. The topic of the study is **"Assessment of stress in caregivers with children admitted in the critical care unit at QECH in Blantyre, Malawi".**

I write this letter to seek permission from your office to conduct this study at your facility. Your favourable consideration will be highly appreciated.

Yours faithfully,

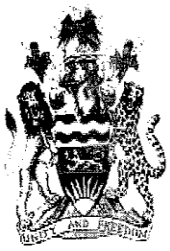


Jester Jere

Appendix F: Letter of approval from Queen Elizabeth Central Hospital Deputy

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

All communications should be addressed to:
The Hospital Director



In reply please quote **No.**

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

Ref. No. QECH/

11th April, 2017

Jester Jere
University of Malawi
Kamuzu College of Nursing
P.O. Box 345
BLANTYRE
MALAWI

Dear Jester,

PERMISSION TO CONDUCT A RESEARCH AT QUEEN ELIZABETH CENTRAL HOSPITAL

I am pleased to inform you that management has no objection for you to conduct a research project on "**Assessment of emotional stress in parents with children admitted in critical care unit**" at Queen Elizabeth Central Hospital.

Remember to provide a copy of your findings to the hospital.

All the best in your studies.

Yours faithfully,

L. Chewere
ACTING DEPUTY HOSPITAL DIRECTOR

Appendix G: Permission seeking letter to Head of Paediatric Department, Queen h Hospital

Kamuzu College of Nursing

P.O Box 415,

Blantyre.

The Head of Paediatric Department

Queen Elizabeth Central Hospital,

P.O Box 95,

Blantyre.

30th March, 2017.

Dear Madam,

REQUEST FOR YOUR PERMISSION TO CONDUCT A STUDY AT QUEEN ELIZABETH CENTRAL HOSPITAL

I am Jester Jere, a Master of Science in Child Health nursing year two student at Kamuzu College of Nursing. As part of the academic requirement for the award of a Master's degree, I am required to conduct a research study. The topic of the study is "**Assessment of stress in caregivers with children admitted in critical care units at QECH in Blantyre, Malawi".**

I write this letter to seek permission from your office to conduct this study in your department. Your favourable consideration will be highly appreciated.

Yours faithfully

Jester Jere

Appendix H: Letter of Approval from Head of Paediatric Department, Queen Elizabeth Central Hospital

UNIVERSITY OF MALAWI

College of Medicine
Private Bag 360
Chichiri
Blantyre 3
Malawi

Telephone: +265993630543

18th April 2017

The Chairperson
College of Medicine Research and Ethics Committee
Private Bag 360
Chichiri
Blantyre

Dear Sir/Madam

Regarding: Assessment of stress in caregivers with children admitted in critical care units at QECH in Blantyre, Malawi

Please accept this letter as evidence of support from the department for this planned research study. Jester Jere is a Master of Science in Child Health nursing student at KCN, and part of the academic requirement is to conduct a research study. This topic is an extremely interesting one as many children admitted to the hospital can be extremely sick and inevitably the main focus is on delivering good quality care for these patients. However, it is important to deliver holistic care and this means considering the parents' level of emotional stress. The proposal developed, is aimed at determining this level of emotional stress in parents with children admitted in critical care units. Ultimately the findings of this study should help paediatricians and paediatric nurses be able to reduce this level of stress and deliver truly holistic care.

Yours faithfully

Dr Josephine Langton
MBChB, MRCPCH

Appendix I: Certificate of approval from research and ethics committee

CERTIFICATE OF ETHICS APPROVAL

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

P.04/17/2168 - Assessment of emotional stress in parents of children admitted in critical care units at Queen Elizabeth Central Hospital in Blantyre, Malawi version 1 dated April 2017 by Jester Jere

On 09-Jun-17

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

Approved by College of Medicine
09 JUN 2017
(COMREC)
Research and Ethics Committee

09-Jun-17
Date

Dr. YB. Mlombe - Chairperson (COMREC)

Appendix J: Permission to use the Abbreviated Parent Stress Score: Paediatric Intensive Care Unit (A-PSS: PICU)

Kamuzu College of Nursing

Post Office Box 415,

Blantyre.

27th January, 2017.

Dear Rocio Rodríguez Rey,

Permission to use Parent Stress Score: Paediatric Intensive Care Unit (PSS: PICU) instrument

I am Jester Jere, a post graduate student at the University of Malawi, Kamuzu College of Nursing in Malawi. In partial fulfilment of the requirements for the award of Master of Science degree in Child Health nursing, I want to conduct a study on:

"Assessment of emotional stress in parents with children admitted to critical care units at Queens Elizabeth Central Hospital".

This is a quantitative study and will recruit not less than 30 parents of children admitted to critical care units for at least 24 hours at Queens Elizabeth Central Hospital (I am still consulting on the exact sample size). This is a tertiary hospital in southern part of Malawi. Data collection will be done between the months of March and May, 2017. The PSS: PICU instrument will only be used once during the child's admission in the critical care unit and for this study only.

I am writing this letter to seek permission to adapt the Parent Stress Score: Paediatric Intensive Care Unit (PSS: PICU) instrument for data collection. Your consideration will be greatly appreciated.

Yours' faithfully,

Jester Jere

Rocio Rodríguez Rey

Appendix K: Questionnaire

Study Title: Assessment of stress in caregivers with children admitted in CCU at Queen Elizabeth Central Hospital.

Date of interview_____ Time of Interview_____

Data Collector _____ Participant ID No _____

Place of Interview_____ Date of admission: _____

Part A: Demographic characteristics of participant (CIRCLE AS APPLICABLE)			
	QUESTION	**ANSWER AND CODE**	**COMMENT**
A1	How old are you?	Mention……	
A2	What is your Gender	Female ……....1 Male ……...2	
A3	Where do you reside?	Urban ……..……...1 Rural……..…….2	
A4	What is your religion?	Christian ……1 Muslim……...….2 None ……..….3	
A5	What is your highest level of education?	No education……...1 Primary education …..... ….2 Secondary education …….3 Tertiary education ……..….4	
A6	Which ethnic group do you belong to	Chewa…….1 Yao …….2 Lomwe …….3 Sena …….4 Ngoni……5 Tumbuka …….6 Other (specify)	
A7	How many children do you have?	1……1 2-4…….2 >5……..3	

PART B: Demographic and clinical characteristics for critically ill child (PLEASE CIRCLE AS APPLICABLE)			
	QUESTION	**ANSWER AND CODE**	**COMMENT**
B1	What is the age of your child?	Mention ……..	
B2	What is gender of your child?	Female ……. 1 Male ……..2	
B3	What was the nature of your child's admission	Planned …….1 Emergency…….2	
B4	Have your children ever been admitted in a critical care unit before?	Yes ……1 No ……. 2	
B5	How long have you stayed in CCU? When were you admitted in CCU?	No of days …….	
Check the child hospital record for the following			
B6	Severity of illness	Unconscious ……1 Respiratory distress…….2 Convulsions…….3 Shock …… ….4 Post-surgery……...5 Other (specify)…….	
B7	Main diagnosis	Write: ……..	

Part C: Abbreviated Parental Stressor Scale: Paediatric Intensive Care Unit (A-PSS: PICU). INSTRUCTIONS: "Items below describe some aspects of the CCU environment that might elicit a stressful response in caregivers during their child's hospitalisation. You are required to circle the number which better expresses how stressful each experience has been for you according to the following scale" (Rodríguez-Rey and Alonso-Tapia, 2016):

C1	Physical appearance of the child (reduced level of consciousness, wounds, changes in skin colour, lethargic and weak, etc.)	Not experienced…….0 Not stressful ……..… 1 Minimally stressful……2 Moderately stressful……..3 Very stressful…….4 Extremely stressful……....5	
C2	Sounds of monitors bCPAP machines, suction machines, and oxygen concentrators, seeing the heart rate on monitors or hearing sudden alarm sounds.	Not experienced…….0 Not stressful ……..… 1 Minimally stressful……2 Moderately stressful……..3 Very stressful…….4 Extremely stressful……....5	
C3	Medical procedures conducted on my child (needles, tubes, incisions, drug administration, lumber puncture, etc.)	Not experienced…….0 Not stressful ……..… 1 Minimally stressful……2 Moderately stressful……..3 Very stressful…….4 Extremely stressful……....5	
C4	Not being able to touch my child, being with my child, and taking care of the child and hold the child whenever I wish.	Not experienced…….0 Not stressful ……..… 1 Minimally stressful……2 Moderately stressful……..3 Very stressful…….4 Extremely stressful……....5	
C5	Seeing my child crying, confused, in pain, unable to speak, sad, or angry or not responding (unconscious).	Not experienced…….0 Not stressful ……..… 1 Minimally stressful……2 Moderately stressful……..3 Very stressful…….4 Extremely stressful……....5	
C6	Seeing the staff from CCU behaving in a way that I consider inadequate (e.g. Laughing, speaking too loud, not telling me their names, etc.)	Not experienced…….0 Not stressful ……..… 1 Minimally stressful……2 Moderately stressful……..3 Very stressful…….4 Extremely stressful……....5	
C7	Communication problems with the doctors/nurses (explaining about the condition of the child in a way that I do not understand, expressing contradictory opinions, talking too little or too fast, using medical jargon, etc.).	Not experienced…….0 Not stressful ……..… 1 Minimally stressful……2 Moderately stressful……..3 Very stressful…….4 Extremely stressful……....5	

Appendix L: Mafunso

Mutu wa kafukufuku: Kuyeza chiphinjo kwa makolo omwe anaawo agonekedwa kumalo kwa ana odwalika kwambiri ku Queen Elizabeth Central Hospital

Tsiku lakafukufuku_____ Nthawi yakafukufuku_____

Nambala ya otengambali mukafukufuku_____

Malo akafukufuku_____ Tsiku logonekedwa _____

Gawo A: Mbiri ya kholo (Chonde zungulizani yankho lomwe mukugwirizana nalo)			
A1	Kodi muli ndi zaka zingati?	…….	
A2	Ndinu akazi kapena amuna?	Akazi …….……1 Amuna……..…2	
A3	Kodi mumakhala kuti?	Mtauni…….……1 Kumudzi…….….2	
A4	Kodi ndinu achipembedzo chanji?	Chikrisitu……..…1 Chisilamu…….……2 Zina …….……3	
A5	Kodi munafika pati ndi maphunziro anu?	Sanayimbe sukulu…...…1 Pulayimale……...2 Secondale ……3 Sukulu ya ukachenjede….4	
A6	Kodi ndinu mtundu wanji wa anthu?	Achewa ……...1 Yao …….…...2 Lomwe ……3 Sena…….4 Ngoni ……...5 Tumbuka ……6	
A7	Kodi muli ndi ana angati?	1……...1 2-4……2 >5…….3	

Gawo B :Mbiri ya mwana			
B1	Kodi mwana wanu ali ndi zaka zingati?	……..	
B2	Kodi mwana wanu ndi wankazi kapena wamuna?	Wankazi ……...1 Wamuna ……..2	
B3	Kodi munagonekedwa muchipatala mokozekera kapena mwazizizi?	Mokozekera …….1 Mwazizizi…….2	
B4	Kodi munadwazikapo matenda amwana ku malo a ana odwakila kwambiri?	Eya …….……1 Ayi ……...2	
B5	Munagonekedwa liti mu wodi ino?	Nambala ya masiku ……	
	Chiphaso cha mwana		
B6	Kukula kwa matenda a mwana	Chikomokere, Kukomoka Kuvutika kupuma Waopareshini Zina ……..	
B7	Dzina la nthenda yomwe mwana akudwa	…….	

Gawo C: Sikelo yoyezela chiphinjo

Izi ndi zinthu zomwe zikufotokoza za malo omwe ana odwalakika kwambiri amagonekedwa. Zinthuzi zimabweretsa chiphinjo kwa makolo pomwe akudwazika mwana wawo mumalowa. Chiphonjo ndipomwe kholo lili lamantha, lokhumudwa komanso lomangika. Mukuyenera ku zunguliza nambala yomwe ikusonyeza mulingo wanu chiphinjo pogwiritsa ntchito sikelo ilimusiyi.

C1	Maonekedwe a mwana (zilonda, kusintha kwa mtundu wa khungu, akuoneka ozidzidwa ndi opanda mphamvu	Simunakumanizane nacho ……0 Simunaphinjike ……....1 Munaphinjika pang'ono…….....2 Munaphinjika mwasaizi…….....3 Munaphinjika kwambiri…….....4 Munaphinjika kwanbiri zedi…..5	
C2	Phokoso la mashini oyesera mwana, kumva phokoso losayembekezera.	Simunakumanizane nacho ……0 Simunaphinjike ……....1 Munaphinjika pang'ono…….....2 Munaphinjika mwasaizi…….....3 Munaphinjika kwambiri…….....4 Munaphinjika kwanbiri zedi…..5	
C3	Zochitika papena ma opaleshoni ochitika pa mwana (ma singano, machubu, chilonda cha opaleshoni)	Simunakumanizane nacho ……0 Simunaphinjike ……....1 Munaphinjika pang'ono…….....2 Munaphinjika mwasaizi…….....3 Munaphinjika kwambiri…….....4 Munaphinjika kwanbiri zedi…..5	
C4	Osamuona mwana moyenelera, kukhala ndi mwana wanu, kumusamalira komanso kumugwira ndikumukumbatira)	Simunakumanizane nacho ……0 Simunaphinjike ……....1 Munaphinjika pang'ono…….....2 Munaphinjika mwasaizi…….....3 Munaphinjika kwambiri…….....4 Munaphinjika kwanbiri zedi…..5	
C5	Kuona mwana akulira, obalalika, akumva kupweteka, asakuyakhula, okhumudwa, okwiya, otakomoka.	Simunakumanizane nacho ……0 Simunaphinjike ……....1 Munaphinjika pang'ono…….....2 Munaphinjika mwasaizi…….....3 Munaphinjika kwambiri…….....4 Munaphinjika kwanbiri zedi…..5	
C6	Kuona ma dotolo ndi ndi anamwino mu khalidwe losayenera (kuseka, kuyankhula mofuula, kusakudziwisani maina awo)	Simunakumanizane nacho ……0 Simunaphinjike ……....1 Munaphinjika pang'ono…….....2 Munaphinjika mwasaizi…….....3 Munaphinjika kwambiri…….....4 Munaphinjika kwanbiri zedi…..5	
C7	Mavuto kukambirana ndi madotolo or anamwino (akufotokoza zinthu zomwe simukumva, akukufotokozerani zinthu zosiyana, kufotokoza zothu pang'ono kapena mwansangansanga, kufotokoza pogwirotsa ntchito mawu achipatala)	Simunakumanizane nacho ……0 Simunaphinjike ……....1 Munaphinjika pang'ono…….....2 Munaphinjika mwasaizi…….....3 Munaphinjika kwambiri…….....4 Munaphinjika kwanbiri zedi…..5	