

**EXPERIENCES OF CAREGIVERS ON INVOLVEMENT IN  
CHILDREN'S CARE AT MERCY JAMES PAEDIATRIC INTENSIVE CARE  
UNIT IN BLANTYRE, MALAWI**

**MSC. (CHILD HEALTH NURSING) THESIS**

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**APRIL, 2020**



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Submitted to the Department of Child Health, Faculty of Nursing, in Partial  
Fulfilment of the Requirement for the Award of Master of Science in Child Health  
Nursing

**University Of Malawi  
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**April 2020**

### **Declaration**

I, Grace Chasweka, hereby declare that this thesis entitled experiences of caregivers on involvement in children's care at Mercy James Paediatric Intensive Care Unit is entirely my work. This thesis has not been presented for any award at any University within or outside Africa. All the sources of information quoted and cited in the thesis have been acknowledged and added to the list of references.

**Grace Chasweka**

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**Full name**

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**Signature**

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**Date**

## **Certificate of Approval**

The undersigned approve that this thesis represents the student's own work and has not been presented anywhere else in or outside Africa.

Signature \_\_\_\_\_ Date \_\_\_\_\_

Mrs. Maureen Daisy Majamanda

**Main supervisor**

Signature \_\_\_\_\_ Date \_\_\_\_\_

Mrs. Annie Namathanga

**Co- supervisor**

## **Dedication**

The thesis is dedicated to all caregivers with critically ill children who were admitted at Mercy James Paediatric Intensive Care Unit for willingly sharing with me their experiences.

## **Acknowledgements**

I give thanks to the Lord for seeing me through my studies in Master of Science in Child Health Nursing, my entire research period and during the write up of this thesis. My vote of thanks should go to the following for helping me in various ways:

- My husband, Robert and our children; Favour and Faith for their support during my studies and Judith, our daughter in the Lord, for her support.
- ELMA foundation through Kamuzu College of Nursing for sponsoring my studies.
- Mrs. Maureen Daisy Majamanda and Mrs. Annie Namathanga, my research supervisors for their untiring support, guidance, contributions and encouragement.
- Pastor Aubrey for his encouragement during my studies.
- Management and staff of Queen Elizabeth Central Hospital (QECH) and Mercy James PICU for allowing me to conduct this study at their institution.

## **Abstract**

A child's illness and admission in hospital is stressful and negatively affects the child, caregivers and the family. The stress is further exacerbated when a child is critically ill and has been admitted in an Intensive Care Unit. The effects can however be reduced when caregivers and families of the sick children are present and involved in the care of their hospitalized children. This practice is known as Family Centred Care (FCC) and it advocates that families should be involved in the care of their children. This was a descriptive study that used qualitative method to explore experiences of caregivers on their involvement in care at MJ PICU in Blantyre, Malawi. Data was collected from a purposive sample of ten caregivers who had been discharged from the PICU through in-depth interviews using a semi- structured interview guide. Qualitative data was analyzed using content analysis. The predetermined themes used were: caregivers' experiences on their presence in PICU, information sharing by health workers to caregivers, participation in decision making and involvement in care activities. The study found several gaps as far as involvement of caregivers in the care of their children at MJ PICU is concerned. The information given to caregivers regarding their children's care in the PICU was inadequate and was not standardized for caregivers to understand and adequately participate in their children's care. Nurses and doctors were both found to have provided the information although ironically caregivers were unable to differentiate the two. The information was given verbally and in a language that the caregivers were able to understand. Caregivers were not adequately involved in decision making regarding their children's care but were however involved in the physical care of their children. As such, it is recommended that specific interventions

be developed to promote involvement of caregivers when they have been admitted with their children at MJ PICU.

## Table of Contents

Declaration .....	i
Certificate of Approval .....	ii
Dedication .....	iii
Acknowledgements.....	iv
Abstract .....	v
List of Abbreviations .....	xii
Operational Definitions.....	xiii
CHAPTER 1 .....	1
Introduction and Background .....	1
Introduction.....	1
Background .....	3
Problem statement.....	9
Objectives of the study.....	10
Broad objective .....	10
Specific objectives .....	10
Significance of the study.....	11
CHAPTER 2 .....	12
Literature Review.....	12
Introduction.....	12
Experiences on caregivers' presence in the PICU .....	13

Caregivers' Participation in Decision Making in the PICU.....	18
Caregivers' Involvement in Care Activities in the PICU .....	21
Conclusion .....	23
CHAPTER 3 .....	24
Methodology .....	24
Introduction.....	24
Study method and design .....	24
Study setting.....	25
Study population .....	25
Sample size .....	25
Sampling method .....	26
Inclusion and exclusion criteria .....	26
Data collection instrument .....	27
Pre-test Interviews .....	27
Recruitment of participants and data collection process.....	28
Data management.....	28
Data analysis .....	29
Trustworthiness of the Data .....	30
Credibility .....	30
Transferability.....	30
Dependability .....	31

Confirmability.....	31
Ethical Consideration.....	31
Dissemination of Study Results.....	32
Conclusion.....	33
CHAPTER 4.....	34
Presentation of Study Findings.....	34
Introduction.....	34
Demographic characteristics of Participants.....	34
Qualitative Findings.....	38
Caregivers’ Experiences on Presence in the PICU.....	40
Information Given to Caregivers about PICU.....	41
Participation in Decision Making.....	43
Involvement in Care Activities.....	46
Chapter summary.....	48
CHAPTER 5.....	50
Discussion of Study Findings.....	50
Introduction.....	50
Demographic Data.....	50
Age of the caregivers.....	50
Gender of Caregivers and Their Relationship with Children.....	51
Experiences of Caregivers’ Presence in PICU.....	51

Information given to caregivers .....	53
Participation in decision making.....	56
Involvement in Care Activities .....	60
Conclusion of the study .....	63
Recommendations.....	63
Practice.....	63
Management.....	64
Policy .....	65
Areas for Further Research .....	65
Study Limitations.....	66
References.....	67
Appendices.....	80
Appendix 1A: Informed Consent Form (English version) .....	80
Appendix 1B: Informed Consent Form (Chichewa).....	88
Appendix 2A: In depth interview guide: Question for Caregivers .....	97
Appendix 2B: In depth interview guide: Question for Caregivers (Chichewa ..... version)	99
Appendix 3: Permission Letter to Conduct Research at QECH .....	102
Appendix 4: Permission Letter to Conduct Research at Mercy James .....	103
Appendix 5: Permission Letter to Conduct Research at QECH in Paediatrics Department.....	104

Appendix 6: Approval Certificate from college of Medicine Research Ethics  
Committee (COMREC) ..... 106

### **List of Abbreviations**

COMREC	:College of Medicine Research and Ethics Committee
HDU	: High Dependence Unit
FCC	:Family Centred Care
ICU	: Intensive Care Unit
IPFCC	: Institute for Patient and Family Centred Care
KCN	: Kamuzu College of Nursing
MJ	: Mercy James
PICU	: Paediatric Intensive Care Unit
QECH	: Queen Elizabeth Central Hospital

### **Operational Definitions**

Caregiver:	Any family member taking care of a child who contributes to his/her upbringing as well as physical, psychological and financial support.
Caregiver involvement:	The act of allowing caregivers to participate in care of their hospitalized children
Child:	Any person aged zero to eighteen years
Health care worker:	Medical, nursing and allied health personnel working in hospital

## **CHAPTER 1**

### **Introduction and Background**

#### **Introduction**

Hospitalization of a child brings stress to the child, parents and family. The stress is further increased when the child's condition is critical and requires admission to the Intensive Care Unit (ICU), (Foster et al., 2015; Khajeh et al., 2017). This is due to the fact that the ICU is a unit that admits critically ill patients who require close monitoring, (Alves et al., 2013). This makes the ICU to be different from the general wards, and it can therefore, be a new and strange environment for caregivers and often scary (Majdalani et al., 2014). The stress is further exacerbated by the child's condition, the environment, treatments given to the child as well as equipment put on the child (Alves et al., 2013; Foster et al., 2015). Furthermore, ICU admission is often associated with death and caregivers fear that they will be separated from their child (Molina et al., 2009). These factors may instil fear in the caregivers whose children are admitted in the Paediatric Intensive Care Unit (PICU).

Hospitalization of a child also results in parents' loss of power over the child and can have a negative impact on the development of a child as well as the family (Alves et al., 2013; Marques dos Santos et al., 2013). When a child is hospitalized, the child does not continue with activities usually engaged in when at home such as playing and attending school. Likewise, the family members experience disruption in their daily routines such as

jobs and businesses in order to take care of the hospitalized child. However, availability of a family member to support a child can neutralize the effects of hospitalization. This in turn leads to facilitating provision of holistic care hence improving the child's adaptation to hospital environment (Alves et al., 2013; Molina et al., 2009). Furthermore, there is a lot of evidence that has shown that most parents wish to stay with their hospitalized children in the PICU even if they do not do anything, they would just want to be there for their child (Alves et al., 2013; Ames et al., 2011; Engström, Dicksson, & Contreras, 2014; Marques dos Santos et al., 2013). Besides, many caregivers who desire to stay want to be involved in the care of their hospitalised child (de Melo, Ferreira, de Lima, & de Mello, 2014; Söderbäck & Christensson, 2008).

It is against this background that the practice of Family Centred Care (FCC) has been introduced and adopted by healthcare institutions in many countries (Macdonald et al., 2012). The Institute for Patient and Family Centred Care (IPFCC) (2016) defined FCC as “an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families, and health care professionals.” Family Centred Care recognises the family as an important factor in the life of a child (Harris, 2014), and therefore advocates that caregivers should not only be allowed to stay with their hospitalized children but they also need to be included in the decision making and participate in the actual care of their children (Uniacke et al., 2018). Caregivers can therefore take part in care activities of the child such as bathing, feeding and administering drugs orally or through the nasal gastric tube.

Family centred care has been adopted in America and other developed countries as a standard in paediatric healthcare (Harrison, 2010; Kuo et al., 2012) while in Africa, some

countries such as South Africa and Kenya have also introduced the approach in paediatric care though with low implementation (Makworo, Bwibo, & Omoni, 2016; Roets et al., 2012). Similarly, FCC is not fully implemented in Malawi (Majamanda et al., 2015; Shields et al., 2018).

Mercy James Paediatric Intensive Care Unit (MJ PICU) is the first paediatric ICU in Malawi that incorporates the component of family centred care whereby caregivers of children are allowed to be present on the bedside throughout the time of admission of the children in the PICU. However, being a relatively new concept and unit in Malawi, the extent to which these caregivers are involved in decision making, care provision and information sharing by health care workers has not been explored hence the need for this study.

## **Background**

History of FCC dates back to the eighteen hundreds when sick hospitalized children were solely looked after by the health care workers and parents' visits were prohibited or in other cases, very strict (Harrison, 2010 & Kuo et al., 2012). This was until in 1950's when some psychologists established that a child who has been separated from his/her mother can have developmental, psychological and emotional consequences (Harrison, 2010). Psychologically and emotionally children can have sleep problems, anxiety and irritability, whilst developmentally children tend to play less (van der Horst & van der Veer, 2009) and this may affect their attainment of developmental milestones. In the long term, it may affect their self-esteem and loss of identity (Rokach, 2016).

Likewise, PICU's were restricted places to parents and family members with policies which allowed brief visits to children. This was due to fears of infection transmission, violation of privacy and confidentiality, psychological trauma to patients, parents and siblings and lack of space to accommodate family members (Harrison, 2010; Kuo et al., 2012). However, evidence has consistently shown that families of critically ill patients desire information, assurance from staff, and want to be close to their sick children and family member (Alves et al., 2013). This results in reduction in parental anxiety, less duration of hospital stay and decreased tension between caregivers and health care workers (Ames et al., 2011a).

Paediatric practice has therefore, moved from the paternalistic model where health care workers were regarded as experts of children to family centred care where the caregivers are regarded as partners in planning and provision of care to sick children (Macdonald et al., 2012). This change has resulted in the paediatric general and specialty areas including the PICU adopting the approach (Macdonald et al., 2012). Family Centred Care has four core concepts namely; information sharing, dignity and respect, participation and collaboration (Institute for Patient- and Family-Centred Care, 2016).

Information sharing advocates for sharing of complete, timely and unbiased information regarding the patients' health to the caregiver by the health care workers for participation in decision making and care provision (Institute for Patient- and Family-Centred Care, 2016). Sharing of information by health care workers to caregivers is important because it makes the caregivers less anxious, well prepared and instils a feeling of being in charge of their ill children (Richards et al., 2017a). Caregivers in the PICU need

information regarding their child's condition, medications, procedures and basic knowledge on equipment (Dahav & Sjöström-Strand, 2018). Likewise, caregivers should share information regarding the child with health care workers such as past and present medical history, treatment received in the past and response as well as the child's needs (Carnevale et al., 2016). This information would help health care workers in making diagnosis and management decisions.

Dignity and respect entail that health care workers should take into consideration views and choices of families and incorporate families' beliefs and values when planning and giving care to patients (Institute for Patient- and Family-Centred Care, 2016). This is related to the principle of information sharing in that health care workers should not only give information, rather, they should also be able to listen to what caregivers want or feel regarding their child's care so that it becomes a two way mutual process (Khajeh et al., 2017). Caregivers may contribute towards their child's treatment choices or food preferences.

Participation encourages families to take part in decision making and care provision and that they should be given required support to the extent that they want to be involved (Institute for Patient- and Family-Centred Care, 2016). This entails that health care workers need to give an opportunity to caregivers to choose the type and level of their involvement (Foster et al., 2016). Thus, caregivers can choose to be involved in decision making and/or provision of care to their child and should be at liberty to choose the activities that they can participate in comfortably such as feeding, turning the child and oral care.

Collaboration enables patients, families, health care practitioners and health care leaders to work together in planning, implementation, and evaluation of ward and unit policies, facility design, research as well as in the delivery of care (Institute for Patient- and Family-Centred Care, 2016). Caregivers should have a voice when health institutions such as hospitals are planning to establish programs and policies, and in the actual implementation of the same for effective implementation. This can be achieved through consultative meetings with caregivers who have ever been exposed to a specific system, for example, when formulating policies for a PICU, caregivers who have ever been admitted with children in the PICU can be approached to give their input.

New guidelines for FCC in the neonatal, paediatric and adult ICU recommend that caregivers should be allowed to stay with their patient in the ICU and that health care workers need to support and partner with them in any decisions and care regarding their patient (Davidson et al., 2017). Most departments in the child healthcare institutions including the PICU's are utilizing the concept of FCC in the delivery of care to children and their families (Harrison, 2010). However, recent evidence has shown that the principles of caregivers participation and information sharing are not adequately practised in Malawi due to lack of equal powers between health care workers and caregivers (Shields et al., 2018). It is for this reason that this study will focus on these two principles in exploring the caregivers' experiences at Mercy James PICU.

Having a caregiver on the bedside in the PICU has proved to be beneficial to children in such a way that; hospitalized children feel more secure, confident, protected and have improved behaviour (Alves et al., 2013). Allowing caregivers to be on the bedside

of their sick child in the PICU is a key to children's recovery and it is therefore, important to promote this practice. Moreover, there are more benefits to the caregivers when they are allowed to stay in the PICU, involved in decision making and provision of care. Such benefits include; better coping, empowerment after discharge, joy, a sense of security, it relieves them of stress and restores their confidence (Dahav & Sjöström Strand, 2018; Makworo et al., 2016; Alves et al., 2013). Involvement of caregivers is also beneficial to the health care workers because they are assisted by caregivers with basic skills in caring for the children (Makworo et al., 2016). It is therefore, evident that FCC is advantageous to the child, caregivers, families and health care workers and should thus be encouraged in PICU.

For caregivers to ably participate in decision making and care provision of their hospitalized children, it is necessary for them to have the required information regarding their child's condition and care that will determine their ability to competently participate in decisions and care provision (Béranger, Pierron, de Saint Blanquat, Jean, & Chappuy, 2017; Institute for Patient- and Family-Centred Care, 2016). It is therefore, very important that health care workers utilize every opportunity to give the necessary information to the caregivers if they are to be effectively involved in the care of their children.

Studies from the developed world have revealed different views on caregivers' involvement; a study done in the Netherlands on caregivers who had their children admitted in seven PICU's showed mixed reactions on parents participation where some thought decision making should be left to the health care workers whilst others desired to be involved in the decision making and care of their children (Latour et al., 2011).

Similarly, a study conducted in Brazil found mixed results among caregivers as some preferred to be present and involved during procedures in the PICU whilst other caregivers did not (Alves et al., 2013). However, Canadian caregivers desired to be involved and to partner with the health care workers (Macdonald et al., 2012). Similarly, caregivers in Sweden were very happy to be involved in the care of their children and it made them feel important (Dahav & Sjöström Strand, 2018). This suggests that whenever health care workers working in the PICU's intend to involve caregivers, it is crucial to be sensitive to their unique needs.

Evidence from Asia, particularly Lebanon; a study carried out to understand the lived experience of Lebanese parents of children admitted to the PICU in a tertiary hospital in Beirut found that caregivers desired to be informed about the condition of their child and at the same time involved in decision making regarding their child's care (Majdalani et al., 2014). It is therefore necessary to involve those caregivers in the PICU who are eager to participate in decision making in order to boost their morale.

A few studies have been conducted in sub Saharan Africa; South African caregivers who had their children admitted in PICU's in Bloemfontein desired to be involved in the care of their children because it helped them cope emotionally (Roets et al., 2012). Other published studies in the region have focused on involvement of caregivers in the general paediatric wards. One such study conducted in Mozambique showed that caregivers wanted to be involved in care activities of their hospitalized children, however, most of them opted to leave decision making to health care workers (Söderbäck &

Christensson, 2008). This could be attributed to cultural beliefs, literacy levels and economic status of the caregivers that may affect their decision making ability.

Likewise, a study done in Malawi to describe registered nurses' experiences when involving families in the care of hospitalised children in general paediatric wards found that nurses partnered with caregivers in decision making and involved them in order to share responsibilities and for social support (Phiri et al., 2017). Most nurses thought that family involvement is rewarding because it brings variety to the care and the caregivers help covering up the nursing shortage (Phiri et al., 2017). However, there are no published studies on caregivers' involvement in the PICU in Malawi, hence the need to conduct this study at Mercy James ICU.

### **Problem statement**

Families are considered as experts of their child's abilities and needs (Khajeh et al., 2017), and a child's critical illness and admission to a PICU brings a great impact on the family. However, working in partnership with families by allowing them to be with the child on the bedside and participate in decision making and care provision has been found to improve care outcomes not only to the child but also the family and health care workers (Gerritsen et al., 2017). This practice is termed Family Centred Care.

FCC is however, a new concept in Africa and Malawi in particular. MJ PICU is the first ICU in Malawi to incorporate the recommendation of FCC of allowing caregivers to be on the bedside of their children and participate in decision making and care provision (Davidson et al., 2017). Admission of a child in the PICU can however be stressful to the caregivers due to their child's illness, treatment, parental role change, child's appearance

and the environment among other factors (Foster et al, 2016). Evidence has shown that these factors can affect parents' ability to comprehend information, make informed decisions, and function effectively as regards their children's care (Foster et al, 2016).

Furthermore, the principles of caregivers participation and information sharing have been found not to be adequately practiced in Malawi (Shields et al., 2018). Although MJ PICU is one of the leading departments in incorporating FCC in the routine care of hospitalised children in Malawi, the extent to which this concept is adopted and implemented is still unknown. Particularly, caregivers' experiences regarding their participation and information sharing practices by health care workers at Mercy James PICU is still unexplored. Considering the fact that FCC is beneficial to caregivers, the sick child and health care workers, it is therefore, necessary to explore the experiences of caregivers in these areas in order to understand the strengths and challenges they face whilst in the PICU. This may help to improve the care that is given to the children and their families at the unit.

## **Objectives of the study**

### **Broad objective**

To explore experiences of caregivers on their involvement in children's care at Mercy James Paediatric Intensive Care unit.

### **Specific objectives**

1. To understand the experiences on caregivers' presence in the PICU.
2. To describe the caregivers' perception of information sharing practices by health care workers in the PICU.

3. To determine caregivers' participation in decision making regarding their children's care whilst in the PICU.
4. To describe the nature of care activities that caregivers participate in at the PICU.

### **Significance of the study**

Caregivers of children admitted with critical illness have a big role in the management of children admitted at PICU. Understanding the experiences of these caregivers is therefore important for the improvement of nursing and medical care to the patients admitted in the PICU and enhancing the relationship between the caregivers and health care workers. Malawi does not have policies to guide the practice of FCC (Shields et al., 2018), the findings of the study may help to come up with evidence that can be incorporated in the policies and management guidelines of FCC at the PICU thereby establishing FCC profile for Malawi.

The study findings will inform the curriculum of nursing students and other health care workers with interest to provide comprehensive care to children and their families at the PICU. It will also highlight the areas to include in caregivers' education before, during and upon discharge from the PICU. The study has also come up with areas for further research since it is relatively a new concept in the country.

## **CHAPTER 2**

### **Literature Review**

#### **Introduction**

Literature review refers to a critical analysis of available evidence on the subject under study (Cronin et al., 2008). Literature review was carried out with an aim to unveil the available information on experiences of caregivers on the involvement in their child's care when admitted in the PICU and this helped to come up with a basis for the current study (Cronin et al., 2008).

This chapter presents a review of studies done on involvement of caregivers in the PICU globally, regionally and nationally. Literature from nursing journals and full-text research reports were reviewed. The review of literature has been organized in accordance with the study objectives. The review included peer reviewed articles that were published in English from a period of 2008 to 2018 for up to date information.

Literature search was done through various academic data bases and search engines (PUBMED, EBSCO, JSTOR, HINARI and Google scholar) in order to review what is known about experiences of caregivers on involvement in their child's care in the PICU. The search terms that were used for the literature search were; caregivers OR parents OR guardians AND involvement OR participation AND decision making AND information giving by health care workers AND PICU OR critical care AND care activities OR actual

care. In addition, the researcher reviewed literature from the internet such as national and international reports that were related to the topic.

### **Experiences on caregivers' presence in the PICU**

Caregivers evidently desire to be with their hospitalized children on the bedside even when they are admitted in the PICU (Ames et al., 2011 & Alves et al., 2013). FCC advocates that caregivers should be allowed to visit their children and at any time of the day and stay on their child's bedside (Uniacke et al., 2018). Moreover, providing environments where caregivers can be present and unrestricted visitation forms part of the basic form of respect and dignity that every caregivers should be accorded whilst their child is admitted in the PICU (Hill et al., 2018).

Several studies have been done to ascertain caregivers' experiences on their availability and presence in the PICU. A study by Ames et al (2011) whose purpose was to explore parents' perception of the parental role in the PICU showed that caregivers just wanted to be there for their sick children even if they did not do anything. This concurs with Foster et al., (2013) who through a synthesis of qualitative studies on FCC concepts in PICU found that caregivers described parental presence as being physically present and close to their children and being able to hold and touch the children. Interestingly, some caregivers wanted to stay with their children in hospital for fear of neglect by health care workers (Foster et al., 2013).

Likewise, a study conducted to understand how the families perceive their presence in the ICU and the acceptance of their presence by health professionals in Paran, Brazil showed that caregivers were glad to be present with their children and thought that this

contributed to their children's recovery and it provided opportunities to tighten family ties (Molina et al., 2009). However, some caregivers in the same study thought that their presence at the bedside could be harmful because they may not be emotionally well balanced hence contributing negatively to their children's recovery (Molina et al., 2009). Owing to the various and diverse evidence on caregivers' presence at the bedside of sick children in the PICU, it is therefore necessary to explore how caregivers view their presence at MJ PICU.

### **Caregivers' Perception of Information Sharing Practices by Health care Workers in the PICU**

Communication refers to exchange of information, thoughts and feelings (Kourkouta & Papathanasiou, 2014). Information sharing by health care workers to caregivers regarding their child care is very crucial for successful implementation of FCC in the hospital including the PICU (Foster et al., 2013). Health care workers need to share full and unbiased information to caregivers about their child. This facilitates better decision making and participation by the caregivers and it therefore acts as a prerequisite for caregivers to participate in decision making and care (Ames et al., 2011b; Khajeh, Dehghan Nayeri, Bahramnezhad, & Sadat Hoseini, 2017; Gerritsen, Hartog, & Curtis, 2017). Besides, parents of sick and hospitalized children are always seeking information regarding their child's condition, care and prognosis whilst in hospital (Ames et al., 2011b; Richards et al., 2017a). Therefore, caregivers in the PICU need information regarding their child's condition, medications, procedures and basic knowledge on equipment and monitors (Dahav & Sjöström-Strand, 2018). Empowering caregivers with information can also help

to improve patient care and enhance better relationships between health care workers and caregivers ( Coyne, Amory, Gibson, & Kiernan, 2016; Hoffman et al., 2012). Other benefits of sharing information include; it makes the caregivers less anxious, well prepared and instils a feeling of being in charge of their child (Roets et al., 2012; Richards, Starks, O'Connor, &Doorenbos, 2017).

The quality of communication between health care providers and caregivers determines patient outcomes (Richards et al, 2017). Caregivers' satisfaction of care provided to their critically ill child has also been related to their communication experience with the health care workers (Richards et al, 2017). It is therefore evident that information sharing by health care workers is very beneficial and therapeutic and health care workers should make deliberate efforts to share the necessary information with caregivers in the PICU.

The PICU can however be stressful to the caregivers due to their child's illness, treatment, parental role change, child's appearance and the environment among other factors. Evidence has shown that these factors can affect parents' ability to comprehend information, make informed decisions, and function effectively regarding their child's care (Abela et al., 2020; Foster et al, 2016; Foster et al., 2019). A study conducted in one of the hospitals in Sweden aimed at describing parents' experiences of having their child admitted to a PICU found that caregivers in the PICU require a wide range of information regarding their child's care. Thus, caregivers appreciated information on some basic knowledge on equipment, monitors, tubes connected to their child, medications and procedures. This helped them to familiarise with the environment and activities and thereby relieving stress

(Dahav & Sjöström-Strand, 2018). Similarly, a study conducted in one of the Iranian hospitals aimed at defining the culture of FCC in PICU showed that caregivers desired to be informed about their child's condition and treatment (Vasli et al., 2015). Furthermore, caregivers in the PICU's of Canada and France wanted information on any complications that may come as a result of the critical illness of their child. However, they wanted such information with a sense of hope not with hopelessness whilst at the same time not giving them (caregivers) false hopes (Carnivale et al, 2016).

Swedish caregivers preferred to be given adequate information at a time and not too much at once which became too difficult to comprehend (Dahav & Sjöström-Strand, 2018). Likewise a study conducted in United Kingdom by Meert et al., (2008) which aimed at describing parents' perceptions of their conversations with physicians regarding their child's terminal illness and death in the PICU, reported that caregivers wanted to be given information at a rate that they could understand before they are given more information. However, other research evidence from Iran by Vasli et al (2015) and a review by Foster et al (2013) showed that some caregivers bemoaned to have been given either none or inadequate information, contradicting information and in other cases information was withheld and was misleading. Health care workers may act in this way to protect caregivers from distressing information. However, this can lead to the caregivers being more anxious, feeling powerless and having reduced trust in the health care workers (Richards et al., 2017a). Health care workers therefore need to be sensitive to the unique information needs of caregivers and manage the information sharing appropriately.

Regarding the appropriateness of the communication; evidence has revealed that health care workers tend to use inappropriate language when communicating with caregivers (Richards et al., 2017a). In a study conducted in Brazil by Alves et al., (2013), which intended to describe the opinion of family members of children admitted to the PICU showed that the caregivers were frightened with health care workers' use of technical language. Similarly, a study carried out in Lebanon with the aim of exploring the lived experience of Lebanese parents who had a child admitted to the PICU revealed that caregivers bemoaned use of medical jargons and English language (Majdalani, Doumit, & Rahi, 2014). Likewise, findings from a study which aimed at exploring parents' perception of their parental role in a PICU in Canada showed that despite caregivers learning some medical terms, they preferred to be communicated to in simple words (Ames et al., 2011). These findings are consistent with those of an integrative review of 33 research articles from different PICU's globally which revealed that most health care workers used medical and complex terminology difficult for caregivers to understand (Richards et al., 2017a). Instead, caregivers want to be given information in their local or simple language which is clear and easy to understand (Ames et al., 2011; Carnevale et al., 2016; Majdalani, Doumit, & Rahi, 2014). These findings suggest that health care workers need to refrain from using jargon when communicating with caregivers and instead come to the level of the caregivers if the information sharing with caregivers is to be effective.

Caregivers in one of the PICU's in Iran expressed concern over authoritative nature of information giving by other health care workers which implied that health care workers are superior than the caregivers (Vasli et al., 2015). This can make caregivers to just agree

to the communication without understanding it and may affect the decision making as regards the child's care.

Mozambican caregivers from general paediatric wards lacked information on the condition and management of their child which led to the feeling of neglect and posed a challenge for them to participate in the care of their hospitalized children (Söderbäck & Christensson, 2008). Despite having a good number of evidence regarding information sharing in the PICU in the western countries, African region and Malawi have a few published studies on the area.

Studies focussing on communication between health care workers and caregivers reveal that caregivers in Malawi's general adult and paediatric wards bemoaned poor communication and had challenges in getting information from health care workers. Hoffman et al., (2012), suggests that this could probably be due to illiteracy which made it difficult for them to understand the communication. Although the majority of Malawians caregivers (70%) are indeed illiterate (Hoffman et al., 2012), it is likely that the health care workers were using medical or technical language as evidence seen from studies done in other countries hence making the caregivers not to understand the information. It is therefore necessary to explore the experiences of caregivers with regard to information sharing in a Malawian setting and precisely in the PICU.

### **Caregivers' Participation in Decision Making in the PICU**

FCC advocates for shared decision making between health care providers and caregivers and that the health care providers need to support the caregivers at the level of participation that they want (Institute for Patient- and Family-Centred Care, 2016). This

means caregivers may have different needs in their participation in decision making and health care workers need to tailor the individual needs when involving them in decision making. Gooding et al., (2011), argue that giving information alone is not enough, caregivers need to be given information in their context and be informed of the consequences of the decision and this is what entails shared decision making.

However, it is not easy for both health care workers and caregivers to make decisions regarding a hospitalized child and especially in the PICU due to the uncertainty of the outcome (Carnevale et al., 2016). Health care workers may leave out the caregivers in decision making with the mentality that the caregivers do not have the expert knowledge to make complex decisions and to protect the caregivers from guilt in the event that the child dies (Richards et al., 2017a).

Several studies have been done in developing countries on involvement of caregivers in decision making of their child's care whilst in hospital, a few of these have been done in Africa. For example, a study by Majdalani et al. (2014) whose purpose was to explore the lived experience of parents of children admitted to the paediatric intensive care unit in Lebanon found that caregivers wished to be part of decision making process regarding their child's care and to be regarded as partners in decision making. This is contrary to findings in Mozambique where most caregivers of children from general and emergency paediatric wards did not want to be involved in decision making concerning their child's treatment (Söderbäck & Christensson, 2008). Caregivers, instead preferred that health care workers should make the decisions because they have expertise (Söderbäck & Christensson, 2008). Similarly, in a study by Carnevale et al. (2006), most caregivers

preferred health care workers to make decisions regarding life support of their children because of the same reason (Foster et al., 2013). Likewise, caregivers of children in a Dutch PICU wanted to be involved in decision making of basic issues such as food choices and not those regarding treatment (Latour et al., 2011). This could be attributed to the beliefs that health care workers are the ones to make complex decisions such as treatment because they have the necessary knowledge unlike caregivers (Richards et al., 2017a). Nevertheless, in the event that health care workers have made a decision, caregivers would want to be informed about the decision (Richards et al., 2017a).

Another way to make caregivers participate in decision making is their involvement in family centred ward rounds. Family centred ward round is a platform where a multidisciplinary member team discusses care of the patient at the bedside with the participation of the patient and family members (Rea et al., 2018). These rounds help caregivers to understand the condition of their child and share their perception of how the child is doing (Gooding et al., 2011). Caregivers who are involved in decision making during rounds feel that their expectations are met and this may help to reduce misunderstandings between health professionals and caregivers (Curtis et al., 2016). Furthermore, this makes the caregivers to feel valuable and as vital members of the health care team (Curtis et al., 2016). Other benefits that can be realized when caregivers are involved in family Centred rounds are that caregivers feel to be respected by the health care workers, there is increased team work between health care workers and caregivers and some information that was not previously known from the family can be generated (Kuo et al., 2012; Hill et al., 2018). Noting these benefits, it is therefore necessary for health

care workers to always involve caregivers in decision making of their child's care in the PICU as well as other paediatric wards.

### **Caregivers' Involvement in Care Activities in the PICU**

Involvement does not only entail shared decision making between health care workers and caregivers. It also includes involving caregivers in the physical care of their child in the PICU (Ames et al., 2011). Involvement of caregivers in the physical care of the hospitalised child in general is very crucial and can lead to reduction of stress and anxiety in the caregivers (Dahav & Sjöström-Strand, 2018; Roets et al., 2012; Shields et al., 2018). It promotes physical well-being of the caregivers (Ames et al., 2011b) and instils a sense of being valuable to their child's recovery (Roets et al., 2012). Furthermore, involving caregivers of neonates in care can help in facilitating bonding between the baby and the mother as well as the family (Cockroft, 2012).

However, attachment of many tubes and equipment on the child, the child's appearance as well as having many health care workers around the child in the PICU can deter caregivers from getting involved in the care of their child (Dahav & Sjöström-Strand, 2018). It is maybe therefore relatively easy for a caregiver in a general paediatric ward to get involved as compared to a caregiver with a child admitted in a highly specialized area such as the PICU. Furthermore, some health care workers tend to prevent or allow little participation of caregivers despite the caregivers' desire to participate in care because they think that it is their job to take care of the sick children (Vasli et al., 2015). Some health care workers think that the caregivers will dislodge or disconnect the tubes/ equipment. According to Dahav & Sjöström-Strand (2018), Swedish caregivers who had their child in

a PICU felt the closeness with their child when they were involved in care activities such as changing diapers and feeding their child. These findings were similar to Canadian caregivers with infants, whilst those who had older children helped with feeding, weighing, lifting and turning their children (Ames et al., 2011b).

In Mozambique, majority caregivers of children from general paediatric and emergency wards regarded participating in care activities such as feeding, bathing the child and changing diapers, clothes as well as comforting the child as rewarding. However, only a few wanted to be involved in advanced care activities such as managing wounds (Söderbäck & Christensson, 2008). Likewise a metasynthesis of qualitative studies on FCC within critical care settings showed that most caregivers desired to participate in the non-medical care activities of their children ( Foster et al., 2013). Health care workers can therefore involve caregivers in activities which caregivers already do at home such as activities of living and not technical activities like wound dressing.

Caregivers are a necessity in Malawian general adult and paediatric hospitals due to critical staff shortages and they play a major role in helping out with care activities such as bathing and toileting (Hoffman et al., 2012). In Malawi it is not unusual for a patient to have one or more caregivers by the bedside to assist with various care activities. This can be attributed to the critical shortage of health care workers in the country which makes the health care workers to delegate other nontechnical roles to caregivers so that they concentrate on more professional roles thereby reducing workload (Hoffman et al., 2012). Additionally, Malawi like other African countries believe in having extended families and

therefore when a family member is admitted in hospital, every member of the larger family is affected and is automatically involved in caring for the sick relation.

## **Conclusion**

Involving caregivers of children admitted to the PICU by giving them information, allows them to participate in decision making and physical care of their children is evidently beneficial to both the caregivers and the health care workers. However, many times the expectations of the caregivers regarding their involvement are not met.

There is a lot of evidence on involvement of caregivers in the hospitals and especially the PICU's globally but similar evidence from Africa and Malawi is scarce. One of the published studies conducted in Malawi by (Phiri et al., 2017) focused on involvement of caregivers focussing on health care workers, specifically nurses, and was conducted in general paediatric wards whilst the current study will focus on caregivers in a specialised area, the MJ PICU.

## **CHAPTER 3**

### **Methodology**

#### **Introduction**

This chapter discusses the details of the study methods; design, setting, population, sample size and sampling methods, recruitment criteria, data collection procedure, data management, analysis and trustworthiness of the data. Bradshaw, Atkinson, & Doody, (2017) state that research methods are “tools, techniques, or procedures used to gather and interpret evidence.”

#### **Study method and design**

The study utilized the qualitative method of research and a descriptive design. This is a basic qualitative research design that is utilised in ‘studies that seek to discover and understand a phenomenon, a process, or the perspectives and worldviews of the people involved’ (Bradshaw et al., 2017). This design was used because the researcher wanted to gain insights from informants’ experiences (Kim, Sefcik, &Bradway, 2017). Furthermore, the study was aiming at getting a rich description of an experience (Neergaard et al., 2009). This design is also suited for health research studies because it provides factual responses about how people feel about a phenomena (Colorafi & Evans, 2016) hence making it an appropriate design for this study.

### **Study setting**

The study was conducted at Mercy James Paediatric Intensive Care Unit (MJ PICU) at Queen Elizabeth Central Hospital (QECH) in Blantyre, Malawi. MJ PICU admits children that require critical care with medical or surgical conditions. It is currently the only PICU in Malawi and it is a six- bedded unit. Nurse patient ratio is one to one which is ideal for implementation of FCC in the PICU (Shields et al., 2018). The unit admits children from various neonatal and paediatric wards of QECH as well as referrals from other districts. When discharged from the unit, the children are taken to the High Dependency Units (HDU) or directly to their respective wards. The wards are; Mercy James Surgical Ward, Paediatric Special Care Ward, Chatinkha Nursery, Paediatric Nursery, Burns Unit and paediatric Oncology. Nurse-patient ratio in the unit is one to one which is ideal for implementation of FCC (Uniacke et al., 2018).

### **Study population**

The study population were caregivers of children who had their children admitted at the MJ PICU for the first time. They were chosen because they had no previous experience that could affect results of this study and had been discharged to the wards (Mercy James Surgical Ward and Paediatric Special Care Ward). These caregivers were the child's mother, father or any primary guardian of the child who was taking care of the child when he/she was admitted in the PICU.

### **Sample size**

Moser &Korstjens (2018), estimated descriptive qualitative studies to have a sample size of 15 to 20 participants. It is for this reason that this study had 15 participants

as its sample size considering an average number of discharges per month for the year preceding the study being 17 according to the unit data. Furthermore, evidence from other descriptive qualitative studies have shown that 15 is an adequate sample (Adugbire, Aziato, & Dedey, 2017; Cleveland & Bonugli, 2014; Wu, Thompson, Aroian, McQuaid, & Deatrck, 2016). However, data saturation was reached with 10 participants, before all the 15 interviews. Data saturation refers to the point in qualitative research process when no new information is generated in data analysis and further data collection would yield similar results (Faulkner & Trotter, 2017). It is hoped that the caregivers of the children admitted at the MJ PICU for 72 hours had a considerable amount of experience to be interviewed and reflected their experiences effectively.

### **Sampling method**

Sampling refers to the process of selecting participants that are able to provide rich information of the phenomenon of interest (Moser & Korstjens, 2018). This study utilized purposive sampling method which involves identifying participants that have rich information (Palinkas et al., 2014). This method ensures selection of participants who meet a predetermined criterion which is the admission with a child at MJ PICU. These were identified and asked to participate in the study (Moser & Korstjens, 2018).

### **Inclusion and exclusion criteria**

The inclusion and exclusion criteria identify characteristics of individuals qualifying to be eligible or ineligible for the study population respectively (Garg, 2016). The following was the inclusion criteria for the study;

- Those who were primary caregivers of children admitted at PICU aged 18 years and above
- Caregivers whose children were admitted for 72 hours or more in the PICU.
- Caregivers whose child were discharged alive from the PICU.
- Caregivers that had given consent.

The exclusion criteria included;

- Caregivers aged 18 years and above who were not primary caregivers in the PICU
- Caregivers with children who were admitted for less than 72 hours.
- Caregivers who could not speak English or Chichewa.
- Caregivers that had not given consent.

### **Data collection instrument**

A semi-structured interview guide was used by the researcher to collect data. This type of instrument was chosen because it contains key questions and/or topics that help to clarify the areas being explored and guide the interviewee to give more details on their experiences (Gill, Stewart, Treasure, & Chadwick, 2008; Jamshed, 2014). The interview guide derived the key questions from the specific objectives of the study and have been used in one study (Latour et al., 2011). The interview guide had two sections with a total of 3 questions with other follow up questions.

### **Pre-test Interviews**

The interview guide for data collection was pretested at the same setting, MJ PICU since there is no other similar setting in Malawi. However, the participants who were

interviewed during the pretesting were not part of the main study hence there was no data contamination. This involved a total of two in depth interviews which was ten percent of the sample size. This was to assess the instrument for clarity of questions and to evaluate the content of the interview. The pre-test study improves the study project since it assesses its feasibility, improves clarity, eradicates problems and refines methodology (Polit & Beck, 2010). This also helped the researcher to become familiar with the questions and also to identify any gaps in the tool that were addressed before data collection.

### **Recruitment of participants and data collection process**

Participants were recruited upon discharged from the PICU to the ward. The nurse in charge of the unit identified caregivers and children that had been transferred from MJ PICU and informed the researcher who visited the ward to explain about the research study, get consent and plan day and time for the interview.

The participants were given detailed written information about the study and the consent form to read or read to if they could not read, understand and sign or put a thumb print to indicate their willingness to participate.

All participants who met the inclusion criteria were interviewed. A private room in the ward was used for interviews and all interviews were done in Chichewa. The interviews were audio recorded and lasted a maximum of 45 minutes, so that the caregivers could go and do other activities as well as rest.

### **Data management**

Confidentiality was ensured by keeping files as well as the recorder locked in a safe place and a computer having the information had a secret password to prevent other people

other than the researchers access the data. The tapes and notes taken during the interviews will be deleted in the computers after five years of data collection.

### **Data analysis**

Content analysis is regarded as a primary strategy for data analysis in qualitative descriptive study designs (Colorafi & Evans, 2016; Kim et al., 2017; Moser & Korstjens, 2018). Content analysis is a technique used in qualitative research approach to make replicable and valid inferences from data collected to their own meaning (Bengtsson, 2016). The recorded interviews were transcribed verbatim and analysed using a qualitative content analysis approach.

The analysis utilized the following six steps in data analysis using content analysis approach according to Neergard et al, (2009);

1. Data was coded from notes of interviews.
2. The insights and reflections on the data were then recorded.
3. Thereafter data was sorted in order to identify similar phrases, patterns, themes, sequences and important features.
4. Then the researchers looked for commonalities and differences among the data.
5. The researcher then gradually decided on generalizations from the data.
6. These generalizations were then finally examined in light of existing knowledge.

## **Trustworthiness of the Data**

These are strategies that are put in place to ensure good quality qualitative studies (Cope, 2014). The study utilized four criteria known as credibility, dependability, confirmability, and transferability as developed by Lincoln and Guba (1985) to ensure trustworthiness of this study ( Anney, 2014; Mabuza et al 2014).

### **Credibility**

This refers to the confidence that can be placed in research findings as to whether they are reflecting a true picture of the participants' views and how they have been presented and interpreted by the researcher ( Anney, 2014; Cope, 2014).

To ensure credibility the researchers did the following; Member-checking during data collection was done where, participants were asked to verify if the words used by the researcher accurately captured what they intended to say and detailed field notes of the interviews were kept by the researcher (Cope, 2014;Wu et al., 2016).

### **Transferability**

This is how this study ensured that its results will be applied to other settings with other respondents (Anney, 2014). Thick description, thus rich and extensive set of details on the research process has been provided in the report and purposive sampling, which focuses on selection of key informants who are knowledgeable was used (Colorafi & Evans, 2016). Furthermore, characteristics of the participants have been fully described and reported so that comparisons with other groups can be made (Colorafi & Evans, 2016;Wu et al., 2016).

### **Dependability**

This is simply the ability to make the findings to be consistent over time such that similar results would be obtained if the study was repeated after some time (Cope, 2014; Mabuza et al., 2014). To ensure dependability, the following measures were taken;

- An audit trail has been kept, thus raw data, interview notes and any other documents used to collect data from the field were kept in order to validate data (Cope, 2014).
- The researcher ensured consistency in data collection for all participants by using the same researcher to conduct all interviews and a semi structured interview guide was used (Colorafi & Evans, 2016).
- Methods have been discussed in detail so that another researcher could replicate the study in a process known as step by step audit trail (Mabuza et al., 2014).

### **Confirmability**

This refers to the ability of the researcher to demonstrate that the findings of the study reflects participants views and responses and not the researchers' biases (Cope, 2014). Participants' quotes have been indicated in the findings and all study data have been kept in order to make it available to collaborators for evaluation.

### **Ethical Consideration**

Ethical approval to conduct this study was obtained from the College of Medicine Research and Ethics Committee (COMREC) with approval number: P.04/19/2653. Permission from QECH hospital Director, MJ administrator and head of Paediatric department through letters was sought.

Voluntary participation was observed and participants were informed of this during consenting process and throughout interviews. Informed consent was obtained from the participants involved and this was obtained through verbal and written signature or thumb print. There was no physical harm and no monetary benefits for the participants, however, the participant's participation will help to improve the care of children and families admitted at MJ PICU (Polit & Beck, 2010). However, since participants were required to narrate their personal feelings, psychological harm may have resulted and such participants could have been referred to a psychologist for counselling, however, there was none.

Privacy and confidentiality was observed by keeping the recorder and notes in locked cabinet. The computer which was used to keep the study data had a secret password. Anonymity was also observed because the participants were not linked to the information that they provided, rather numbers were used (Polit & Beck, 2010).

### **Dissemination of Study Results**

Study findings will be presented to MJ PICU staff and a copy of the findings will be given to the unit, COMREC as well as the KCN library. The results will also be disseminated during research seminars at QECH multidisciplinary paediatric research meetings, Continuous Professional Development (CPD) meetings in addition to a written report. The results will be published in peer reviewed Journals and will be disseminated at conferences both locally as well as internationally. Participants will have a copy of the results upon request.

## **Conclusion**

A qualitative descriptive study design was chosen for this study which aimed at exploring experiences of caregivers on involvement in children's care. This study was conducted at MJPICU at QECH. A total of 10 participants were interviewed on one on one basis in a private room. Only participants who met the specified inclusion criteria were recruited in this study. Data collected from the study were handled with highest level of confidentiality. Content analysis was chosen for the analyzing of the data generated from the interviews. A thorough report on the findings in form of thesis has therefore be produced for dissemination of the same findings.

## **CHAPTER 4**

### **Presentation of Study Findings**

#### **Introduction**

This chapter presents the results of the study whose aim was to explore experiences of caregivers on involvement in children's care at Mercy James Paediatric Intensive Care unit in Blantyre. The specific objectives of the study were to; describe the caregivers' perception of information sharing practices by health care workers in the PICU, determine caregivers' participation in decision making regarding their child's care whilst in the PICU and explore the nature of care activities that caregivers participate in at the PICU

The findings are in two sections. The first part contains demographic characteristics of the 10 caregivers who participated in the study. The demographic characteristics also contain information on caregiver's children who were admitted in the PICU. The second part presents the analysis of qualitative data which was derived from one to one in-depth interviews with participants using semi-structured interview guide. The verbatim quotes from the interviews will be provided where applicable in qualitative results to illustrate important points on the caregiver's experiences.

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

The ages of participants ranged from 19-60 years with the mean age of 30 years. The majority of participants were in the age group of 18-23 years, followed by age group

of 24-29. The following age categories had one participant; 30-35, 36-41 and 51-60 while the age category of 42-50 had none. Table 1 presents demographics of participants.

**Table 1: Demographic information of participants (n=10)**

<b>Characteristic</b>	<b>Number</b>
<b>Age in Years</b>	
18-24	4
25-29	3
30-35	1
36-41	1
42-50	0
51-60	1
<b>Sex</b>	
Male	2
Female	8
<b>Religion</b>	
Christian	9
Muslim	1
<b>Level of education</b>	
No formal education	1
Primary school	7
Secondary school	2
<b>Residence</b>	

Southern region	7
Central region	1
Northern region	1
Mozambique	1

Majority of the participants were females n=8 (80%), whilst only 2 (20%) were males. All the participants were married. Most participants had some schooling with majority of participants, n=7 (70%) having attended primary school level. Two of the participants (20%) had attempted secondary school level but did not complete form 4 while one (10%) did not attend any formal education.

Regarding occupation, most of the women (n=4) were housewives, three (3) were farmers and one was a business lady. Both men were farmers and one was also doing business. On religion, nine participants (90%) were Christians belonging to different denominations while one (10%) was Moslem. Majority of the participants were residing in the southern region (n=7) with four (4) participants from Blantyre district while central and northern regions had one participant each. There was one participant from Mozambique who was referred from Mulanje district hospital.

Regarding demographics of children whose caregivers participated in this study; majority of children, n=7 (70%) were males with only 3 females (30%). The age range of children who were admitted at the PICU was from 7 days to 15 years of age. The majority of the children were in the age group of 0 to 6 weeks and 13 months to 5 years which had 3 children each respectively. The length of stay of these children in PICU ranged from 3 to 50 days. The average length of stay was 16 days. Majority of the children (70%) were

admitted due to surgical conditions such as Gastroschisis (2), foreign body (2), trauma (2) and one had a tumor while 3 of the children (30%) were admitted with medical conditions; asthma, tuberculosis and hypertension. Table 2 presents demographics of the children.

**Table2: Demographic information of children (n=10)**

<b>Characteristic</b>	<b>Number</b>
<b>Age range of children</b>	
0-6weeks	3
7 weeks-12 months	1
13months-5 years	3
6 -12 years	1
13-18years	2
<b>Sex</b>	
Male	7
Female	3
<b>Reason for admission</b>	
Surgical condition	7
Medical condition	3
<b>Duration of stay in PICU</b>	
<b>(Days)</b>	
1-7 days	6
8-14 days	1
22-28 days	1

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>28 days

2

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### **Qualitative Findings**

The main objective of this study was to explore the experiences of caregivers on involvement in children's care at Mercy James Paediatric Intensive Care unit. Data was collected using semi-structured interviews on 10 caregivers. The caregivers of children who had been admitted in the PICU but got discharged to the wards were asked about their experiences regarding their presence in the PICU, their perception of information sharing practices by health care workers in the PICU, their participation in decision making and care activities that they were participating in at the PICU. The predetermined themes used during analysis were caregivers' experiences on their presence in the PICU, information giving to caregivers in PICU, participation in decision making and involvement in care activities. The themes and the subthemes have been presented in table 3.

**Table 3: Themes and Subthemes**

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<b>Themes</b>	<b>Subthemes</b>
<b>Theme 1:</b> Caregivers experiences on their presence in the PICU	<ul style="list-style-type: none"><li>• Caregivers reception and stay in PICU</li><li>• Visiting hours in PICU</li></ul>
<b>Theme 2:</b> Information giving to caregivers in PICU	<ul style="list-style-type: none"><li>• Infection prevention messages</li><li>• Information on condition and management of children</li><li>• Mode of communication</li><li>• The importance of the information given</li></ul>
<b>Theme 3:</b> Caregivers' participation in decision making	<ul style="list-style-type: none"><li>• Mixed feelings</li><li>• Mere spectators</li><li>• Language barrier</li><li>• The desire to participate</li></ul>
<b>Theme 4:</b> Nature of care activities that caregivers participate in at the PICU	<ul style="list-style-type: none"><li>• Activities by caregivers</li><li>• Importance of involvement in care activities</li><li>• Support by health care workers</li></ul>

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### **Caregivers' Experiences on Presence in the PICU**

Since FCC advocates that caregivers should be allowed to stay with their children on their child's bedside even in the PICU (Uniacke et al., 2018), the study sought to have caregivers' experiences on this at Mercy James Paediatric Intensive Care Unit and got the following findings; Subthemes that emerged from this theme were; caregivers' reception and stay in the PICU and visiting hours in the PICU.

#### ***Caregivers' Reception and Stay in PICU***

All the participants explained that they were happy with the way health care workers welcomed them at the PICU. The participants explained that they were warmly welcomed by the nurses and were assured that their child will be well taken care of. One of the participants narrated; *"they welcomed us well and told us not to worry and they said that they have welcomed the child and is in good hands."* (Participant #10). Furthermore, majority of the participants were happy with the care that was being provided to their children as one of the participants explained; *"I was happy to see the doctors and nurses taking care of my child, playing with her like their own."* (Participant #4). One participant also showed her appreciation to health care workers, particularly nurses, for always being available for the children and their caregivers. The participant explained; *"I was very appreciative of the care that we got there till we got discharged, the nurses were always on the bedside with us..."* (Participant #3).

### ***Visiting hours in the PICU***

The study findings showed that majority of the participants were allowed to stay on the bedside of their children and could visit at any time they would wish, although, some were reportedly told that not everyone was allowed to visit the child in the PICU. One of the participants explained; *“The information which I received from there was that not any one could go and see her except her father and myself, some relatives wanted to see her but could not because of the rules and I was making sure that I abide by the rules.”* (Participant #3).

Despite being told that they were allowed to stay with their child on the bedside, some participants reported they were not allowed to spend a night at the PICU as narrated by one of the participants; *“....they also said that they don’t allow parents to sleep there so you leave the child and just visit and that they will do everything for him.”* (Participant #10).

### **Information Given to Caregivers about PICU**

Information sharing by health care workers to caregivers is very vital for successful implementation of FCC in the hospital including the PICU (Foster et al., 2013). The following were the subthemes that emerged from this theme; infection prevention messages, information on child’s condition and treatment, mode of communication and importance of communication.

### ***Infection Prevention Messages***

Majority of the participants were told to wash hands before and after visiting the PICU and some were told to put on gloves. One of the participants said; *“They told us that*

*we should wash our hands when we were entering the PICU and upon getting out and we should put on gloves when touching the bed.” (Participant #7).*

Two participants said that they were not told anything about the PICU, one of them said that; *“They did not explain to me anything regarding the PICU or if they did, I may have forgotten.” (Participant #9).*

### ***Information on Child’s Condition and Treatment***

A lot of the participants were able to explain their child’s condition and the treatment the child was getting in the PICU as narrated by one of the participants; *“They said that my child was found to have tuberculosis; they said that he had pus collected in his lungs and they took her to theatre to remove it, then she was given blood and they started giving her medications then we started seeing some improvement” (Participant #1).*

This means that the health care workers were explaining the condition and management of the children to the caregivers. However, one participant bemoaned not to have been told about the results of some investigations as narrated; *“They explained to me other investigations except a certain blood test which they took in some 4 or 5 tubes which they said they wanted to investigate what the problem was but they didn’t tell me the results.” (Participant # 3).* Some participants went further to explain that it was important to have health care workers explain to them about their child’s condition and treatment because it helped them to be less anxious.

### ***Mode of Communication***

All the participants said that they were given the information verbally and the communication was given in Chichewa, one of the main local languages and some explained that this was being interpreted from an English speaker as narrated by participant

number 5; *“The information was being given in Chichewa. Sometimes there would be a senior white doctor and a fellow Malawian who would interpret.”* All the participants said that this was the language they were able to understand.

The results showed that most participants got information from both nurses and doctors. One participant said; *“Nurses who were taking care of the patients were the ones giving us the information.”* (Participant #6). Most participants were however not able to differentiate between nurses and doctors like one of them explained; *“I cannot tell which one is a nurse or a doctor since we just see all of them.”* (Participant # 8). Another participant said that nurses put on different attire from doctors; *“Doctors were putting on white attire whilst nurses were putting on different attire.”* (Participant #9).

### ***The Importance of the Information Given By Health Care Workers***

All the participants said that the information that was given to them was very important and some of the reasons cited were; the information updated them how their child was fairing, and the problem of the child. This made them less anxious. One of the participants narrated; *“The information was important to inform us on how my child was faring and if anything happened we would have known that we were informed.”* (Participant #1).

### **Participation in Decision Making**

Giving opportunities to caregivers to participate in decision making as regards their hospitalized children is very important as far as FCC is concerned (Institute for Patient- and Family-Centred Care, 2016). The subthemes that emerged from this were; mixed feelings, mere spectators, language barrier and the desire to be involved.

### *Mixed Feelings*

Some of the participants thought that they were involved in decisions regarding the care of their child whilst some thought they were not involved. For those who felt they were involved cited being asked by health care workers on how the child was fairing, reporting what they were observing on the child and consulted before the doctors did any procedure as some of the ways. One of the participants narrated; *“I was being given an opportunity to participate in decision making because every time they wanted to do something on my child they would ask me first then I would agree.”* (Participant #3). However, one of the participants explained that although they were consulted on what they thought about the care and treatment given to their child, they didn’t have to refuse or give contradicting ideas and so they would just accept; *“They were giving us a lot of opportunities to get involved on everything they wanted to do, like they wanted to take him to theatre again they asked what we think and we would say that whatever you say, do it then we would sign on a form.....”* (Participant #7).

Yet some participants thought they were not given opportunities to get involved in the decisions of their child because the health care workers did not consult them rather they could just inform them what had transpired, one of them had this to say; *“We did not participate in any decision making since they did everything and just explained to us, our role was to just visit her and come back.”* (Participant #1).

Similarly, when narrating on whether the participants felt they needed to be involved in decision making or not; some thought they should whilst others thought it was not necessary. For those who thought that it was necessary, said that this makes a caregiver to feel important and respected; *“When given an opportunity to participate in decision*

*making, makes you realize who you are.*” (Participant #2). Nevertheless, other participants did not mind whether they are involved or not; *“It could be both necessary and not necessary to be given an opportunity to participate in decision making.”* (Participant #1)

### ***Mere Spectators***

Majority of the participants explained that they were not given a chance to participate in the discussions during ward rounds regarding their child, instead they could just watch as the health care workers discussed amongst themselves. One participants narrated; *“...as I said already during ward rounds we were not involved, they were just discussing amongst themselves as you are on the bed side.”* (Participant #5). Another participant had this to say; *“They were usually several of them both white and black people and they surrounded the patient but we didn’t have any chance we could just sit aside and watch to see what they were doing and we thought since whatever they were doing was helping the patient, it was fine.”* (Participant #7). However, one participant explained that they would take an effort to ask the health care workers what they were discussing during the ward round as narrated; *“During ward rounds they would be discussing the patient amongst themselves so you had to be take an effort to ask since they were discussing in English which I couldn’t understand.”* (Participant #7).

### ***Language Barrier***

Some of the participants attributed language barrier as factor for them not to participate in decision making. One of the participants explained; *“During ward rounds, the doctors were just talking in English without giving us opportunity to talk in our Chichewa language.”* (Participant #2). However, some participants said that after the health care workers had discussed they were being explained to in the local language by an

interpreter; *“During ward rounds, the doctors would be discussing in English and an interpreter would explain to me the progress of the child so that I am aware of how the child is faring.”* (Participant #3).

### ***The Desire to Participate In Decision Making***

Most of the participants bemoaned not being given the opportunity to participate and wished for such opportunities as one of the participants explained; *“As parents we would love to be called when they are discussing because they just tell us to say please sign here we would like to take the child to theatre but we don’t know anything....we do not participate because they are the health care workers.”* (Participant #7). Nevertheless, some participants thought it was not necessary because even if they took part in treatment decisions of their child, they would not take part in its implementation such as administering the drugs.

### **Involvement in Care Activities**

The following were the subthemes that were generated; activities by caregivers, importance of involvement in activities and support by Health care workers.

#### **Activities by Caregivers**

The results showed that most participants were involved in one or several physical activities in caring for their child in the PICU. Most of the participants who had neonates and infants mentioned expressing breast milk and feeding their child, helping in bathing the child and applying powder, cuddling and comforting the child as common activities they were engaged in. One of the participants explained; *“I would help in consoling him when crying, holding him when they are administering medications or doing other procedures. I would also feed him. I would also assist to carry him as they made his bed*

*and I was involved in feeding my child.*” (Participant #5). Another participant narrated; *“When my child was at the PICU, I used to do the following; cuddle her, delivered expressed breast milk, visit and bath her and putting some lotion on her body.”* (Participant #1).

For those with older children, the common activities the participants were involved in include; helping in turning, bathing and showing their child love and affection. This is what one of the participants had to say; *“They told us to be going at 4 o’clock in the morning to help out in bathing the child because they could not do it themselves. We were just helping out to turn and hold the child but everything else they would do themselves.”* (Participant #7).

Almost all the participants mentioned one or several activities that they were involved in at the PICU, although some of them did not regard what they were doing as an activity and were explaining that they weren’t doing anything. For instance, this is what participant number 10 explained; *“When I went there, I was not doing anything, was just staying at the bedside but I would calm my child when crying.”* Similarly, another participant said; *“I was showing my child love, counselling her on a few things. The nurses and doctors were doing everything on my child. I was just watching them; they did not even tell me that hold here.”* (Participant #3).

### ***Importance of Involvement in Care Activities***

All the participants who talked about the importance of them getting involved in care activities explained that it was important for them to participate in the care of their children. The reasons being; they thought they were helping out the nurses who were busy most of the times, they were glad to give care to their child and one thought that this was

what they had to do. Participant number 7 explained; *“It was important to get involved in the care because he is my child.”*

Furthermore, one participant explained that they were satisfied to do the activities they were doing; *“I was happy to do what I was doing because I thought it’s according to their protocol that they should do the rest.”*(Participant #5).

### ***Support by health care workers***

The participants appreciated the support given by health care workers as they carried out the care activities. The participants thought the health care workers did the following to support them in the care activities; giving them information on how to do the activity, providing guidance on the activities and doing the activities together with the caregivers. One participant explained; *“The nurses were telling me to be observing as they bathed her, on her last day there, they taught me how to do it, not forcing it on me but that I could be able to do it after being discharged from the ward.”* (Participant #3)

Nurses were the ones being frequently mentioned to have provided the support to the caregivers. Participant number 2 explained; *“Nurses were assisting in bathing and giving him medications.”* However, one participant mentioned that doctors were also providing support; *“The doctors would also help to calm him down when crying.”* (Participant #10).

### **Chapter summary**

This chapter presented the study findings and in a nutshell, the findings have shown that; participants were given information verbally and in a language that the caregivers were able to understand. Nurses and doctors were both found to have provided the information but caregivers were not able to differentiate the two. However, the information given was

inadequate and not standardized for caregivers. Caregivers were not adequately involved in decision making regarding their children's care but were however involved in the physical care of their children and this was found to be gratifying to them.

## **CHAPTER 5**

### **Discussion of Study Findings**

#### **Introduction**

This chapter presents a discussion of findings of the study which aimed at exploring the experiences of caregivers on their involvement in children's care at Mercy James Paediatric Intensive Care unit in Blantyre. It discusses findings on the caregivers' experiences on their presence in the PICU, caregivers' participation in decision making regarding their child's care whilst in the PICU and the nature of care activities that caregivers participated in at the PICU.

The discussion includes how the study relates to other research findings. The findings have been discussed consistent with the themes which were derived from the study objectives. Recommendations, areas for further research and limitations of the study are also presented in this chapter.

#### **Demographic Data**

##### **Age of the caregivers.**

The study findings on demographic data revealed that all the 10 caregivers were aged from 18 years and above. The researcher noted that it was ethically right to interview the caregivers since someone who is 18 years is considered a legal adult who can consent to research in Malawi (Mangochi et al., 2019). The findings that the majority of participants were in the age group of 18-23 years, are similar to findings of another study

by Gondwe et al. (2017). This is consistent to Malawi's data that most majority of childbearing women are in this age group of 15-24 (Self et al., 2018).

### **Gender of Caregivers and Their Relationship with Children**

Majority of the caregivers who participated in this study were females and all of them mothers of the children who were admitted in the PICU. This is similar to findings of another study in Mozambique whereby mothers were the most common of the family caregivers staying with the sick children in hospital (Söderbäck & Christensson, 2008). This is not very surprising because in Malawi, Africa and even beyond, a mother is regarded as the primary caregiver of children at home and even during hospitalization. This is probably due to the nature of mothers' love and could be culturally motivated too. Study findings have shown that having a mother at the bedside of her hospitalized child is a source of affection and security to the child and facilitates child's adaptation to the hospital environment (Molina & Marcon, 2009).

### **Experiences of Caregivers' Presence in PICU**

Allowing caregivers to visit their children at any time of the day, and staying on their child's bedside is fundamental in implementing FCC in the hospital and particularly in the PICU (Uniacke et al., 2018). Having caregivers on the bedside is advantageous because it creates opportunities for health care workers to build relationships and trust with caregivers and to provide information and caregivers to participate in care (Coats et al., 2018). It is therefore commendable to have most caregivers in this study acknowledge to have been allowed to be with their children at any time of the day in MJ PICU. This is contrary to what caregivers in one of the PICU's in Iran experienced as nurses were

reluctant to allow the caregivers to stay at their children's bedside because they thought they disturbed care giving of the patient and that their presence caused the children to be restless. (Vasli et al., 2015). This practice by health care workers in Iran was found not to be consistent with the FCC which recommends that caregivers of patients in ICU should be offered to stay with their sick children at the bedside (Davidson et al., 2017). Due to the concerns raised by the nurses, the caregivers were restricted to short visits such as one hour visit during the evening shift (Vasli et al., 2015), and this is similar to the findings in this study where one participant explained that they were given specific time when they were to visit their child, although it was not explicit on how much time they were given. This may probably be due to the same reason that the health care workers are not comfortable to have caregivers at the bedside. However, allowing caregivers to be at the bedside at any time they wish is good because it helps health care workers to build relationships with caregivers and makes it easy to include them in the care of children (Coats et al., 2018). Findings in this study also revealed that despite that caregivers were being allowed to visit their child and be on the bedside anytime most of the participants mentioned that they were not allowed to sleep in the PICU. This could be due to lack of sleeping places for the caregivers in the PICU and/or infection control purposes (Frazier et al., 2010). Findings on restrictions of people who could visit the child in the PICU are similar to findings of a study in America where it was observed that only immediate family members of the child were allowed to visit the child in the PICU in order to maintain patient confidentiality and traffic control (Macdonald et al., 2012). The latter may also have been done as an infection control measure.

### **Information given to caregivers**

Caregivers of sick children in PICU want to be given honest, clear and complete information and this can help them to be more prepared, less helpless as well as have sense of control (Richards et al., 2017). The results showed that most participants were told about infection prevention messages such as washing hands before and after visiting the PICU and putting on gloves when touching the bed of the child and some health care workers went an extra mile and showed the caregivers where they should wash hands. This is very important information to be given to caregivers in the PICU and in the hospitals and communities at large because hand hygiene is considered the most common factor in infection prevention (Yunxia et al 2019).

Most caregivers in this study were able to explain the condition of their child and the treatment that he/she was getting in the PICU. This shows that the caregivers were properly explained to by the health care workers. This is a good practice and it is commendable because when caregivers are well informed of their child's condition and management they feel secure, comfortable and competent to be involved in the care (Dahav & Sjöström-Strand, 2018). Furthermore, this needs to be encouraged because it satisfies the caregivers' desire to be informed about their child's condition and treatment (Vasli et al., 2015).

However, beyond knowing about child's condition and treatments, caregivers also desire to know the tests being carried out on their children and their results (Ames et al., 2011) which was not the case in this study. This is consistent with findings of a study in Sweden which found that caregivers were not involved in their child's tests and diagnostic

procedures (Vasli et al., 2015). This can lead to caregivers being anxious and having fears of uncertainty (Roets et al., 2012) hence the need for health care workers to always explain information regarding child's care and treatment including tests and investigations to caregivers.

Nevertheless, two of the participants said that they were not told anything regarding the child's condition. This finding is consistent with findings from a study conducted in critical neonatal units in Malawi which revealed that few participants reported not to have received any information from health care workers (Gondwe et al., 2017). Some health care workers may withhold information to caregivers with an aim of protecting them from distressing information (which may include the child's condition) but this may consequently lead to more stress in the caregivers, stressful search of information and loss of trust in health care workers (Richards et al., 2017). Other findings have indicated that caregivers would love to get information regarding their child even if it is distressing (Molina & Marcon, 2009; Richards et al., 2017). Therefore health care workers have a responsibility to always inform caregivers.

All the caregivers in this study who got some information, got it verbally. The information was given in Chichewa language, although in some instances it was interpreted from an English speaker. This was the language which all the caregivers said were able to understand. This is quite commendable as caregivers in various PICU's emphasized the need to communicate any information regarding the child in the caregivers' language. Caregivers want to be given information in their local or simple language which is clear and easy to understand (Ames et al., 2011; Carnevale et al., 2016; Majdalani, Doumit, &

Rahi, 2014). This is contrary to what other studies found that most health care workers in the PICU tend to use inappropriate language such as medical jargons, and English language to caregivers who cannot understand (Alves et al., 2013; Majdalani, Doumit, & Rahi, 2014; Richards et al., 2017a). It is therefore commendable that health care workers in this study were able to share information in a language that the caregivers understood consistent with the FCC principle of information sharing (Institute for Patient- and Family-Centred Care, 2016).

The results showed that most participants got information from both nurses and doctors, although some said doctors or nurses only. The results are similar to other studies which were conducted in general paediatric wards at QECH as well as a PICU in Michigan, United States of America where participants acknowledged to have received information from both nurses and doctors (Gondwe et al., 2017; Laudato, Yagiela, Eggly, & Meert, 2019). This is however contrary to findings from studies conducted in France and Canada where caregivers identified physicians or doctors only as common sources of information (Carnevale et al., 2016). Another study finding in one PICU in Colombia also found that doctors were the ones giving out information to caregivers as a unit policy but it showed that caregivers wanted to get information from the nurses too as long as it was clear and easy to understand (Valderrama & Muñoz de Rodríguez, 2016). Apart from nurses and doctors being the most common sources of information, caregivers in one PICU in the USA cited the internet as another source of general information on PICU (Laudato et al., 2019). This is probably due to the fact the USA is a developed country with easy access to the internet and most caregivers are literate which is not the case in Malawi and many African countries.

Remarkably, most participants in this study were however not able to differentiate between nurses and doctors. This finding is consistent to a study which was conducted at QECH on caregivers who had their children put on Bubble Continuous Positive Airway Pressure (bCPAP) in which the caregivers could not differentiate a nurse and a doctor (Gondwe et al., 2017). The differences may come about due to the hospitals in the developed world having well educated caregivers who can differentiate a nurse and a doctor whilst in Malawian hospitals and as evidenced in this study, most caregivers have not gone beyond primary school level and may therefore have challenges differentiating the two. Nevertheless, regardless of caregivers' level of education, health care workers need to introduce themselves to caregivers in order to establish a therapeutic relationship with them and this would help to facilitate their involvement in care (Burke et al., 2016).

The findings of the study revealed that all the participants appreciated the information that was given to them as very important and some of the reasons cited were; it made them aware of how the child was faring, the problem of the child and made them less anxious among others.

### **Participation in decision making**

Participation of caregivers in their hospitalized children's care is one of the pillars of FCC (Institute for Patient- and Family-Centred Care, 2016). In this study, some participants thought that they were involved in decision making regarding the care of their children whilst some thought they were not involved. Actively involving caregivers in their child's healthcare decisions increases their competence and engagement in preparing their child's health care (Aarthun et al., 2018). Furthermore this is good because it increases

family satisfaction, better communication, coordination of care and enhances patients safety (Laudato et al., 2019). Involving caregivers in decision making cannot be overemphasized, it is very crucial and important to caregivers hence the need to be encouraged where the caregivers have been given the required information so that they ably contribute to the decisions being made.

However, one of the participants explained that although they were consulted on what they thought about the care and treatment given to their child, they didn't have to refuse or give contradicting ideas and so they would just accept. This may be attributed to the authoritative nature of information given by other health care workers which can make caregivers to just agree to the communication and/or decision without understanding thereby affecting the decision making as regards their child's care (Vasli et al., 2015). But this ought not to be so, caregivers need to participate in decision making after they have fully understood the information being given by the health care workers.

Yet some participants thought they were not given opportunities to get involved in the decisions of their child because the health care workers did not consult them rather they could just inform them what had transpired. These findings are similar to another study in Netherlands whereby caregivers bemoaned for not being asked for their opinions rather the health care workers just told them what needs to be done (Latour et al., 2011). This can be attributed to lack of equal powers between health care workers and caregivers common in Malawi whereby most caregivers are illiterate and health care workers may regard them as unimportant (Shields et al., 2018). But this is not a right attitude, the caregivers need to be given opportunities to participate in decisions because they are the best expert of their

child (Khajeh et al., 2017), hence they may know something that the health care workers would not know which can affect care being given.

Similarly, when narrating whether the participants felt they needed to be involved in decision making or not; some thought they should whilst others thought it was not necessary. For those who thought that it was necessary, said that this makes a caregiver to feel important. Nevertheless, other participants did not mind whether they are involved or not. The findings are similar to those of caregivers in Mozambique who could not decide if they wanted to get involved in decision making or not (Söderbäck & Christensson, 2008). This could be related to varying information needs of caregivers in the PICU whereby some wanting to know everything whilst other wanting little or no information at all and this is attributed to coping styles (Laudato et al., 2019).

Caregivers may leave health care workers to do treatment decisions due to the belief that health care workers are the best people to do it (Latour et al., 2011). There are some beliefs that physicians should make decisions for caregivers because they believe that parents do not have the necessary knowledge to participate in such complex decision-making (Richards et al, 2017). This therefore means that some caregivers would cope well when they are involved whilst other would prefer not to be involved and would cope better. However, Hill et al., (2018) suggests that for caregivers who decline to participate in rounds because they find them stressful, health care workers should find alternative ways of sharing information with such caregivers. Moreover, because evidence has shown that FCC rounds are an important forum for information sharing and communication (Lopez et al., 2019). It is further recommended that the health care workers should frequently discuss

with caregivers whether their preference about participating in rounds has changed as their child's stay in the PICU progresses and as the environment becomes more familiar, the child's condition improves, and parent anxiety fluctuates(Hill et al., 2018).

Involving caregivers in FCC ward rounds has proved to be beneficial to caregivers in that it brings a feeling of being respected and valued by the health care team and in turn leads to improved communication between caregivers and health care workers (Curtis et al., 2016). However, in this study, majority of the participants thought they were not involved during ward rounds as they could just watch as the health care workers discuss amongst themselves. As reported by Cameron et al (2009), involving caregivers may bring other inconveniences on the part of health care workers and this may lead to non-involvement of caregivers. The reasons include; increased duration of rounds, limits discussion among the health care workers and decreases teaching time in the case when there are trainee health care workers. Such factors may discourage health care workers to involve caregivers during ward rounds. Nonetheless, health care workers need to provide opportunities for caregivers to be involved during ward rounds.

Although caregivers explained that they were able to understand the information given to them regarding the PICU and their children's care, ironically they faced challenges in understanding information during ward rounds. Some of the participants attributed language barrier as a factor for them not to participate in decision making during ward rounds. The findings are in agreement to those of another study where caregivers thought that the language used by health care workers was too technical which may lead to parental

stress and misunderstanding the information during the rounds (Cameron et al., 2009). As a result, caregivers may opt not participate in the ward rounds.

Most of the participants bemoaned not being given the opportunity to participate and wished for such opportunities rather than just being told to sign on form as consent for a certain procedure. This is similar to what caregivers who had their children admitted to a PICU in Lebanon who wished to be part of the decision making process reported or experienced (Majdalani et al., 2014). Participation should therefore indeed go beyond signing a consent form and making sure that caregivers are aware of what they are consenting for.

### **Involvement in Care Activities**

The results showed that most participants were involved in one or several physical activities in caring for their child in the PICU. Most of the participants who had neonates and infants mentioned expressing breast milk and feeding their child, helping in bathing the child and applying oil, cuddling and comforting the child as common activities they were engaged in. For those with older children, the common activities the participants were involved in include; helping in turning the child, helping in bathing the child and showing their child love and affection. Similar findings have been observed in some studies done in Malawi where caregivers with hospitalized children were involved in feeding, changing nappies, cleaning, turning, bathing their patient (Gondwe et al., 2017; Hoffman et al., 2012; Söderbäck & Christensson, 2008). This is consistent with findings from a study in one of the PICU's in Sweden where caregivers participated in the care of their children by feeding and changing diapers (Dahav & Sjöström-Strand, 2018). In a study by Coats et al., (2018)

nurses reported to have given caregivers ‘little jobs’ such as changing diapers and bathing the child which helped the caregivers to regain their parental roles and it gave them some control on their child. Furthermore, it instilled a sense of trust in caregivers towards the nurses hence being a commendable practice. However, in the same study by Coats et al (2018), nurses reported some challenges having caregivers on the bedside at any time such as; it was both distracting and exhausting to provide care to the child as the caregiver observes and the need to share attention between the child and the caregiver. Health care workers may therefore need to learn how to accommodate caregivers in the care of the hospitalized children in PICU and the hospital in general.

The participants explained that it was important for them to participate in the care of their children. The reasons being; they were helping out the nurses who were busy most of the times, they were glad to give care to their child and one participant said that this was what they had to do. This could be the reason why some caregivers did not regard what they were doing as an activity. This could be so because most of the activities the caregivers were doing are parenting tasks which they normally do at home such as feeding, bathing etc. However, the PICU being a highly specialized area with a lot of equipment and gadgets on the sick child, health care workers need to take time providing guidance to caregivers in their undertaking of the care activities. Furthermore, one participant explained that they were satisfied to do the activities they were doing and this is consistent with study findings in Sweden that caregivers found being involved in their children’s care as gratifying (Dahav & Sjöström-Strand, 2018). This is consistent with findings of another study conducted in caregivers who had their children admitted in one of the PICU’s in Brazil who reported that their participation in their children’s care brought them feelings of

happiness, pleasure and security (Molina & Marcon, 2009). Another study conducted in some ICU's in South Africa showed that caregivers wanted to be involved in their child's care because it made them feel better emotionally and they felt to have made valuable contribution to their child's recovery (Roets et al., 2012). It is therefore very important that caregivers are offered opportunities to participate in their children's care even when they are admitted in critical care settings such as PICU's.

Guidelines for FCC in ICU recommends that caregivers of critically ill patients should be taught how to assist with the care of their patients in order to improve their confidence and competence in their caregiving role as well as improve parental psychological wellbeing during and after the ICU stay (Davidson et al., 2017). Moreover, evidence has shown that caregivers can be uncertain on how to do care activities and desire health care workers support (Ames et al., 2011; Hill et al., 2018). It is therefore a commendable thing that participants in this study acknowledged that health care workers were providing support as they carried out the care activities. The participants mentioned that they were being given information on how to do the activities, provided with guidance and health workers were doing the activities together with the caregivers as ways of support. This is similar to what health care workers suggest as prerequisite for caregivers to participate in care thus they need to be supported with information, supervision and doing care together with them (de Melo et al., 2014). Mostly nurses were the ones providing support probably because they are the ones who are consistently at the bedside of patients and therefore have constant contact with patients and their families (Coats et al., 2018). Additionally, nurses form a critical part of health care delivery system and they make up the majority of the health care workforce (Haddad et al., 2020).

## **Conclusion of the study**

This chapter presented the discussion based on the study findings. Caregivers were given information regarding their children's care in the PICU. However, the information was inadequate and was not standardized for caregivers to understand and in turn to adequately participate in their children's care. Nurses and doctors were both found to have provided the information although ironically caregivers were not able to differentiate the two. The information was given verbally and in a language that the caregivers were able to understand. Caregivers were not adequately involved in decision making regarding their children's care but were however involved in the physical care of their children and this was found to be gratifying to them. The findings have shown that there are gaps in how health care workers are involving caregivers in the care of their children at MJ PICU and FCC principles are not adequately adhered to.

The findings of this study can assist health care workers in developing interventions to effectively involve caregivers in children's care with the FCC approach at MJ PICU.

## **Recommendations**

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

### **Practice**

The findings of this study have shown that information given to caregivers concerning the PICU and their children's conditions, investigations and treatment by health care workers is often inadequate and not standardized. Caregivers need adequate information about their children's care for them to ably participate in decision making and

care provision. There is a need for the MJ PICU team to develop a standard information package on what caregivers should expect when their child is admitted to the PICU and this should be taught to caregivers on admission to the unit and during their stay as well as on discharge. This could be in form of a leaflet that can be given to the caregivers that are able to read. For the caregivers that are not able to read and understand the information, their family members can help in reading the information and discuss with the caregivers. Guidelines for FCC recommend that ICUs should provide families with leaflets that give information about the ICU setting to reduce anxiety (Davidson et al., 2017). This would also help to compliment the information that is given verbally. Evidence has shown that information given in multiple formats such as spoken, written and visual can help stressful caregivers to absorb complex information (Hill et al., 2018). There is also a need for health care workers to create time for giving the family caregivers information about their children's conditions and care.

The unit may also develop a checklist of information needs of caregivers in the PICU such as explaining child's condition, investigations done, treatment and possibly prognosis and daily monitor if one of these have been explained to a caregiver. Alternatively, information giving can be added as one of the things to be monitored on PICU monitoring sheets to ensure that at least once a day, every caregiver has received some information regarding their child's care.

## **Management**

The PICU management team should facilitate a system whereby all caregivers are offered to participate in the ward rounds to promote their participation in decision making. Language barrier was one of the challenges for caregivers to participate in ward rounds,

the unit may consider having an interpreter during the rounds, and this could be any member of the multidisciplinary team who can ably communicate with the caregiver in his/her local or preferred language. Engaging interpreters during rounds with caregivers with limited English proficiency has shown to have led to increased participation of caregivers in family centred rounds (Cheston et al., 2018).

The management team may need to ensure that all health workers are having identities such as name cards with their cadre as well as ensure that all health care workers introduce themselves to caregivers when providing care so that the caregivers are familiar with who is taking care of their child.

### **Policy**

The unit management may utilize the study findings to develop a FCC policy for MJ PICU which would guide implementation of FCC at the unit.

### **Areas for Further Research**

The study identified the following gaps that need to be addressed through further studies:

- An ethnographic study on experiences of caregivers on involvement in care at MJ PICU.
- The nurses' experiences of caregivers' participation in the care of children at MJ PICU.
- Bereaved caregivers' experiences in care involvement by health care workers during the time of admission at PICU.

- A similar study should be conducted in a community setting after discharge from hospital to get a true reflection of what caregivers experienced in PICU.

### **Study Limitations**

- Due to time constraints, the study did not include an observation component which is important in generating rich, complete and contextual understanding of the experiences of the caregivers in the PICU. An ethnographic study would have been more suitable for the research.
- Exclusion of caregivers whose children died whilst in the PICU could be another limitation since this group can also be a source of rich information owing to their experiences.
- Caregivers may have responded positively on their experiences on their stay in the PICU and not give their true experience as they were interviewed in the hospital and may have thought true responses would affect their child's care while in hospital.

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## Appendices

### Appendix 1A: Informed Consent Form (English version)



#### KAMUZU COLLEGE OF NURSING

#### **Informed Consent Form for Caregivers of Children Who Were Admitted At Mercy James Paediatric Intensive Care Unit**

This informed consent form is for caregivers of children who were admitted at Mercy James Paediatric Intensive Care Unit who I am inviting to participate in a research study titled *“Experiences of caregivers on their involvement in children’s care at Mercy James Paediatric Intensive Care Unit in Blantyre, Malawi: A family Centred care perspective.”*

Name of Principal Investigator: Grace Chasweka

Name of Organization: University of Malawi – Kamuzu College of Nursing

Name of Sponsor: Elma foundation scholarship

Name of Project and Version: Project carried out as partial fulfilment of Master of Science degree in Child Health Nursing

This Informed Consent Form has two parts:

- **Information Sheet (to share information about the study with you)**
- **Certificate of Consent (for signatures if you choose to participate)**

You will be given a copy of the full Informed Consent Form

## **Part I: Information Sheet**

### **Introduction**

I am Grace Chasweka, a student at University of Malawi, Kamuzu College of Nursing for Master of Science degree in Child Health Nursing. I am doing research on caregivers' experiences regarding their involvement at Mercy James Paediatric Intensive Care unit as a partial fulfillment of my program. I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research.

This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me and I will gladly answer you.

### **Purpose of the research**

Caregivers who have their children admitted in hospital have a role to play in the care of their children. I believe that what you will tell me will assist in responding to caregivers' needs and help Health care workers to give quality care to children and their caregivers at the Paediatric Intensive Care Unit.

I would like to learn the information you got from health care workers in the PICU and what role you played in decision making and care of your child.

### **Type of Research Intervention**

This research will involve your participation in an interview which will last 45 minutes.

### **Participant selection**

You are being invited to take part in this research because I feel that your experience as a caregiver (mother, father or child's guardian) can contribute much to my understanding of how caregivers are involved in care of their children.

### **Voluntary Participation**

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. If you choose not to participate all the services you are receiving at this hospital will continue and nothing will change.

### **Procedures**

I am asking you to help me learn more about caregivers' involvement in care of their children at Mercy James PICU hence this invitation for you to take part in this research project. If you accept, you will be asked to participate in an interview with me.

During the interview, I will sit down with you in a comfortable and private place in the ward. If you do not wish to answer any of the questions during the interview, you may say so and I will move on to the next question. No one else apart from me will be present unless you would like someone else to be there. The information recorded is confidential, and no one else except Mrs M. Majamanda and Mrs A. Namathanga, who are my research supervisors will access to the information documented during your interview. The entire interview will be tape-recorded, but no-one will be identified by name on the tape because numbers will be used. The tape will be kept in a locked cabinet. The information recorded is confidential, and no one else except my supervisors will have access to the tapes. The tapes will be destroyed after five years.

### **Duration**

The research takes place over 12 months in total. During this time, you will be interviewed only once.

### **Risks**

I am asking you to share with me some very personal information and opinions, and you may feel uncomfortable talking about some of the feelings. You do not have to answer every question during interview if you don't wish to do. You do not have to give me any reason for not responding to any question, or for refusing to take part in the interview.

### **Benefits**

Please note that there will be no direct benefits to you for participating in the study. However, exploring the experiences of caregivers of children admitted at Mercy James Paediatric Intensive Care Unit will assist in responding to caregivers' needs and guide nursing care to minimize parental stress during admission of children and their families at the PICU.

### **Reimbursements**

You will not be provided any incentive to take part in the research.

### **Confidentiality**

The research being done in the hospital may draw attention and if you participate you may be asked questions by other caregivers in the hospital. I will not be sharing information about you to anyone outside of the research team. The information that I will collect from this research project will be kept private. Any information about you will have a number on it instead of your

name. Only I will know what your number is and will lock that information up with a lock and key. It will not be shared with or given to anyone except my supervisors.

### **Sharing the Results**

Nothing that you will tell me today will be shared with anybody outside the research team, and nothing will be attributed to you by name. The knowledge that we get from this research will be shared with the Health care workers at Mercy James Paediatric Intensive Care Unit and will be presented at Queen Elizabeth Central Hospital Paediatric research meeting. Following the meetings, we will publish the results so that other interested people may learn from the research.

### **Right to Refuse or Withdraw**

You do not have to take part in this research if you do not wish to do so, and choosing to participate will not affect your child's care in any way. You may stop participating in the interview at any time that you wish without your child's care and treatment being affected. I will give you an opportunity at the end of the interview to review your remarks, and you can ask to modify or remove portions of those, if you do not agree with my notes or if I did not understand you correctly.

### **Who to Contact**

If you have any questions, you can ask them now or later. If you wish to ask questions later, you may contact any of the following;

**Grace Chasweka (Mrs.),**  
University of Malawi,  
Kamuzu College of Nursing,

Post Office Box 415,

**BLANTYRE**

**0999 727 325/ [chasweka2017grace@kcn.unima.mw](mailto:chasweka2017grace@kcn.unima.mw)**

**Maureen Majamanda (Mrs.),**

University of Malawi

Kamuzu College of Nursing

Post Office Box 415,

**BLANTYRE**

**0992 160 415/[mdmajamanda@kcn.unima.mw](mailto:mdmajamanda@kcn.unima.mw)**

You may wish to know that the study has been approved by College of Medicine Research Ethics Committee (COMREC) which is the board that looks into protection of research subjects in Malawi and has been authorized by Queen Elizabeth Central Hospital.

If you may wish to find out more about the COMREC, please contact the following;

The chairperson,

COMREC Secretariat,

P/Bag 360,

**Chichiri. BLANTYRE**

**Phone number: 01989766**

## **Part II: Certificate of Consent**

I have been invited to participate in research about the experiences of caregivers on involvement in children's care at Mercy James Intensive Care Unit.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of Participant \_\_\_\_\_

Signature of Participant \_\_\_\_\_

Date \_\_\_\_\_

Day/month/year

*If illiterate*

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness \_\_\_\_\_ Thumb print of participant

Signature of witness \_\_\_\_\_

Date \_\_\_\_\_

Day/month/year

**Statement by the researcher**

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands that the following will be done:

1. Participant will be enrolled upon voluntary participation
2. Participant has the right to withdraw from the study at any time
3. Confidentiality and privacy will be respected

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this ICF has been provided to the participant.

Print Name of Researcher/person taking the consent\_\_\_\_\_

Signature of Researcher /person taking the consent\_\_\_\_\_

Date \_\_\_\_\_

Day/month/year

## Appendix 1B: Informed Consent Form (Chichewa)



### **KAMUZU COLLEGE OF NURSING**

**Kalata Yofotokoza za kafukukuku kwa makolo omwe anagonekedwa ndi ana ku Chipinda cha ana odwalitsitsa ku Mercy James ndi chibvomerezo chotenga nawo mbali mu kafukufuku**

Ndalemba kalatayi ndi cholinga chofuna kukupemphani kuti mutengepo mbali polowa nawo mukafukufukuyu. Cholinga cha kafukufukuyu ndi kusanthula maganizo amakolo pa zomwe adakumanana nazo pa kutenga nawo mbali pa chisamaliro chomwe mwana wawo amapatsidwapa panthawi yomwe anagonekedwa ku chipinda cha ana odwalitsitsa ku Mercy James.

**Mkulu wa kafukufuku: Grace Chasweka**

**Dzina la bungwe: University of Malawi – Kamuzu College of Nursing**

**Opeleka thandizo la kafukufuku: Elma foundation**

**Dzina la pulojekiti: Kafukufukuyi ndi mbali imodzi ya wofunikira ku maphunziro a za ukachenjede ku Kamuzu Koleji ya Univesite ya Malawi**

Fomu iyi ili ndi magawo awiri:

- Tsamba la chidziwitso (kugawana zambiri zokhudza kafukufuku ndi inu)

- Kalata ya Chivomerezo (ngati mutasankha kutenga nawo mbali)

Mudzapatsidwa fomu yachivomerezoyi kuti mutenge

### **Gawo loyamba: Kalata yofotokoza za kafukufuku**

#### **Mauoyamba**

Ndine Grace Chasweka, wophunzira zaunamwino kusukulu yaukachenjede ya Malawi ku Kamuzu Koleji, amene ndikuphunzira zokhudza umoyo wa ana ndipo ndikupanga kafukufuku wokhuza maganizo amakolo ndi zomwe anakumana nazo pa kutenga nawo mbali pa chisamaliro chomwe mwana wawo amapatsidwapa panthawi yomwe anagonekedwa ku chipinda cha ana odwalitsitsa ku Mercy James.

Ndikufotokozerani zambiri zokhuza kafukufukuyi kenako ndikupemphani kuti mutenge nawo mbali pa kafukufukuyi. Simukuyenera kuvomera lero lomwe kuti mutenga nawo mbali kapena ayi. Musanavomere, mungathe kukambirana ndi aliyense amene mumakhala naye momasuka zokhuza kafukufukuyi. Fomu yobvomereza ikhoza kukhala ndi mawu omwe simukuwamvetsetsa, chonde ndifunsemi kuti ndiyime kaye ndipo ndizatenga nthawi ndikukufotokozerani bwino lomwe. Ngati muli ndi mafunso, khalani omasuka kundifunsa ndipo ndizayankha mosangalala.

#### **Cholinga cha kafukufuku**

Makolo omwe ana awo agonekedwa m'chipatala ali ndi udindo pa chisamaliro cha ana awo. Ndikukhulupirira kuti zomwe mudzandiuza zidzathandizira kuyankha zokhumba za makolo komanso kuthandiza ogwira ntchito zachipatala kuti azisamalira bwino ana ndi makolo awo panthawi imene agonekedwa ku chipinda cha ana odwalitsitsachi. Ndikufuna

kudziwa uthenga umene mumalandira kuchokera kwa ogwira ntchito zachipatala komanso gawo lomwe mumatenga pa kupanga ziganizo komanso chisamaliro cha mwana wanu.

### **Mtundu wa kafukufuku**

Muzatenga mbali mu kafukufukuyi pa kutenga nawo mbali mu zokambirana zomwe zidzatenga pafupifupi mphindi 45.

### **Kasankhidwe ka otenga nawo mbali mu kafukufuku**

Mukupemphedwa kuti mutenge nawo mbali pa kafukufukuyi chifukwa ndinu mmodzi mwa wosamalira ana (mayi, bambo kapena wachibale) amene munagonekedwa pa chipinda cha ana odwalitsitsa ndipo ndikukhulupilira kuti muli ndi ukadawulo umene ungathandize kumvetsetsa bwino lomwe momwe makolo amatengera nawo mbali pa chisamaliro cha ana awo.

### **Kutenga nawo mbali mwaufulu**

Dziwani kuti kutenga nawo mbali mu kafukufukuyi ndi mwa ufulu komanso mosakakamizidwa. Ndipo muli ndi ufulu kusankha kutenga nawo mbali kapena ayi. Ngati musankha kusatenga nawo mbali, dziwani kuti thandizo lililonse lomwe mwana wanu akulandira pa chipatala pano lizapitilira popanda kusintha kulikonse.

### **Ndondomeko ya kafukufuku**

Ndikukupemphani kuti mundithandize kudziwa zambiri zokhudza mmene makolo amatengera mbali pa chisamaliro cha ana awo panthawi yomwe agonekedwa kuchipinda cha ana odwalitsitsa ku Mercy James kotero ndi pempho langa kuti mutengepo mbali mu

kafukufukuyi. Ngati muvomereza, mudzapemphedwa kutenga nawo mbali pa zokambirana ndi ine.

Panthawi ya zokambirana, ndidzakhala nanu pamalo abwino komanso akumbali mu wodi yomwe mwana wanu wagonekedwa. Ngati simukufuna kuyankha mafunso ena omwe ndizakufunsani, mukhoza kundiuza ndipo ndidzapita ku funso lotsatira. Palibe wina kupatula ine amene azakhalepo pokhapokha ngati mukufuna kuti wina akhalepo. Zomwe zalembedwazo zidzabisidwa bwino lomwe, ndipo palibe wina kupatula mayi Majamanda ndi mayi Namathanga, omwe ndi ondiyang'anira ku sukulu pantchito za kafukufukuyi amene azakhale ndi mwayi womvetsera. Zokambirana zonse zizajambulidwa pa tepi, koma palibe-mmodzi adzazindikiridwa ndi dzina pa tepi. Tepi idzasungidwa mu kabati yotsekedwa bwino ndi makiyi. Zomwe zalembedwazo zidasungidwa malo obisika, ndipo palibe wina kupatula ondiyang'anira amene azamvera nawo matepiwo. Matepi onse adzawonongedwa patatha zaka zisanu.

### **Nthawi ya kafukufuku**

Kafukufukuyi azatenga pafupifupi chaka chimodzi koma tidzakhala ndi zokambirana ndi inu kamodzi kokha.

### **Chiopsezo**

Ndizakupemphani kuti mugawane nane nkhani zenizeni komanso maganizo anu, ndipo nkutheka simungakhale womasuka kulankhula za kukhosi kwanu. Simukusowa kuyankha funso lirilonse pa zokambirana ngati simukufuna kutero ndipo simukusowekeranso kuti

mundipatse ine chifukwa chirichonse chosayankhira funso lirilonse, kapena kukana kutenga nawo mbali mu zokambirana.

### **Ubwino**

Chonde dziwani kuti sipadzakhala phindu lenileni kwa inu pakuchita nawo kafukufukuyi. Komabe, kufufuza zochitika zimene makolo amakumana nazo posamalira ana omwe amagonekedwa ku chipinda cha ana odwalitsitsa cha Mercy James kuzathandizira kukumama ndi zosowa za osamalira ana odwala komanso kuchepetsa nkawa za makolo panthaŵi yomwe agonekedwa ndi ana mu chipindachi.

### **Zobwezeredwa**

Dziwani kuti simudzalandira chiwongola dzanja chilichonse potenga nawo mbali mu kafukufukuyi.

### **Chinsinsi**

Pakuti kafukukuyi akuchitikila pa chipatala nkutheka makolo ena komanso ogwira ntchito za chipatala atha kumakufunsani mafunso ngati inu mutavomera kutenga nawo mbali. Dziwani kuti sindidzagawira zomwe mwandiuza wina aliyense amene ali kunja kwa gulu lakafukufuku. Zomwe ndizasonkhanitse kuchokera mu pulojekitiyi zidasungidwa pamalo obisika. Zambiri zokhudza inu zidzakhala ndi nambala m'malo mwa dzina lanu. Ndipo ine ndekha ndi amene ndizathe kudziwa nambala yanu komanso zonse zidasungidwa mu kabati yotsekedwa bwino ndi makiyi ndipo izi sizidzaperekedwa kwa wina aliyense kupatula ondiyang'anira.

### **Kugawana Zotsatira za kafukufuku**

Palibe chimene mudzandiuza chidzaperekedwa kwa wina aliyense kunja kwa gulu lakafukufuku, ndipo palibe chomwe mudzandiuza chizazindikirike ndi dzina lanu. Zotsatira za kafukufukuyu zidzafotokozeredwa kwa ogwira ntchito zachipatala ku chipinda cha ana odwalitsitsa ku Mercy James komanso ku msonkhano wa kafukufuku wa madotolo ndi anamwino ogwira ntchito ku mbali ya ana pa chipatala cha gulupu. Pambuyo pa misonkhano, tidzasindikiza zotsatira kuti onse okhudzidwa ndi kafukufukuyi aphunzire ku zotsatirazo.

### **Ufulu wokana kapena kusiya kutenga nawo mbali mu kafukufuku**

Simukukakamizidwa kutenga nawo mbali mukafukufukuyi ngati simukufuna, ndipo kusankha kusatenga nawo mbali sikudzakhudza chisamaliro cha mwana wanu mwanjira iliyonse. Mukhoza kusiya kutenga nawo mbali pa zokambiranazo nthawi iliyonse yomwe mwafuna popanda chithandizo cha mwana wanu kukhuzidwa. Ndidzakupatsani mwayi pamapeto a zokambirana kuti mumvetsere zomwe mumanena, ndipo mukhoza kupempha kusintha kapena kuchotsa magawo ena, ngati simukugwirizana ndi zolembe zanga kapena ngati sindinakumvetseni bwino.

### **Amene mungawafunse za kafukufuku**

Ngati muli ndi mafunso, mutha kufunsa pompano kapena nthawi ina. Ngati mungakhale ndi mafunso nthawi ina, chonde afunsemi anthu otsatirawa;

**Mayi Grace Chasweka,**

University of Malawi,

Kamuzu College of Nursing,

Post Office Box 415,

**BLANTYRE**

**0999 727 325**

**Email: [chasweka2017grace@kcn.unima.mw](mailto:chasweka2017grace@kcn.unima.mw)**

**Mayi Maureen Majamanda,**

University of Malawi

Kamuzu College of Nursing

Post Office Box 415,

**BLANTYRE**

**0992 160 415**

**Email: [mdmajamanda@kcn.unima.mw](mailto:mdmajamanda@kcn.unima.mw)**

Dziwaninso kuti kafukufukuyi anavomelezedwa ndi a komiti yowonetsetsa kuti anthu otenga nawo mbali mu kafukufuku ndi otetezedwa la ku Koleji ya madotolo komanso anavomelezedwa ndi akulu akulu a pachipatala cha pa gulupu pano.

Ngati mungakonde kudziwa zambiri za komitiyi, chonde funsani kwa;

Wa pampano,

Ku likulu la komiti,

P/Bag 360,

**Chichiri. BLANTYRE**

**Phone number: 01989766**

### **Gawo lachiwiri: fomu yachivomerezo**

Ine ndafunsidwa kutenga nawo mbali mu kafukufuku osanthula zimene makolo komanso oyang'anira ana amakumana zokhuza kutenga nawo mbali mu chisamaliro cha ana awo panthawi yomwe agonekedwa ku chipinda cha ana odwalitsitsa ku Mercy James.

Ndawerenga/ena andiwerengera zinthu zonse zokhuza kafukufuku ndipo ndinali ndi mwayi wofunsa mafunso ndipo ndakhutira ndi mayankho omwe aperekedwa. Ndikuvomera kutenga nawo mbali mukafukufuku mwakufuna kwanga.

Dzina la otenga mbali \_\_\_\_\_

Ndikusayina \_\_\_\_\_

Tsiku \_\_\_\_\_

Tsiku/mwezi/chaka

### ***Ngati ndi osadziwa kuwerenga/kulemba***

Ndachitira umboni kuwerengedwa bwino lomwe kwa kalata ya chivomerezo kwa omwe angathe kutenga nawo mbali mu kafukufuku ndipo ndikuvomereza kuti anali ndi mwayi wofunsa mafunso. Ndikuchitira umboni kuti iwo avomera kutenga nawo mbali mwakufuna kwawo ndi mosakakamizidwa.

Dzina la ochitira umboni \_\_\_\_\_ Chidindo cha chala cha opereka chivomerezo

Sayini ya ochitira umboni \_\_\_\_\_



Tsiku \_\_\_\_\_

Tsiku/mwezi/chaka

### **Ndemanga ya wofufuza**

Ndawerenga bwino lomwe ndiponso mwatsatanetsatane chidziwitso kwa omwe angathe kutenga nawo mbali mu kafukufuku, ndipo mwakuthekera kwanga ndawonetsetsa kuti wotenga mbali akudziwa kuti zotsatirazi zidzachitika:

1. Wotenga nawo mbali azatero mwakufuna kwawo
2. Wotenga nawo mbali ali ndi ufulu kusiya nthawi ina iliyonse yomwe angafune
3. Wotenga nawo mbali azasungiridwa chinsinsi

Ndikutsimikiza kuti wotenga nawo mbali anapatsidwa mwayi wofunsa mafunso wokhuzana ndi kafukufuku, ndipo ndayankha mafunso onse mwa kuthekera kwanga. Ndikutsimikiza kuti iwo sananyengeleredwe kuti avomere kutenga nawo mbali ndipo kuti kutenga mbali kwawo ndi kufuna kwawo ndi mosakakamizidwa.

Wotenga mbali apatsidwa kalata ya chivomerezoyi.

Dzina la wakafukufuku amene wotenga chivomerezo \_\_\_\_\_

Tsiku \_\_\_\_\_

Tsiku/mwezi/chaka

## **Appendix 2A: In depth interview guide: Question for Caregivers**

### **Section A: Demographic Data and Child Information**

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

### **Section B: In-Depth Interview Guide**

1. Tell me your experience of staying in the PICU at Mercy James?

**Probe:** how were you welcomed? What was your impression of the unit)

2. Tell me how you look at information sharing of Health care workers regarding your child in the PICU?

**Probe:** what information were you given about the PICU, your child's condition and treatment, how did they give this information to you written or verbally, in what language was it given, when was the information given (before, during or after procedures), who gave you the information (Doctor/Clinician, Nurse or if others specify), how important was this information during the care of child in the PICU).

3. How did you participate in decision making regarding your child's care whilst in the PICU?

**Probe:** Were you given opportunities to participate in decisions being made for your child regarding procedures, treatment and general care, were you involved in ward rounds, how did you feel when you were involved or not involved in decision making, are there any benefits you realized when you were involved? What was your experience like? Any likes and dislikes on your involvement in decision making at the PICU?

4. What were the care activities that you were allowed to participate in whilst at the PICU?

**Probe:** What care were you giving to your child in the PICU, how important was your involvement, what role did the Health care workers play in supporting you when caring for your child, how important was their role during care of your child in the PICU? What did you like and dislike about your involvement in the care?

**Thanks for Your Participation!**

**Appendix 2B: In depth interview guide: Question for Caregivers (Chichewa version)**

**Gawo loyamba (a): mbiri ya oyang'anira mwana ndi mwana**

1. Mungandifotokozeleko za mbiri yanu; (Muli ndi zaka zingati, tsiku lobadwa, mumapanga chiyani kuti mupeze ndalama zothandizila pakhomo, munaphunzira kufika pati, muli pabanja, ubale wanu ndi mwanayu ndi otani, mumapemphera mpingo wanji, mumakhala kuti, nanga kumudzi ndikuti)?
2. Mungandifotokozereko pang'ono za mbiri ya mwana yemwe akudwalayu; (ali ndi miyezi ingati/zaka zingati, anabadwa liti, ndiwamwamuna kapena wamkazi, muli mchipatala chifukwa cha vuto lanji, munabwera mchipatala liti, chibwerereni ndi chithandizo chanji chomwe mwanayu walandila)?

**Gawo Lachiwiri (B): Mafunso akuya a Oyang'anira Mwana**

1. Mungandifotokozereko mmene munali kukhalira ku chipinda cha ana odwalitsitsa ku Mercy James?

**Mafunso othandiza kupeza zambiri:** munalandiridwa motani?

2. Mungandifotokozereko mmene mumalandilira uthenga okhuza mwana wanu panthawi imene anagonekedwa ku chipinda cha ana odwalitsitsa ku chipatala cha Mercy James?

**Mafunso othandiza kupeza zambiri:** Munapatsidwa uthenga wanji wokhuza vuto la mwana wanu, chithandizo chimene amalandira komanso za mbali imeneyi ya chipatala cha ana odwalitsitsa, munapatsidwa uthengawu muzolembedwa kapena pakamwa, amakufotokozelani mu chiyankhulo chanji, mumapatsidwa uthengawu ndi ndani (adokotala, anamwino, kapena ndani),

uthengawu unali wofunikira bwanji pokhuzana ndi kasamalidwe ka mwana wanu mu chipinda cha ana odwalitsitsa?

3. Mumatenga nawo mbali motani popanga ziganizo zokhuza chisamaliro cha mwana wanu pamene anagonekedwa ku chipinda cha ana odwalitsitsa ku Mercy James?

**Mafunso othandiza kupeza zambiri:** kodi munali kupatsidwa mwayi otenga nawo mbali pa ziganizo zomwe zinali kupangidwa zokhuza mankhwala, zochitika komanso thandizo la mtundu uliwonse lomwe limaperekedwa kwa mwana wanu, munali kutenga nawo mbali panthawi imene adokotala anali kuyendera ndi kumuwona mwana wanu, mumamva bwanji pamene mwapatsidwa kapena simunapatsidwe nawo mwayi wotenga nawo mbali, pali ubwino wanjji womwe munawuwona ngati mwapatsidwa mwayi wotenga nawo mbali pa ziganizo zokhuza mwana wanu mu chipinda cha ana odwalitsitsa? Ndi zinthu ziti zimene munazikonda kapena simunazikonde zolingana ndi kutenga nawo mbali pa ziganizo zokhuza mwana wanu?

4. Mungandifotokozereko zinthu zimene mumatha kumpangila mwana wanu pamene anagonekedwa mu chipinda cha ana odwalitsitsa pa chipatala cha Mercy James?

**Mafunso othandiza kupeza zambiri:** ndi chisamaliro chotani chimene mumapeleka kwa mwana wanu panthawi imene anagonekedwa mu chipinda cha ana odwalitsitsa, kunali kofunikira bwanji kuti mutenge nawo mbali popereka chisamaliro cha mwana wanu, ogwira ntchito yachipatala amakuthangatirani motani panthawi imene mumapereka chisamalirochi kwa mwana wanu? Ndi zinthu ziti zimene munazikonda kapena simunazikonde zolingana ndi kutenga nawo mbali pa chisamaliro cha mwana wanu?

**Zikomo Potenga Nawo Gawo Pa Kafukufukuyi.**

### Appendix 3: Permission Letter to Conduct Research at QECH

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

All communications should be addressed to:  
The Hospital Director



In reply please quote **No.**

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

**Ref. No. QE/20**

**18<sup>th</sup> March, 2019**

Grace Chasweka  
Kamuzu College of Nursing  
P.O. Box 415  
**BLANTYRE**

Dear Grace,

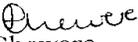
**PERMISSION TO CONDUCT A RESEARCH AT QUEEN  
ELIZABETH CENTRAL HOSPITAL**

I am pleased to inform you that management has no objection for you to conduct a research project on "**Experiences of Caregivers on Their Involvement in Children's Care at Mercy James Centre for Paediatric Surgery and Intensive Care in Blantyre, Malawi: A Family Centered Care Perspective**" 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  
**DEPUTY HOSPITAL DIRECTOR - NURSING**

## Appendix 4: Permission Letter to Conduct Research at Mercy James



### MERCY JAMES CENTRE FOR PAEDIATRIC SURGERY AND INTENSIVE CARE

C/O QECHI  
P.O Box 95,  
Blantyre.

13<sup>th</sup> March, 2019

To Whom It May Concern:

I am the head of Mercy James Centre and Consultant Paediatric Surgeon. I have received the proposal for a study from Grace Chasweka on "*Experiences Of Caregivers On Their Involvement In Children's Care At Mercy James Centre for Pediatric Surgery And Intensive Care In Blantyre, Malawi: A Family Centered Care Perspective*".

I believe this study will provide useful information on guardian perspective for those whose children are admitted in the Paediatric ICU. I am fully supportive of the study that is being proposed, and am happy to make Mercy James a site for this study as we are practicing Family Centered Care in our ICU.

Please do not hesitate to contact me if you have any questions.

Sincerely,

**Prof. E Borgstein**

ps Please send us a copy  
of the ethical approval  
letter from COMREC before  
you commence the study

## Appendix 5: Permission Letter to Conduct Research at QECH in Paediatrics Department



### COLLEGE OF MEDICINE

Principal:  
M. H. C. Mipando MSc PhD

College of Medicine  
Private Bag 360  
Chichiri  
Blantyre 3  
Malawi  
Telephone: 01 871911  
01 874107  
Fax: 01 874 700

Our Ref:

Your Ref:

The Chairperson,  
College of Medicine Research Ethics Committee,  
March 26th, 2019

Dear Chairperson

**Support for application for the protocol: "Experiences of caregivers on their involvement in children's care at Mercy James Paediatric Intensive Care Unit- A family centered care perspective"**

With this letter we would like to confirm the College of Medicine Department of Paediatrics and Child Health's support for the request for COMREC review of the protocol with the above title, by Ms Grace Chasweka and team.

A child's critical illness and admission to a Paediatric Intensive Care Unit is stressful to the family. The stress can affect their ability to comprehend information and participate in their child's care. However, this can be reduced when families are involved in the care of their hospitalized child, a practice known as Family Centred Care

In our setting, parents, especially mothers are expected to be at the bedside of a sick child during acute illness. The extent these caregivers are involved in their child's care is not known and their experiences regarding their participation and information sharing practices by health workers have not been previously studied hence the need for the study.

The proposed study would add to our understanding of the experiences that care givers have when they look after their acutely ill children in hospital, and help guide further research and evidence-based care and policies for intensive care units in Malawi and elsewhere

This study has been discussed within the Paediatrics and Child Health department. We therefore support this amendment to be reviewed by the COMREC.

Therefore, we hope that COMREC will consider the request of Ms Chasweka and her team positively.

Kind regards,

A handwritten signature in black ink, appearing to read 'Kondwandi Kawaza'.

**Dr Kondwandi Kawaza.** MBBS (MW), FC Paeds (SA), Cert. Neonatology (SA)  
Senior Lecturer, Paediatrician and Neonatologist,  
Director of Research, Department of Paediatrics and Child Health  
College of Medicine, University of Malawi



**Dr Yamikani Chimalizeni.** MBBS (Mw), MMed Paeds (Mw), FC Paeds (SA), Cert. Paed. Cardiology (SA)  
Senior Lecturer, Paediatrician and Paediatric Cardiologist  
Academic Head, Department of Paediatrics and Child Health  
College of Medicine, University of Malawi

**Appendix 6: Approval Certificate from college of Medicine Research Ethics Committee (COMREC)**



**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.04/19/2653 - Experiences of Caregivers on Their Involvement in Children's Care at Mercy James Paediatric Intensive Care Unit in Blantyre, Malawi: A Family Centered Care Perspective. Version 1.0 by Grace Chasweka

On 10-May-19

*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 some of which are indicated on the next page for your study*

*YBNA Loumba*

Dr. YB. Mlombé - Chairperson (COMREC)

Approved by  
College of Medicine

12-May-2019  
10-May-19

Date  
(COMREC)





## 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.04/19/2653 - Experiences of Caregivers on Their Involvement in Children's Care at Mercy James Paediatric Intensive Care Unit in Blantyre, Malawi: A Family Centered Care Perspective. Version 1.0 by Grace Chasweka

On 10-May-19

Approved by  
College of Medicine

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 some of which are indicated on the next page for your study

*YB Mlombe*

12-May-2019

10-May-19

Dr. YB. Mlombe - Chairperson (COMREC)

Date  
(COMREC)