PERCEPTIONS OF RELATIVES REGARDING FAMILY-CENTERED CARE AT A SOUTH AFRICAN PRIVATE HOSPITAL ADULT INTENSIVE CARE UNIT

Siyabonga Buthelezi

A research dissertation submitted to the
Faculty of Health Sciences, University of the Witwatersrand, Johannesburg
in fulfilment of the requirements for the degree
of
Master of Science in Nursing

Johannesburg, 2020

DECLARATION

I, Siyabonga Buthelezi, declare that this research dissertation is my own work. It is being submitted for the degree of Master of Science (in Nursing) at the University of the Witwatersrand, Johannesburg. It has not previously been submitted for any degree or examination at this or any other university.

Signature

......27th......day of.....October.....2020

Protocol Number: M181166

DEDICATION

Research report dedicated to my heavenly father (Almighty God), my late brother (Sibusiso Buthelezi) and to my late grandmother (Anna Buthelezi), May your souls rest in peace. My grandmother you will always be in my heart with your everyday words of wisdom that you spoke to me: “*In life you keep on pressing towards the goals you want to achieve”*.

ACKNOWLEDGEMENTS

In thee oh Lord I put my trust. I thank you my saviour (Jesus Christ) for giving me the strength every day to move on and leading me through mountains and hills. You did this to ensure my research study becomes successful at the end. Lord you deserve all the glory and praises.

I wish to express my deepest gratitude to my study supervisors, Professor Shelley Schmollgruber and Doctor Ntombifikile Klaas. I would like to thank you for the support, supervision, guidance and motivational words you gave me during the course of my MSc nursing research study with University of Witwatersrand. I thank you so much for taking me through the research journey. To both of you I raise a cheerful salute!

To my colleagues in multi intensive care unit of Life Rosepark Private Hospital in Bloemfontein, I thank you for the support you gave me through the entire coarse of this study and do not forget together we can be a leading intensive care unit (ICU) in the Free State Province. My colleagues at University of the Free State School of Nursing I appreciate from the bottom of my heart the support and encouraging words you gave me before and during the study period.

To my father (Fanifani Buthelezi) and my mother (Shonephi Buthelezi) thank you for encouraging me to study further, you said to me: “*Only the sky can limit our abilities*”. I thank you for all the support you provided to me, may the Lord bless you abundantly. I thank God for giving me parents like you. To my sibling brothers thank you for being there when I needed you the most in life.

Lastly I would like to thank my spiritual family and friends, thank you so much for the support and help you provided to me during this study. It takes many people really to raise a child. I was not alone in this but you were there as spiritual brothers, sisters and parents. I appreciate all of you from the bottom of my heart.

ABSTRACT

Aim: The purpose of this study is to describe the perceptions of family members regarding family-centred care in an adult intensive care unit at a private hospital in the Free State province, South Africa.

Setting: The setting for this study was the adult intensive care unit of a private hospital in the Free State province, South Africa. This is a general intensive care unit.

Methods: An explanatory sequential mixed method design was utilised for this study; it comprised of both quantitative and qualitative methods. The qualitative data was collected after the quantitative data collection. The sample consisted of 80 family members of patients admitted to adult ICU of the study site from September 2018 to February 2019. Random sampling will be used to select the family member participants. Data was collected using a validated questionnaire: Family Centred Care Survey developed by Mitchell *et al.* (2009). In addition, semi-structured interviews were conducted with a sample of 20 purposively selected family members.

The quantitative data analysis was analysed using descriptive summary statistics such as frequencies, percentages, medians and inter-quartile ranges. Also, the qualitative data was analysed using the method of Clarke and Braun (2013). Themes and sub-themes were identified and reported in the narrative. Findings of both quantitative and qualitative methods were reported separately and then integrated to make recommendations for FCC in the adult intensive care unit.

Results: In phase 1: quantitative findings indicated that out of 80 relatives who participated in the study, 60% agreed with the existence of respect in ICU as 70% of participants felt welcome to attend in ICU with their relatives. The median response on the aspect of respect was 3 (IQR 2-4) still show average agreement on respect as perceived by relatives. On the collaboration aspect on family centred care from 80 relatives who participated 74% agreed to have perceived collaboration in family centred care as attested by 63.8% of respondents who agree to have received honest information and 72.5% of participants knew the treating Doctor for their loved one. The median response on support scale was 3 (2-4) meaning relatives were on average agreement with adequate support in ICU of South African Private Hospital. Out of 80 participants, 60% agreed with the existence of support in the unit.

In phase 2: qualitative study explored the perceptions of relatives regarding family-centred care through semi-structured face to face interviews. Emergent themes that came up from the interviews were communication, partnership, caring environment, Proximity need, religion and cultural practices. These emergent themes were accompanied by sub-themes with the following prevailing issues of lack of updates, health care providers attitude, communication technology, incomplete hand over, involvement in activities, learning opportunities, feeling of relief, respect and dignity, family support, fair treatment, visiting hours, family bonding, cultural and religious inclusion.

Communication came up as the main theme; participants were satisfied with communication with the nurses and answers given by nurses at the bedside. Relatives perceived that nurses were treating their relatives with respect and dignity as they communicated with mechanically ventilated patients, sedated and ensuring privacy. Families were not satisfied with communication with treating Doctors as they did not get updates about their loved ones. Relatives described communication with Doctors in ICU as “rushed communication”. The lack of proper communication exacerbates stress and suffering to family members—incomplete handover between health care providers perceived to be disturbing adequate health care service delivery to patients.

Family members want to collaborate with health care providers in rendering health care to their loved ones. Most family members are willing to be involved in the plan of care, like bathing, combing hair and cut nails. Families suggested that activities of collaboration with nurses should be under supervision. Other family members felt that they do not want to interfere with health care providers. Families who wish to participate in care feel that they are helping their loved one in ICU. Families reported that being part of care provides the feeling of relief to family members. Relatives voice out concerns about cultural and religious practices that still need improvement in the unit. The ICU should allow them to do their rituals and prayers as they believe it helps and also provides support to patients. Participants want to be treated the same and fair despite religion, colour, gender and race as they visit in the intensive care unit. Most participants appreciated the support received in the unit from health care providers, and they ended up developing a trust relationship with nurses in the unit. Families that required further support emotionally were referred for further counselling and support.

Key words: family-centred care, adult intensive care unit, South Africa

TABLE OF CONTENTS

Page

DECLARATION ii

DEDICATION iii

ACKNOWLEDGEMENTS iv

ABSTRACT v

TABLE OF CONTENTS vii

LIST OF FIGURES xii

LIST OF TABLES xiii

CHAPTER ONE: OVERVIEW OF THE STUDY

1.0 INTRODUCTION 1
1.1 BACKGROUND OF THE STUDY 1
1.2 PROBLEM STATEMENT 5
1.3 AIM OF THE STUDY 5
1.4 RESEARCH QUESTION 5
1.5 OBJECTIVES 6
1.6 SIGNIFICANCE OF THE STUDY 6
1.7 RESEARCHER’S ASSUMPTIONS 6
1.7.1 Meta-theoretical Assumptions 6
1.7.2 Theoretical Assumptions 8
1.7.2.1 Definitions of concepts 9
1.7.3 Methodological Assumptions 11
1.8 OVERVIEW OF RESEARCH METHODOLOGY 11
1.9 OUTLINE OF THE DISSERTATION 12
1.10 SUMMARY 12

CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION 13
2.2 GENERAL FAMILY SYSTEMS THEORY AND APPLICATION TO 13

THE STUDY
2.2.1 Family Coping during Critical illness 15
2.3 CRITICAL ILLNESS 17
2.3.1 The Effects of Critical illness to Family Members 17
2.3.2 Role Changes in the Family due to Critical illness 18
2.4 PATIENT AND FAMILY CENTERED CARE 19
2.4.1 Family Needs 20
2.4.2 Informational Support, Anxiety and Satisfaction with Care 22
2.4.3 Family Satisfied with Care 23
2.5 FAMILY FOCUSED AND FAMILY CENTERED CARE 25
2.5.1 Theories Underlying Family Centered Care 27
2.5.1.1 Carl Rogers theory 27
2.5.1.2 General Family Systems Theory 28
2.5.1.3 Models of Family Centered Care 29
2.5.2 Family Members Perceptions of Participation of Support 31
2.5.3 Nursing Support of Family Members in ICU 33
2.6 SUMMARY 34

CHAPTER THREE: RESEARCH METHODOLOGY

3.1 INTRODUCTION 36
3.2 RESEARCH PARADIGM 36
3.3 RESEARCH DESIGN 38
3.3.1 Mixed Methods 38
3.3.2 Explanatory study 38
3.3.3 Sequential study 39
3.4 RESEARCH SETTING 39
3.5 PHASES OF RESEARCH 40
3.5.1 Phase One: Quantitative Study 41
3.5.1.1 Population 41
3.5.1.2 Sample and sampling 41
3.5.1.3 Data collection 42
3.5.1.3.1 Pilot testing 43
3.5.1.3.2 Data collection process 43

3.5.2 Phase Two: Qualitative Study 44
3.5.2.1 Population 44
3.5.2.2 Sample and sampling 44
3.5.2.3 Data collection 45
3.5.2.4 Data collection process 45
3.6 DATA ANALYSIS 47
3.6.1 Quantitative Data Analysis 47
3.6.2 Qualitative Data Analysis 47
3.6.3 Interpretation of Results and Integration of Data 49
3.7 ACADEMIC RIGOUR 49
3.7.1 Validity and Reliability 50
3.7.1.1 Validity 50
3.7.1.2 Reliability 50
3.7.2 Measures of Trustworthiness 50
3.7.2.1 Credibility 51
3.7.2.2 Transferability 51
3.7.2.3 Dependability 51
3.7.2.4 Confirmability 51
3.8 ETHICAL CONSIDERATIONS 52
3.8.1 Permission to Conduct Research 52
3.8.2 Informed Consent 52
3.8.3 Anonymity and Confidentiality 53
3.8.4 Management of Data and Security 53
3.9 SUMMARY 53

CHAPTER FOUR: DATA ANALYSIS AND RESULTS

4.1 INTRODUCTION 54
4.2 PHASE ONE: QUANTITATIVE FINDINGS 54
4.2.1 Demographic Data of the Relatives 54
4.2.2 Demographic Data of Patients in the ICU 60
4.2.3 Relatives Perceptions of Family Centered Care in ICU 60
4.2.3.1 Perceptions of relatives regarding respect in family centred care 62
4.2.3.2 Perceptions of relatives regarding collaboration in family centred 65

care
4.2.3.3 Perceptions of relatives regarding support in family centred care 67
4.3 PHASE TWO: QUALITATIVE FINDINGS 67
4.3.1 Demographic Data of the Participants 68
4.3.2 Emergent Themes 68
4.3.2.1 Theme One: Communication 70
4.3.2.1.1 Lack of updates 70
4.3.2.1.2 Healthcare providers' attitudes 70
4.3.2.1.3 Communication strategies 71
4.3.2.1.4 Incomplete handover 71
4.3.2.2 Theme Two: Partnerships 72
4.3.2.2.1 Involvement in activities 72
4.3.2.2.2 Feeling of relief and helping 74
4.3.2.2.3 Learning opportunities 74
4.3.3.3 Theme Three: Caring Environment 76
4.3.3.3.1 Respect and dignity 76
4.3.3.3.2 Unfair/Unequal treatment 76
4.3.3.3.3 Family support 78
4.3.3.4 Theme Four: Proximity Feeling/Need 80
4.3.3.4.1 Visiting hours 80
4.3.3.4.2 Family bonding 83
4.3.3.5 Theme Five: Religion and Culture 85
4.3.3.5.1 Cultural Inclusion 85
4.3.3.6.2 Religious practices 86
4.6 SUMMARY 88

CHAPTER FIVE: DISCUSSION OF FINDINGS

5.1 INTRODUCTION 89
5.2 PHASE ONE: DISCUSSION OF QUANTITATIVE FINDINGS 89
5.2.1 Respect in family centred care 89
5.2.2 Collaboration in family centred care 90
5.2.3 Support in family centred care 91
5.3 PHASE TWO: DISCUSSION OF QUALITATIVE FINDINGS 93

5.4 INTERPRETATION OF RESULS AND INTEGRATION OF DATA 101
5.4 SUMMARY 103

CHAPTER SIX: SUMMARY OF THE STUDY, MAIN FINDINGS, CONCLUSION AND RECOMMENDATIONS
6.1 INTRODUCTION 104
6.2 SUMMARY OF THE STUDY 104
6.2.1 Aim of the Study 104
6.2.2 Objectives 104
6.2.3 Methodology 104
6.3 SUMMARY OF MAIN FINDINGS 105
6.4 APPLICATION OF THEORY TO FINDINGS 107
6.5 LIMITATIONS OF THE STUDY 108
6.6 RECOMMENDATIONS ARISING FROM THE STUDY 109
6.6.1 Recommendations for Clinical Practice 109
6.6.2 Recommendations for Education 110
6.6.3 Recommendations for Further Research 110
6.7 Conclusions 111

LIST OF REFERENCES 112

APPENDICES

APPENDIX A Data Collection Instrument 120
APPENDIX B Information Letter 123
APPENDIX C Consent Form 124
APPENDIX D Consent for Audio Tape Recording during the Interview 125
APPENDIX E Semi-Structured Interview Guide 126
APPENDIX F Example of Transcript from the Interview 127
APPENDIX G Ethical Clearance Certificate 131
APPENDIX H Permission to Conduct Research 132
APPENDIX I Postgraduate Approval of Study 133
APPENDIX J Permission to use Instrument 134
APPENDIX K Language Proofing and Editing 135

LIST OF FIGURES

Figures		Page
2.1	Family centred care concepts	27
2.2	The three models of benefits of family centred care approach	31
4.1	Age distribution of the participants	56
4.2	Ethnic background of the participants	56
4.3	Participants’ relationships to patients	57
4.4	Level of education of the participants	57
4.5	Distance to the hospital	58
4.6	Reason for patients’ admission to ICU	58
4.7	Patients’ severity of illness in ICU	59
4.8	Patients’ length of stay in ICU	59

LIST OF TABLES

Table		Page
3.1	Summary of study phases	40
3.2	Thematic analysis steps by Clarke and Braun (2013)	48
4.1	Demographic characteristics of the study sample	55
4.2	Descriptive statistics of perceptions of relatives regarding respect in family centred care	61
4.3	Descriptive statistics of perceptions of relatives regarding collaboration in family centred care	63
4.4	Descriptive statistics of perceptions of relatives regarding support in family centred care	66
4.5	Themes emerging from qualitative interviews	69

CHAPTER ONE

OVERVIEW OF THE STUDY

1.0 INTRODUCTION

This chapter provides an overview of the study and includes the background, problem statement, research questions, aim and objectives of the study and its significance. The researcher's assumptions and key concepts of the study are defined and elaborated upon, and an overview of the research methodology and layout of the study are briefly described.

This research dissertation sought to investigate the perceptions of family members of critically ill patients regarding family centred care in the South African context.

1.1 BACKGROUND OF THE STUDY

Nursing care practices have evolved from patient-centered care to family-centred care. Family-Centred Care (FCC) is a paradigm shift in the healthcare system striving to change nurses from viewing families as visitors, to being partners in healthcare. This type of care in adult Intensive Care Units is still under improvement, and more needs to be done to move it to adult settings. It is broader than what has been implemented in paediatric units and palliative care, which shortens the philosophy of FCC (Mitchell *et al.*, 2009).There are principles and components integrated into FCC.

The Institute of FCC outlines the vital components of this care as to treat someone with respect and dignity, sharing of information between healthcare providers and families, participation in decision making, and collaboration between families and the interdisciplinary team. These components are underpinned by the following principles: a) family and interdisciplinary team working as partners for the best interest of the patient, b) respect of skills and knowledge in a relationship, c) trust is an essential aspect to families and healthcare providers, d) open communication, e) sharing of objective data, and f) participative decision making as well as negotiations; these are the principles of strengthening FCC in children`s units and palliative care (Mitchell *et al.*, 2009).

The FCC approach originated in paediatric care domains, but its use has extended to other domains of nursing such as palliative care. This mutually grounded care has shown positive outcomes to these domains. Parents felt more satisfied when they participated in the care of their children,and the children`s needs were met children want to be around familiar faces, and feel like they are at home. This care is becoming popular in adult Intensive Care Units because we are bridging the gap and trying to improve family experiences. Research states there is still a gap to incorporate FCC to adult Intensive Care Units (Mitchell *et al.*, 2009).

The ecological theory emphasises the significance of treating a patient in a family context;this means in addition to immediate family, extended family members should be considered. Carl Roger`s theory emphasises therapeutic relationships in family life and society. This theorist views the individual interacting with other people. The Association for the Care of Children`s Health states the importance of family in a child`s well-being and health (Bamm and Rosenbaum, 2008). The General Family Systems Theory considers the family as a system made up of elements (family members) with functional interactions amongst each other. There are subsystems (extended family members) that function in the same manner as the primary system. The equilibrium state of the family remains constant until external factors like critical illness attack the system and bring chaos in the family by disorganising the whole system. Family is stronger together as a unit rather than one individual (Morgaine, 2001). The FCC approach serves a specific purpose in health care.

The main aim of FCC is to bring patient`s families into partnership with healthcare providers in planning, rendering and evaluating effectiveness of care in adult Intensive Care Units. Satisfaction with the ICU experience is enhancedby allowing families to be extensively involvedduring the treatment of their family member. The families should be at the centre of care for their loved ones and be supportive (Latour and Coombs, 2017), as there are benefits for both parties associated with this care. The theories, in short, have provided a broader view of understanding FCC (Bamm and Rosenbaum, 2008).

Patients feel safe and assured that family members were well looked after, and family members provide support which relieves the feeling of struggling for the patient (De Beer and Brysiewicz, 2016a). They bring the spiritual and cultural practices to the patient, and they know the patient better than the nurses (De Beer and Brysiewicz, 2016a). Critically ill patients cannot make decisions for themselves due to the severity of the condition; in this instance, family members serve as advocates for the patient. They discuss amongst themselves about the care of their loved one then bring the joint decision to healthcare providers. Patient`s rights are advocated by the family. Family and healthcare professionals advocate the right of keeping confidential information and other private matters of the patient. They also help the patient during recovery to backup lost memory. All this contributes to positive outcomes for patients (Bailey *et al.*, 2010).

Families also want to be part of the recovery of their family members, partake, render emotional support and provide hope, as well as to collaborate with nurses. Family-centered care promotes participative decision making, information sharing and honest information to be given to families, all of which contributes to family satisfaction (De Beer and Brysiewicz, 2016b). The grounded mutual care requires them to be involved in planning and rendering of care to patients. They should be involved in the structured care of the patient, and minimal training or guidance from the Intensive Care nurse helps them. They also help with small activities, such as wiping of the face and washing hair, to complex activities, such as assisting ICU nurses in changing the positions of the patient on the bed. Research reveals that families feel they are part of the care and help. They know the patient`s preferences from experience at home, and this is integrated intothe plan of care (Mitchell and Chaboyer, 2010).

Family-centered care promotes the respect of family culture beliefs and religious affiliations. Families feel accommodated when they are allowed to do some cultural rituals and religious beliefs, such as placing their Gods' pictures next to the critically ill member (De Beer and Brysiewicz, 2016a). Healthcare providers should remain sensitive to culture and religious affiliations of families.

The family has a need to be given enough clear and consistent information about the patient. Literature can be included whenever they do not understand something explained to them. Family-centered care provides a holistic approach to caring for patients and families.

To provide holistic care to a patient, all patient and family needs have to be met,and family participation in the care should be a part of holistic care (Mitchell *et al.*, 2009). Families function as a unit, which means an injury to one is an injury to all. The admission of the critically ill family member into the Intensive Care Unit is a stressful and challenging moment for the family, and critical care nurses should be ready to face disorganised and anxious family members. Intensive Care nurses need skills to deal with the situation in a manner that promotes FCC (van Mol *et al.*, 2017).

When collaborating with the family, the ICU nurse should explain and provide education where it is needed, and this comes with effective communication (De Beer and Brysiewicz, 2016a). Some Critical Care nurses accept that families provide good connections about the patient and they are a source of patient information (Mitchell *et al.*, 2009). Healthcare providers are still concerned about open visit policies, some of them mention the increase in workload, the patient right of privacy not being ensured and changes in patient condition (Chapman *et al.*, 2016).

There is a mix of both negative and positive experiences from the nurses regarding FCC in Intensive Care Units. There are more ICU nurses who are satisfied withfamily-centered care in Intensive Care Units than those not in favour (Chapman *et al.*, 2016).The difference between the nurse’s attitudes was the experience of working in the ICU and old training versus new training. The nurses who trained 20 years ago see family as interfering, compared to those who trained recently (Chapman *et al.*, 2016). The ICU takes responsibility to care for the family members of the sick patient (Latour and Coombs, 2017).

Research states that there is still a gap to incorporate FCC in adult Intensive Care Units (Mitchell *et al.*, 2009). This is due to certain aspects that need to be modified because they are barriers to FCC to take place. The visitation restriction policies in the adult ICU are stressful for family members, and research has shown that a visit from the family enhances cardiovascular function to the ill person (Chapman *et al.*, 2016). Healthcare providers are however concerned about open visit policies, some mention the increase in workload, the patient’s right of privacy not being ensured and changes in patient condition (Chapman *et al.*, 2016);other barriers are poor communication by the healthcare providers and negative attitude from the personnel. Nurses’ behaviours are driven by unit policies, busy unit routines and level of education to Intensive Care nurses (van Mol *et al.*, 2017).

1.2 PROBLEM STATEMENT

Family involvement in the care of patients has been found to have a positive effect on the patient’s well-being and recovery. The concept of caring in the context of family refers to the support and family involvement in the care and decision making of the critically ill patient; however this has never been formally evaluated. The lack of a well-established FCC model of care in the ICU contributes to incidents of dissatisfaction with care; the introduction of such care would reduce family complaints, improve family satisfaction and patient outcomes. In order to establish a family-centred environment, the researcher intends to explore the views of families regarding FCC in the ICU and recommend strategies to enhance a family-centred critical care environment, thereby reducing family dissatisfaction.

1.3 AIM OF THE STUDY

Based on the problem, the aim of the study was to describe the perceptions of family members of patients admitted in the adult ICU regarding family-centred care.

1.4 RESEARCH QUESTION

The study attempted to address the following research question:

- What are the perceptions of family members of patients admitted to a general Intensive Care Unit regarding family-centred care?

1.5 OBJECTIVES

The objectives of the study were:

- To describe the perceptions of family members of patients admitted to a general ICU regarding FCC (quantitative study).
- To explore the views of family members of patients admitted in a general Intensive Care Unit concerning family-centred care (qualitative study).

1.6 SIGNIFICANCE OF THE STUDY

This study intended to obtain an understanding of family members’ perceptions of family-centred care in adult ICUs. Without this knowledge, it is difficult to implement appropriate nursing care that is deemed important to family members. By conducting this study, the results could contribute towards clinical practice in the drive towards family-centred care. It could improve or reinforce the quality of care offered by nurses, as well as highlight and help to define what family members perceive as important in a South African context.

1.7 RESEARCHER`S ASSUMPTIONS

1.7.1 Meta theoretical assumptions

Meta theoretical assumptions are basic principles acknowledged to be true without being proven, these principles are based on logic, customs, theories and nursing research (Polit and Beck, 2012). The meta-theoretical assumptions of nursing comprise the person, environment, health and nursing, particularly applied to the specialty of Intensive Care nursing.

- **Person**

A person is a holistic individual with complete body, mind and spirit and not to be viewed as the sum of body organs (Schmollgruber, 2015). In this study, the person will be the critically ill patients in the adult Intensive Care Unit and their family members.

A person is someone who interacts with other people on Earth, and because life has its difficulties, there is interdependency of a person with other people. A person is a person because of other people, which simply means you do not live alone as you need to interact with other individuals. The social life drives people from being alone, with no social interaction amongst each other, by bringing the society into a state of socialising in nature.

- **Environment**

This is a place where human beings live and interact amongst each other. The environment remains stable but due to changes in human behaviour, these changes are noted in the environment as brought by humans. There are two environments in nature, the internal and the external environments, and they both in interact with the external influencing the external environment.

- **Health and wellness**

Health is a state of being free from illness or sustained injury and incorporates human beings` physical and mental condition (Oxford English Dictionary, 2015). The World Health Organization (2016) defines health as “A state of being complete physical, mental and social well-being and not merely the absence of disease or infirmity.”

This is the state of being fully functional and normal with all your body systems, without any illness bothering you and everything within you being satisfied; this contributes to state of wellness. The state of being in good health encompasses all the psychological dimensions of human beings, spiritual, physical, cultural and social dimensions.

- **Nursing**

Nursing refers to a profession of caring for sick individuals by people regulated by the profession to render healthcare to those in need of it. Nursing entails providing support, hope and treating someone with dignity and respect until death (South

African Nursing Council, 2005). For this study, nursing implies Intensive Care nursing rendered to a critically ill patient in an adult Intensive Care Unit.

Nursing entails the provision of holistic care to people who are sick, which is a required component wherever human beings exist and function. It does not necessarily imply giving treatment to a person, but comprehending the unique meaning of life for that individual and setting a specific nursing care plan for that individual. Nursing begins when someone is being conceived, because the wellness of that individual needs to be looked after, and continues there onwards.

1.7.2 Theoretical Assumptions

Theoretical assumptions refer to theories or models used as a point of departure for the study. Two theories used in this study were the Family-Centred Theory by Carl Roger in (1959) and the Ecological Theory by Bronfenbrenner (1979). These theories will explain the starting point of FCC (Bamm and Rosenbaum, 2008).

The family-centred theory talks about therapeutic relationships between family life and society. The main point from this theory is that the therapeutic care and recovery can become affected if the person is not part of the family dynamic and social life involvement. The study is on family-centred care therefore the admitted patient is part of the family, and while in hospital, he is concerned about social life and the events happening in the family. The patient needs family support and life continues while he/she is in hospital. Family also forms part of a patient`s wellbeing (Shields, 2010).

The ecological theory emphasises not only the immediate family, but also extended family and the environment. This theory gives the understanding that a person is not only vital to his family members living with him under the same roof, but also to people living far from him. This theory incorporates friends of the patient, as they play a part in his social life.

This study is on family-centred care as it shifts from client-centred care. The study emphasises the importance of treating the patient in a family context. Although the patient is critically ill, he/she needs people close to them, even relatives and friends (Bamm and Rosenbaum, 2008).

1.7.2.1 Definitions of concepts

- **Intensive Care Unit (ICU)**

This refers to a multidisciplinary and inter-professional specialty dedicated to the comprehensive management of patients having, or at risk of developing, acute life threatening organ dysfunction. Intensive Care uses a wide range of technologies that provide support of failing organ systems, particularly the lungs, cardiovascular system and kidneys (Marshall *et al.*, 2017). Intensive Care is a unit within a hospital where critically ill patients are cared for under continuous observation by speciality-trained healthcare personnel from various fields in the interdisciplinary team. For this study, the ICU is a place in hospital where the critically ill adult family member is admitted in a critical condition and visited by family members during the critical illness.

- **Critically ill patient**

This is a person who is a recipient of care in the healthcare institution (Oxford English Dictionary, 2015). In the study, the patient will be an adult person who is admitted in the adult Critical Care Unit and receiving healthcare treatment. The researcher will align himself with this definition.

- **Family**

Family is “a unit whomever participants identified as a family, people offering support to the patient and they are related to the patient” (Kean and Mitchell, 2014). Family in this study are the persons living with the patient under the same roof, or extended family members who regularly visit the patient but are not living under same roof.

- **Family-Centred Care (FCC)**

Refers to “an approach grounded in mutually beneficial partnerships between patients, families and health care professionals.” Family-centred care has the following components: dignity, respect, information sharing, participation and collaboration. It is a way of caring for patients and their families with all healthcare services. This is done by ensuring that family members participate in the decision making process and are actually care recipients (Shields, 2010). This is a main concept of the study with its concepts incorporated in the definition; the researcher will broaden the understanding of this concept through the study being conducted. The family is allowed to be part of care of their loved one and not limited, and they carry out some activities of care for the patient. The researcher will align himself with this definition.

- **Intensive Care Nurse**

Intensive Care nurse is a person who has completed a basic nursing degree, four years diploma or qualified in general nursing science and has advanced training in the critical care-nursing field through specialisation in Intensive Care nursing sciences. This person is accredited by the South African Nursing Council and is registered under R212 of 1993, as amended (Scribante *et al*., 2004). In this study, a registered nurse refers to a qualified or experienced Intensive Care nurse, registered with the South African Nursing Council and providing care in an adult ICU.

Registered nurse refers to a qualified or experienced Intensive Care nurse, registered with the South African Nursing Council and providing care in an adult ICU.

- **Perceptions**

Perception is someone’s ability to see, hear and become aware of something through his or her sense organs. It entails the way something is viewed, understood and interpreted by a person (Oxford English Dictionary, 2015). In this study, this will be the perceptions of families who will be interviewed on how they perceived the family-centred care in the adult Intensive Care Unit, and will involve their feelings and views about such units.

1.7.3 Methodological Assumptions

The research paradigm for this study is pragmatism (Welford *et al*., 2011). The study will utilise a sequential explanatory mixed method design. It involves first collecting quantitative data (phase 1) to help explain or elaborate on the qualitative data (phase 2) results (Creswell and Plano Clarke, 2011). The reason for this approach is that quantitative data provides a general picture of the research problem, and more analysis, through qualitative data collection is needed to explain the general picture.

1.8 OVERVIEW OF RESEARCH METHODOLOGY

A sequential explanatory mixed methods design was used to achieve the study objectives. The study respondents were family members of patients admitted to ICU in a private hospital in Bloemfontein, Free State Province. The ICUs included were General ICU.

Ethical clearance and permission to conduct the study was sought from the relevant university committees, Department of Nursing, and School of Therapeutics in the Faculty of Health Sciences. Participation in the study was voluntary and participants were free to withdraw at any time. After permission had been obtained from the hospital and relevant ICU nurse managers, consent was obtained from the family members who agreed to participate in the study.

The study comprised of two sequential phases, namely a quantitative phase (Phase 1) followed by a qualitative phase (Phase 2). In Phase 1, data was collected using a self-administered survey questionnaire (Mitchell *et al*., 2009). Descriptive and inferential statistics were used to analyse the results of the study. Reliability of the study was maintained by ensuring the researcher was the sole data collector of the data, the sample size was achieved purposively and the data was verified by a biomedical statistician to ensure accuracy of the findings. The validity of the research was achieved by ensuring the data collection instrument was verified by ICU clinical and education experts to fit into the South African context.

In Phase 2, data was collected using semi-structured interviews. Qualitative thematic analysis was used to analyse the data (Clarke and Braun, 2013). Concepts of credibility, reliability, dependability and conformability were used to maintain trustworthiness of the study. The accuracy of the study was enhanced by ensuring the researcher was the sole collector of the data, with an enquiry audit by the supervisors, the sample size was achieved purposively, and data was verified by participants through member checking. An audit trail was done by an experienced researcher to ensure truth of findings.

1.9 OUTLINE OF THE DISSERTATION

The dissertation entails the following chapters in which the research study is described:
Chapter One: Overview of the study
Chapter Two: Literature review
Chapter Three: Research methods
Chapter Four: Findings of the study
Chapter Five: Discussion of findings and limitations
Chapter Six: Summary of the study, main findings, limitations, recommendations and conclusion

1.10 SUMMARY

This chapter has given an overview of the study. It incorporated the background of the study, problem statement, study aim, objectives of the study, significance of the study, researcher`s assumptions, definitions of concepts, research methods, population and unit of analysis. There is data collection, data analysis, validity and reliability, trustworthiness and ethical considerations.

In the next chapter, the review of the literature will be discussed in detail.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter presents the discussion of the literature reviewed about the perceptions, opinions and experiences of family members of critically ill patients regarding family-centred care. A literature review provides evidence that research was undertaken within an existing or current knowledge background, the existing literature was considered, and the knowledge has been critically appraised by reading broadly on literature (Polit and Beck, 2012).In the literature review, the key concepts of the study and theory guiding the research are explained as well as the discussion of the conceptual framework (Badenhorst, 2012).

The literature review will begin with the discussion of theory and the application of this theory to the study. This is followed by a family coping during critical illness, the concept of critical illness, and the impact it has on the family, role changes in family due to critical illness, family needs, patient and family-centred care, informational support, anxiety and satisfaction with care, family member’s perceptions of participation of support and nursing support of family members in the Intensive Care Unit. The chapter concludes with the summary.

2.2 GENERAL FAMILY SYSTEMS THEORY AND APPLICATION TO THE STUDY

The General Family Systems Theory comes from General Systems Theory by scholars who found it applicable to families and other social systems. Families are regarded as systems because they interact amongst themselves due to sharing certain elements. These interactions are accompanied by interdependency between family members that exist because of family function, such as a stable unit. Family members are regarded as elements of the system (Morgaine, 2001).

The system has subsystems attached to it, and these subsystems are people related to the family. Each element in the system has unique characteristics, and there are existing relationships between the elements. The system interacts in predictable patterns. The continued cycle helps the family by maintaining equilibrium and gives direction to the functioning of elements. There are open and closed boundaries existing in the system. The open boundary system allows external factors to influence the system, while the closed boundary system creates an atmosphere of isolation; as a result, the system is not completely closed. The system is also composed of parts, with the ‘whole’ being more than the sum of the parts. The equilibrium state of family dynamics is kept constant until the external factors disturb the equilibrium, such as during a critical illness period. The family remains united at all times, but during the chaos, the roles in the system become disorganised. Other elements in the system should take on new roles for the system to continue functioning during the loss of equilibrium. The whole picture of the family is reflected holistically. In the system, there are subsystems that interact in relation to the system, sharing the same rules and characteristics with the main system (Morgaine, 2001).

The General Family Systems theory describes the family as composed of family members with different characteristics; the family remains united despite different characteristics. Family members are brought together by family beliefs, values and cultural practices. Family members know each other very well, and they have a way of interacting with each other, which helps to keep the state of equilibrium in the family. In the end, the family has to function as a unit, but some factors affect the state of equilibrium. Critical illness of one family member disorganises the whole family, crashing down the equilibrium of the family system (Koukouli *et al.*, 2018);all family members will be affected. Life does have ups and downs’ that bring tension to the family. The sudden admission of a family member in an Intensive Care Unit (ICU) is chaotic and brings disruption to the family system (Schmollgruber, 2019).

The family shares the same cultural beliefs, values and performs their rituals together those not living under the same roof but are still related to the family, either biological related or not, also have the same cultural background with the affected family. The family is stronger than is one individual member. Family members care about each other, and that caring recognises the family as a unit, not individuals.

Family care that exists amongst family members promotes therapeutic relationships in the family (De Beer and Brysiewicz, 2019).

Family is “a unit whomever participants identified as a family,”“people offering support to the patient and they are related to the patient” (Kean and Mitchell, 2014). Family in this study is the person living with the patient under the same roof, or extended family members who come regularly to visit the patient but not living under the same roof. Mitchell and Chaboyer (2010) defined family as “someone who visited the patient and had a direct relationship with the patient.” The role of family members in Intensive Care Units is perceived to be significant because it aids in providing holistic care to the critically ill patient. Bailey *et al.* (2010), found that family members played a significant role by enhancing psychological wellbeing of critically ill patients through a familiar, caring presence, providing support, and interacting with the patient and partnering with healthcare providers in order to get the patient`s needs and family needs met.

Family members have their needs as they come to the Intensive Care Unit to see their loved ones. Bailey *et al.* (2010), describes a Critical Care family needs inventory that outlined the needs of ICU family members. These family needs were grouped into five domains, 1) need for assurance, 2) proximity need, 3) need for comfort, 4) need for support and 5) need for information. To enhance positive outcomes for both the critically ill patient and family members, healthcare providers should attend to the needs of family members during the critical illness period (Bailey *et al.*, 2010).

2.2.1 Family Coping during Critical illness

Rückholdt *et al.*(2019), define coping as someone’s cognitive and behavioural abilities to react during stressful events in life to neutralise the stressful situation. Coping is a process that includes strategies to bring a state of equilibrium during a crisis to prevent physical and emotional effects brought by stressors. The sudden admission of a family member into an Intensive Care Unit is chaotic and disrupts the ‘whole’ family system from functioning smoothly. Family members also experience emotional, physical and psychological symptoms (Schmollgruber, 2019). The experiences of these symptoms are worsened by the unmet needs of family members in ICUs: the proximity need, information and support needs (Bailey *et al.*, 2010). Coping of family members during critical illness period in the ICU is affected by different factors. Research has found that the age of the family member, the relationship between family members and their closeness, being a decision-maker, gender of a family member, previous ICU experiences and available social support are all factors that affect coping of family members in ICU (Rückholdt *et al.*, 2019). The unfamiliar ICU environment and the financial burden adds more pressure to family members who are struggling with coping strategies (Schmollgruber, 2019).

Family members struggle to cope during critical illness due to tension and changes brought by the sudden admission of a critically ill family member in ICU. This tension brings psychological instability that leads to post-traumatic distress, anxiety, struggle to sleep at night, malaise, stress and difficulties with eating habits (Koukouli *et al.*, 2018; Jordan, 2018). A South African study by Jordan (2018) outlines the same psychological symptoms experienced by family members during and post-critical illness period, and elaborates that they can end up developing Post Intensive Care Syndrome – Family (PICS-F) due to the illness of their family member admitted in ICU (Jordan, 2018).

The chaos brought by anxiety during critical illness results in altered ability of family members to cope and maintain independency during difficult times of ICU admission (Schmollgruber, 2019). Family members during critical illness develop coping responses or strategies to enable them to cope. These coping strategies are linked with cognitive and behavioural patterns of individuals. (Koukouli *et al.*, 2018). These coping strategies are described as 1) emotion-focused strategy, where the family member becomes submissive while showing helplessness signs, 2) dispositional coping, a person becomes more depressed and displaying more depression symptoms, 3) an avoidant coping strategy, the individual here is in denial and trying to employ more coping strategies, and there is an increase in post-traumatic stress symptoms, and 4) problem-focused coping strategies that are divided into three subcategories namely optimistic approach, supportive and positive reframing approach (Rückholdt *et al.*, 2019).

2.3 CRITICAL ILLNESS

Critical illness “refers to patients who have life-threatening illness who are on supportive treatments and close monitoring to prevent life-threatening complications” (De Beer and Brysiewicz, 2016b). Critical illness is any deterioration from a sick individual due to a medical condition or surgical intervention and necessitates further management of the patient condition in the Critical Care Unit. Critical illness is mostly linked with infections, complications from surgical interventions, severe traumatic injuries, inflammation of pancreas, burns, bleeding and from a disturbance in blood flow (Sharma *et al*., 2019). Critical illness is a very stressful event that disorganises the ‘whole’ family system and structural function. During critical illness, family members of critically ill patients have financial concerns, changes in family roles and alterations in daily activities (Hickman and Douglas, 2011).

2.3.1 The Effects of Critical illness to Family Members

Critical illness of one family member brings stress and suffering to other family members. Healthcare providers attending to critically ill patients’ needs should consider this and attend to the needs of family members as well (Davidson, 2009). The anxiety and stress brought by the critical illness of a loved one to family members also brings physiological and behavioural changes. The physiological changes include dry mouth, fast heart rate and sweating, while behavioural changes include family members not being able to express themselves and experiencing difficulties in sorting life events (Obringer *et al*., 2012). This is a difficult situation for all family members as they are experiencing shock and stress.

The shock and stress brought by the critical illness to family members is related to the outcome of the illness of their loved one. The anxiety experienced by family members of critically ill patients is often accompanied by depression. According to Brysiewicz and Chipps (2006), 35.4% of family members suffered anxiety and depression during the admission period of a family member in ICU. The post-traumatic stress symptoms were found to affect the quality of life of family members. This was found in approximately 33% of family members three months post ICU discharge of the patient (Garrouste-Orgeas *et al.*, 2010). These effects led to the development of research on the impact of critical illnesses to family members. This provides evidence that critical illness does not bring stress and shock out of nowhere.

The sources of stress, anxiety, fatigue, depression and fear, arise from role changes at home, financial factors, concerns about prognosis and disruptions from daily routines at home and social life (Wong *et al.*, 2018). The admission of a family member that is a breadwinner in the Intensive Care Unit increases the stress on other family members in the house. The ICU environment exacerbates the stress levels for family members, especially if it is their first time encountering critical illness and family member admission to ICU. The high technology used in the Intensive Care Unit and the lack of information to address the family increased the stress levels of families (Wong *et al.*, 2017).

2.3.2 Role changes in the Family due to Critical illness

Critical illness brings changes in the family. These changes include role changes and responsibilities amongst family members of a critically ill patient. Van Horn and Tesh (2000) evaluated the effects of critical care hospitalisation on family members of critically ill patients in ICUs. The study had a population of 50 people from 28 different families of critically ill patients; 35 (n=35) were women 15 (n=15) were males. The study's findings revealed that about 56% of family members had experience of role and responsibility changes in their families (Van Horn and Tesh, 2000).

Family members reported that helping at home with different activities was a problem; this statement also came from extended family members of the patient. Other respondents raised concerns about looking after children, some family responsibilities had to be put on hold, family members not going to work and having the burden of decision-making process accompanied financial issues in the family. All these add to the multiple stressors experienced by family members during critical illness (Van Horn and Tesh, 2000; Hickman and Douglas, 2011).

Admission of a family member into the ICU affects the social life of family members. A study by Van Horn and Tesh (2000) found that about 68% of participants reported a decrease in time of watching television and 26% reduced exercising (Van Horn and Tesh, 2000). The disturbance in regular daily routines interferes with family member's ability to deal with stressful events and to cope effectively during the critical illness period (Hickman and Douglas, 2011). The role changes in the family due to critical illness results in psychological disturbance to family members. Healthcare professionals should be ready to assess the family and help with the psychological needs that need to be addressed (Davidson, 2009; Hickman and Douglas, 2011).

2.4 PATIENT- AND FAMILY-CENTRED CARE

The concept of family-centred care came about in the 1970s. According to Wetzig and Mitchell (2017), the idea started in paediatric domains then expanded to other healthcare domains and eventually to the adult Intensive Care area. Family-centred care is regarded as care that brings changes in healthcare practice. FCC is there to enhance the way healthcare professionals render healthcare service to patients and family members (Clay and Parsh, 2016). The research found that healthcare service delivery that has a culture of family-centred care improves patients' outcomes, enhances patient and family satisfaction and reduces psychological symptoms (Latour and Coombs, 2017). The other positive effect of family-centred care approach in healthcare service delivery is that family members' needs are addressed and reduces psychological effects on the family (Almaze and De Beer, 2017; Clay and Parsh, 2016). The family-centred care approch outlines four significant concepts, which are defined by the Institute of Patient- and Family-Centered Care (Baas, 2012).

The four key concepts of family-centred care are 1) respect and dignity, 2) collaboration, 3) information sharing and 4) participation and support (Mitchell and Chaboyer, 2010; Baas, 2012). Family-centred care evolves from paediatric healthcare settings and has expanded to other domains of nursing, such as palliative care. The philosophy of FCC is broader than what has been implemented in these healthcare domains (Latour and Coombs, 2017; Shields, 2015). There is a gap to implement this mutually grounded healthcare approach in adult settings. A study by Gerritson *et al.*(2017) highlights the importance of involving family members in treating critically ill patients admitted in ICU.

The same study of Gerritson *et al*.(2017) states four important reasons for collaborating with family in rendering healthcare service to patients. These reasons are, 1) the effects of critical illness to family members can be identified, 2) family members acting as advocates in decision making for patient, 3) patients require family members to be part of care with healthcare professionals and 4) evidence that supporting family members improves patients' outcomes. Research states that family needs in ICU are still not met by healthcare professionals of the Intensive Care Unit. There is a lot of research, on paper, about family members' needs in the Intensive Care Unit, but these needs are still underestimated by healthcare providers (Davidson, 2009).

2.4.1 Family Needs

The significant part of the family-centred care approach is the sensitivity of healthcare providers in addressing family needs, values and cultural practices of families. Critical Care highlights the significance of family members' needs and patients' needs as important in enhancing satisfaction in ICU as well as in reducing psychological symptoms in family members (Almaze and de Beer, 2017). Many studies investigated the perceived needs of family members in Intensive Care Units. Obringer *et al*. (2012), states that family needs were evaluated using the Critical Care Family Needs Inventory (CCFNI).

The CCFNI instrument was created by Molter in (1979) and is used to study family needs using a Likert-type scale ranging from (1) not vital to (4) being very significant. There are 45 needs listed in the scale, which are divided into five dimensions (Al-Mutair *et al.*, 2013). These five dimensions of family needs are namely 1) need for assurance, 2) need for information, 3) the proximity need, 4) the need for comfort and 5) the need for support. The assurance dimension of family needs entailed family members requiring assurance from the healthcare providers regarding their family member's illness. The information dimension was about family members trying to get all information about the illness of their loved one; the proximity dimension was significant to the family because they were stressed about the critical illness, and they wanted to be close to the patient. The comfort dimension of needs comprises all spheres of emotional, physical, spiritual and cultural needs. The support needs dimension entails support from the healthcare providers, family members, friends and religious groups (Al-Mutair *et al.*, 2013).

Nelson *et al*. (2009) outlined the top 10 needs of family members in critical care settings using the Critical Care Family Needs Inventory (CCFNI). These needs are 1) feeling there is hope, 2) need for staff to care about the patient, 3) need for a closer waiting room to ICU, 4) need to be informed about changes in patient condition, 5) need to be given information about patient prognosis, 6) having all questions answered to them honestly, 7) need to be given important facts about the patient prognosis, 8) need to be informed about the patient at least once a day,9) information to be given to them at a level that they could comprehend and 10) the need to be given the opportunity to see the patient more frequently. Healthcare providers are still challenged to satisfy and meet these needs of family members in critical care settings (Al-Mutair *et al.*, 2013).

Studies done by (Wong *et al*., 2018; Al-Mutair *et al.*,2013), found the need of getting information and the need of assurance was a high priority in family members of critically ill patients. These needs offer a challenge to healthcare professionals to provide information to family, and this information should be at the family members' level of understanding. Research also found that if the information provided to the family was clear, and simple terms were used, this fosters the family members' understanding and they eventually get the assurance from healthcare providers (Al-Mutair *et al.*, 2013). A study by Obringer *et al*. (2012) also discovered that the need for information and for assurance was of high priority in ICU families.

Obringer *et al*. (2012) states that studies were conducted to examine satisfaction of family members of ICU patients who died, to see if their needs were met in the unit. A survey of 256 family members and found that more than 34% of family members reported having their needs met, and about 57% received support from the healthcare providers. Another study used a sample of 539 (n=539) family members and utilised the Family Satisfaction survey. The participants of the study were family members of patients (n=264) who did not survive in ICU, and family members of patients who did survive(n=275). Family members of patients who died expressed satisfaction with the care compared to those who survived.

Family members of patients who died, prioritised satisfaction concerning communication with healthcare providers and emotional support, and reported respect and compassion from healthcare providers (Obringer *et al*., 2012). The need for good communication between the healthcare providers and family members is required to enhance assurance to families of critical care patients (Davidson, 2009). Conversely, family members still feel their needs are not being addressed by healthcare providers. Nurses were prioritised by family members to be the best in meeting family needs, followed by the doctors (Al-Mutair *et al.*, 2013).

The Critical Care Family Needs Inventory shows mean scores when it came to the need for proximity and the need for comfort and support. The decrease in subscales of these needs reveals that these needs were not of high significance to family members (Al-Mutair *et al.*, 2013). The need for assurance on the ranking priority ranked third place, while support was perceived as least significant by family members (Obringer *et al*., 2012). Family members present themselves in the Critical Care Unit as having different needs, either psychological, social or physical needs (Mph *et al.*, 2015). There is more literature that explored family needs in ICU, but there is a gap in implementingthe family-centred care approach. There is not enough literature on family care and family involvement in the plan of caring for critically ill patients in ICU (Davidson, 2009).

2.4.2 Informational Support, Anxiety and Satisfaction with care

A cross-sectional descriptive pilot study conducted by Bailey et al. (2010) gathered information from 29 family members, utilising self-report questionnaires. This study examined the relationship between informational support, anxiety and satisfaction with care from family members of critical ill patients. The correlation analysis revealed positive relationships between informational support and satisfaction with care. There was no important relationship between informational support and anxiety or satisfaction with care and anxiety. Family members stated that information sharing by healthcare providers gives psychosocial support to family members (De Beer and Brysiewicz, 2016a). Information sharing is one of the needs to be met by healthcare providers to satisfy family members (Al-Mutair *et al.*, 2013).

2.4.3 Family satisfaction with care

Frivold *et al.*(2018) found that family members were satisfied with the care; high scores in the results of studies showed this. Despite these high levels of scores indicating satisfaction from family members, there were areas of improvement noted from the healthcare providers. These areas were interaction with physicians, being part of patient care and playing a role and inclusion of family in the decision making process about the patient. Frivold *et al.*(2018) conducted a study that examined family member's satisfaction with care and decision-making in the Intensive Care Unit. The study had a population of 123 family members, of which 32.5% were family members of non-survivors in ICU and 67.5% were families of survivors.

The results of the study revealed higher scores showing more satisfaction with support in decision making from families of ICU non-survivors compared to lower scores from families of survivors. The scores were documented as follows, support in decision-making (mean = 72.4 vs. 59.7, p = .01) and with inclusion in decision-making (mean = 73.3 vs. 60.1, p = .01). Conversely, family members of patients who were mechanically ventilated were highly satisfied with care and decision making than families of patients who were not mechanically ventilated; the following mean scores reveals that (mean = 74.8 vs. 58.0, p = .01; FS- Care: mean = 77.2 vs. 62.6, p = .01; FS- DM: mean = 70.9 vs. 51.8, p = .002). The study utilised family satisfaction in ICU scale to gather data (Frivold *et al.*, 2018).

Karlsson *et al*.(2011) conducted a descriptive pilot study that utilised a Critical Care Family Satisfaction Survey (CCFSS) in describing family member's satisfaction with care in the Intensive Care Unit. The CCFSS focuses on the need for assurance, informational need, the proximity need, support and comfort needs. The study was conducted on 35 family members of general ICU patients. The study's results show the need for assurance was significant to feel hope of the intended outcome, and family members perceived this need was well provided to them. The need of information, which was described by the family to be consistent, truthful and be given in time, was provided to them as family (Wong *et al*., 2018). Family members also stated that treating doctors did not provide enough information to family members (Davidson, 2009).

The results of the study still showed that the satisfaction of family members with care was linked with meeting the family needs. The other need that formed part of the study instrument was proximity need, and family members felt that need was well provided. The need for support was also a need that most family members were satisfied with, and this included the quality of care the healthcare providers rendered. The comfort need was the need that family members were not satisfied with in this study. Family members felt that the visitor’s room was cold, and shared with other families. Families found it challenging to sit and share confidential information amongst their relatives as they support each other at this time (Clark and Guzzetta, 2017).

Family members are perceived as significant in the patient’s life, and the family-centred care approach acknowledges the contribution brought by family members in caring for patients. Families are not only a substantial part of a patient`s life, they form part of the healthcare team (Jones and Khan, 2017). Family-centred care has been noted to be the key in enhancing total patient care in healthcare systems. The patient– and family-centred care process is grouped into three aspects, namely 1) holistic care, 2) collaborative care and 3) responsive care (Backman *et al.*, 2017). To provide a family-centred care approach, healthcare providers need to collaborate with families to know their beliefs, values and preferences. To effectively implement family-centred care, organisations should have a culture that looks after the implementation of this approach in all spheres (Baas, 2012). There are four significant concepts included in family-centred care approach, as outlined by the Institute for Patient- and Family-Centred Care in (2010). The concepts are 1) dignity and respect, 2) information sharing, 3) participation and 4) collaboration (Baas, 2012). The implementation of a family-centred care approach according to these concepts of FCC remains a challenge, and becomes more challenging in a country with different ethnic, cultural and racial groups (De Beer and Brysiewicz, 2016).

2.5 FAMILY- FOCUSED AND FAMILY-CENTRED CARE

Family-focused care, as defined, refers to care planned at providing support to families in relation to wishes and needs of the family as a unit, and considers relationships between healthcare providers and family to ensure that holistic care and family needs are met. Healthcare is thought around family in family-focused care. The intention of family-focused care is to treat family with respect and dignity. The concept of family-focused care was embraced by the concept of family-centred care, and is used more in family nursing (Denham, 2015).Family-focused care utilises the four concepts of 1) communication, 2) integrated care, 3) relationships and 4) coordinated team work (Denham, 2015) These concepts are also used in family-centred care .

Family-centred care “is an approach to the planning, delivery and evaluation of healthcare that is governed by mutually beneficial partnerships between healthcare providers, patients and families” (Institute of Family-Centred Care, 2010). Shields *et al.*(2010) define family-centred care as a way of caring for children and their families within healthcare services, by ensuring that care is planned around all family members not just the patient as the recipient of healthcare. Family-centred care can be implemented to all nursing domains (Mitchell *et al.*, 2009). The understanding of family-centred care goes hand-in-hand with these four significant concepts of family-centred care and the underpinning elements. Family-centred care comprises the following four concepts, 1) respect and dignity, 2) information sharing, 3) collaboration and 4) participation support. These concepts are described below in relation to family-centred care (Mitchell and Chaboyer, 2010). The examples that further provide clarity to each concept are provided by the element of family-centred care. Family-centred care concepts are described as follows:

- *Respect and dignity*: the process of accepting and valuing other people in what we are doing in healthcare institutions. Respect also encompasses respecting patients’ values, preferences and their expressed needs’ as well as decision making (van Mol *et al.*, 2017). Respecting their beliefs and cultural backgrounds and attained rituals (Institute of Family-Centered Care, 2017). Respecting race, ethnicity, and culture of families, was identified as a very important element by the Institute of Family-Centred care. Creating healthcare that is flexible, culturally competent and responding to family needs is vital.

- *Collaboration:* this is the act of building partnerships and working together as partners between families and healthcare providers in the best interest of the patient (Mitchell and Chaboyer, 2010). The plan of care by healthcare professionals and family members is integrated and well-coordinated in rendering holistic care for the patient (van Mol *et al.*, 2017). The element of promoting and encouraging family-to-family support and interaction, states that healthcare providers should work hand-in-hand with family and provide health talks to families. Promoting parent–professional interaction at all healthcare levels allows good collaboration with families, and reacts to child and family developmental needs as a part of healthcare practices.

- *Participation Support:* this relates to accepting and providing assistance to someone's needs. Family-centred care goes hand-in-hand with understanding the needs of families and their background (Mitchell and Chaboyer, 2010). The needs of Intensive Care Unit patient`s families are support, education, communication, physical and emotional support (van Mol *et al.*, 2017). Considering policies and practices that render family emotional support and financial support, this element of family-centred care is a challenge to healthcare institutions in adjusting their policies according to family-centred care.

- *Information sharing* entails engaging with the family through communication. Healthcare providers are giving the patient and family member's information that is not biased, at the right time to give them enough time to make informed decisions. Family members expect the nurse to provide them with information regarding vital signs, patient comfort levels and patient wellbeing. The nurses are not entitled to give information beyond their scope of practice, such as patient prognosis and treatment plan, as that information is with the physician (Ciufo *et al.*, 2011). Progressive information sharing with families without hiding anything from them reduces fear, and there are few concerns from the patients' side. The following diagram illustrates the concepts of family-centred care.

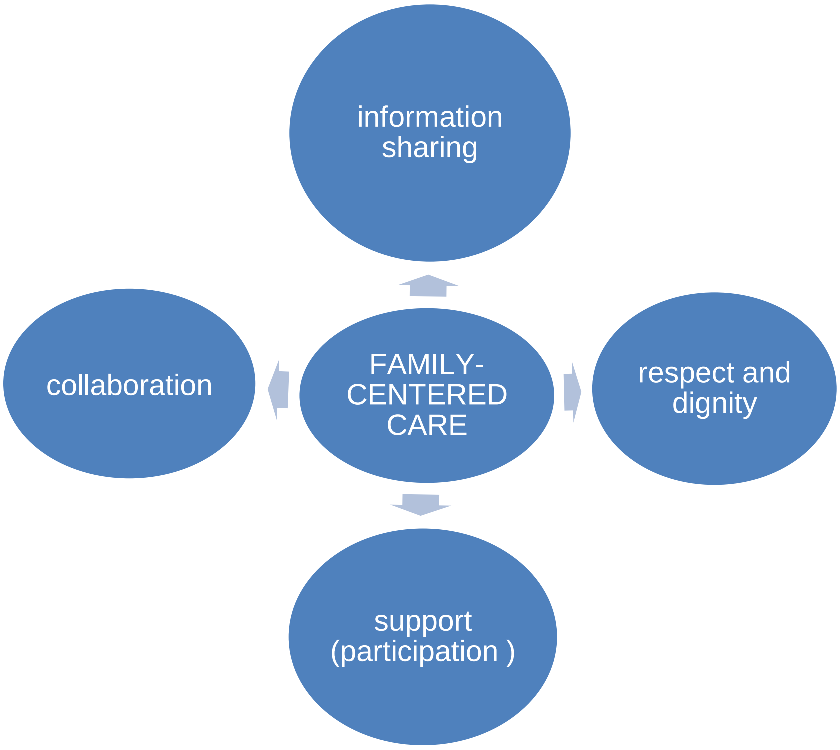


Figure 2.1: Family-Centred Care Concepts

2.5.1 Theories underlying Family-Centred Care

There are two theories outlined underlying family-centred care approach. These theories are Carl Roger`s theory and General Family Systems theory.

2.5.1.1 Carl Roger`s theory

Carl Roger`s humanistic theory sees a client in a social and natural context. He focused on treating the patient as a total human being and not just as a medical sign and symptom or diagnosis. In his model of care, he moved away from the predominant medical model that focuses on psychopathology. He describes life as a process of being and becoming. Therapy is to enter realities of life, seeking change in the whole gestalt of life, and not one or two spheres. It is not just to change one or two habits or behaviours, as this leads to falling back into old patterns. Change is holistic or transformative. Therapy is to provide the right environment and to advance relationships. For Carl Rogers, three characteristics are vital: acceptance as a feeling of being valued, empathy explained as engaged understanding and honesty as an uncensored feelings.

These feelings should be provided to the person to discover who he is, resulting in the environment for change. Carl Rogers stated that "*only if I accept myself then I can change*." The activity that results from allowing is becoming who you are. Who we are requires fostering. Therapy involves reflecting back on what the client says and experiencing the here and now. The aim of the therapy is to liberate the client, to become more real and engaged. The main aim of this theory by Carl Rogers is to persuade treatment process, family dynamics, the individual function and interaction in social life (Bamm and Rosenbaum, 2008). The ideas of this theory were supported by the Association for the Care of Children`s Health (ACCH). The ACCH stated the significance of family in children`s wellbeing as well as the parents advocacy role in children`s lives. Taking this theory to adult Intensive Care Units, family-centred care looks at advocating for the patient to remain with the family members (Clay and Parsh, 2016).

2.5.1.2 General family systems theory

General Family Systems Theory comes from the General Systems Theory by scholars who found it applicable to families and other social systems. Families are regarded as systems because they interact amongst themselves as they share certain elements, and these interactions are accompanied by interdependency between family members. There is an existing interdependency between family members as the family function as a unit. Family members were regarded as elements of the system (Morgaine, 2001).

The system has subsystems attached to it that will be people related to the family. Each element in the system has unique characteristics and there are existing relationships between the elements. The system interacts in predictable patterns. The continued cycle helps the family in maintaining equilibrium and gives direction to the functioning of the elements. There are open and closed boundaries existing in the system. The open boundary system allows the external factors to influence the system, while the closed boundary system creates the atmosphere of isolation;

as a result, the system is not completely closed. The system is also composed of parts. The whole is more than the sum of the parts, and the equilibrium state of family dynamic is kept constant. The whole picture of the family is reflected holistically. Within the system there are subsystems that interact in relation to the system sharing the same rules and characteristics with the main system (Morgaine, 2001).

2.5.1.3 Models of family-centred care and their views

Baas (2012), describes family-centred care as a tripod; there are three legs that form FCC. The models in FCC are healthcare providers, patients and families, which form the three legs of a stool. Family-centred care (FCC) is there to provide collaboration between patients, families and healthcare providers. FCC promotes respect of other people`s culture, religion and support to families through healthcare providers understanding of different cultures (Kean and Mitchell, 2014). Family members are getting the opportunity to be around the patient and receive information, and to ask questions of healthcare professionals (Soury-Lavergne *et al.*, 2011). Family-centred care brings changes to clinical settings and some of these changes are not yet implemented successfully, such as open visitation policies. Open visitation policies are starting to be put in place in adult Intensive Care Units, as they improve patient`s families satisfaction and reduce complaints (Chapman *et al.*, 2016).

Complaints from the family members of patients are the sign they are not satisfied with the healthcare service rendered. Family-centred care provides family members with the chance to participate in basic care activities for the patient, such as keeping the patient’s lips moisturised, combing the hair and assisting with bed bathing. All these activities relieve the emotional suffering from a family member. Studies also emphasise that in providing holistic care, critical care nurses should involve families in patient care. This helps in meeting the needs of families and they are providing psychological relief for relatives (Mitchell *et al.*, 2009). Families perceived communication by healthcare professionals as a big aspect in family-centred care. Family-centred care was found to run smoothly through communication.

Communication by healthcare providers to family members was significant, especially during decision-making processes. Family-centred care should be coordinated with family members, and family should be integrated into the plan of care by healthcare providers (Jordan, 2018). Healthcare providers get an opportunity to provide health education to family members through collaboration in the Intensive Care Unit (van Mol *et al.*, 2017). Healthcare professionals perceive families as sources of information about the patient; this is more important in unconscious patients, who were admitted to hospital in a critical condition and mechanically ventilated. The collaboration between healthcare professionals and family creates the relationship of trust. There is a relief of anxiety from the patient as family get along with healthcare professionals. Research emphasises the significance of collaboration between healthcare professionals, patients and family members, as there are reduced effects of hospitalisation and anxiety, and the family gets an opportunity to bond with the patient (Coyne, 2013).

There are positive outcomes and comments from patients regarding family-centred care. The presence of a family member at the bedside brings a sense of touch to the patient and improves cardiovascular function. The critically ill patient has rights and needs to be advocated by family members. Patients also have social life outside the hospital that still needs to continue, and family member provide that connection (Bailey *et al.*, 2010). The benefits of the family-centred care approach focused on three models of FCC, 1) family, 2) patient and 3) healthcare providers. The following diagram illustrates these models.

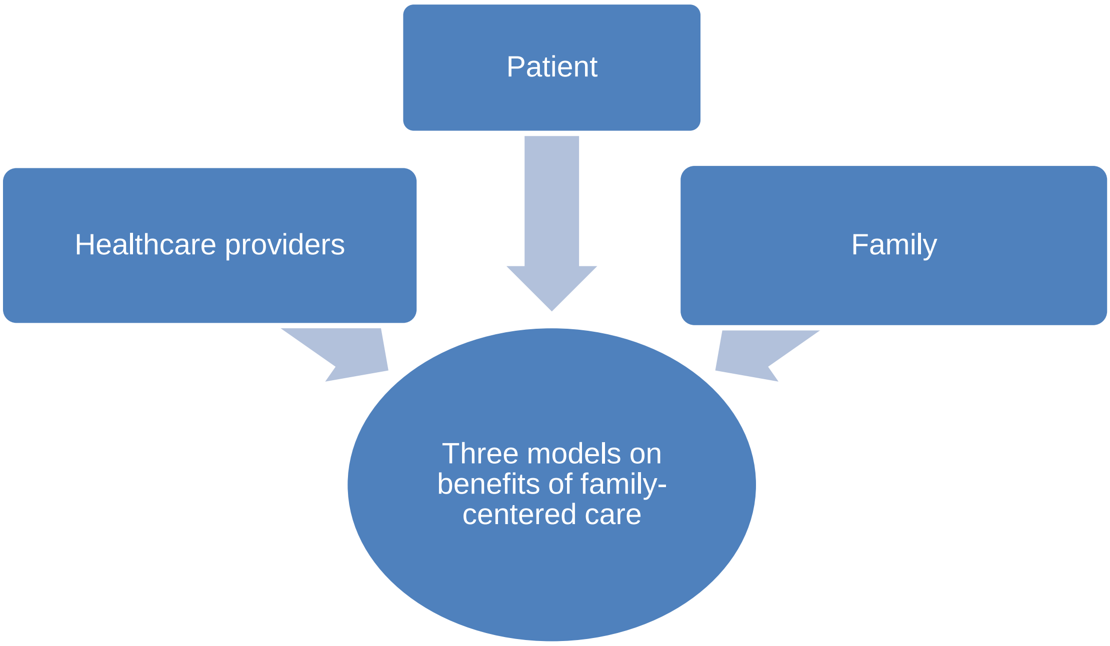


Figure 2.2: The three models on benefits of family-centred care approach.

2.5.2 Family Members Perceptions of Participation of Support

When a family member becomes critically ill and subsequently admitted into the ICU, the whole family is affected. Patients come in hospital physically sick, but families enter the unit in psychological crisis. That is why the Intensive and Critical Care Units have a responsibility to care for families as well (Latour and Coombs, 2017). The evidence from other research studies states that family members are happy with family-centred care coming into practice in adult Critical Care Units. Families are aware that the FCC approach has been happening in paediatric units and other nursing domains, but there are still concerns about the adult ICU (Mitchell *et al.*, 2009).

Families are impressed with the family-centred care approach because they think their needs will be met. There is a lot of research about the needs of family members in the ICU, the need of getting information from healthcare professionals about their family members, the need of advocating, providing support to the patient and the proximity need. Family members are still concerned about being involved in the plan of care for their loved one, being involved in decision making and collaborating with healthcare providers in rendering healthcare to their loved ones (Mitchell *et al.*, 2009).

Family members also bring cultural and religious practices for the patient and that provides spiritual healing to the patient. They bring a link or connection with social life outside the hospital for the patient. The feeling of being around familiar people improves cardiovascular function for patient (Mitchell *et al*. 2009, De Beer and Brysiewicz, 2016a). It seemed to be that there were more positive effects of family-centred care for families and patients, however not all families were satisfied. Some parents in children`s units felt they were being forced to stay and take care of the child, and nurses were expecting them to assist in the care of the child. These parents adopted a mode called "*defensive parenting,"* as they felt that they would be nuisance to nursing personnel (Shields *et al*., 2010).

Family members' complained about their proximity need not being well addressed in Critical Care units due to short visiting times (Obringer *et al*., 2012). The need to access enough information from the treating doctors and other healthcare providers still needs to be improved. Family members are not being involved in the plan of care for their loved ones, which leads to family members experiencing less support from the healthcare providers during this vulnerable period to their lives. There is a gap in existing literature in South Africa about family support in Critical Care Units. International research has shown positive outcomes on integrating family into the plan of care (De Beer and Brysiewicz, 2016b). Family-centred care is there to acknowledge the contribution brought by relatives to the plan of care and perceives the family as a vital part of caring for patients (Jones and Khan, 2017).

The outcome of family members collaborating with healthcare providers benefits the patient, healthcare providers and the family members. The presence of family members in the ICU has a positive experience for the patient and has a good effect on patients' wellbeing and recovery as it bring sense of security (Obringer *et al*.,2012). The presence of family members also helps to reduce stress levels to both patients and family members. The collaboration brought by family members between the healthcare providers and the patient makes the treatment plan easier (De Beer and Brysiewicz, 2016). Family members have a need to be partners with healthcare providers and to be close to their loved ones. There should be no limits about proximity need during partnership and families should be allowed to do activities for the patient.

2.5.3 Nursing Support of Family Members in ICU

Healthcare professionals were pleased to see patients and family members going home after rendering healthcare in a family-centric approach. The experience of reliving the Intensive Care trauma was addressed by the family-centred care approach. Nurses addressed the needs of families in the Intensive Care Unit through collaboration with families (Mitchell *et al.*, 2009). Nurses mentioned that providing support and education to family members in the ICU reduced anxiety levels for the family. This enhances their coping strategies and contributes to patient recovery (Mitchell *et al.*, 2009).

The nurse's views were different due to contributing factors, such as barriers to successful implementation of family-centred care (FCC); other factors were personal experiences or views. These experiences were 1) working in Intensive Care Units for a long time, and 2) the level of education to the nursing personnel. The nurses who were previously hospitalised were less satisfied with visitation policies. These nurses felt that this does not support family-centred care approach. Nurses with experience of working in ICUs for more than 15 years perceived families as interfering with their work, and consequently suggested that families should come in during visitation hours only (Chapman *et al.*, 2016). This evidence reveals that families are still perceived as visitors in Critical Care Units.

Some healthcare professionals found it very difficult to initiate conversation with patient`s relatives at the bed side. A study done by Al-Mutair *et al.* (2014) discovered that presence of family members creates work stress for the ICU healthcare professionals due to less time to accomplish the work they must do. Nurses do not want emotional interference together with technical requirements of their work and they feel threatened (van Mol *et al.*, 2017). Nurses also reported that staff shortages have a negative impact because they might need to go out of the unit but cannot because there is no one available to look after the patient (van Mol *et al.*, 2017).

Overall, based on these views form the nurse’s side, it still remains a challenge to create an organisational culture that is in support of family-centred care (van Mol *et al.*, 2017). According to research, there are still some improvements to be added into clinical practice of family-centred care and be applied at international level. For successful family-centred care approach to take place, it needs interdisciplinary team attitude to change and hospital cultural changes; these changes should be supported by all healthcare professionals (van Mol *et al.*, 2017). Nurses who showed positive attitudes towards FCC were those with high levels of education, senior positions, older and more experienced, being married and being a parent (Coyne *et al.*, 2011).

2.6 SUMMARY

The literature review has dealt with the definition of family-centred care and related concepts with elements. The discussions regarding the theoretical foundations on family-centred care, family and nursing support of family-centred care.

Family-centred care aims to unite the plan of care to all the nursing care domains. Families are familiar with this type of care as it is a common practice in paediatric nursing. There is a need to implement FCC in adult Intensive Care Units.

Family-centred care originates in paediatric nursing domains and now we are shifting the paradigm by taking FCC to adult Critical Care nursing domains. FCC philosophy is broader than what has been implemented in paediatric and children`s units. FCC is not just for paediatrics, it can be applied to all nursing domains.

Family-centred care provides a holistic approach in rendering healthcare services to patients and families. Family is also regarded as part of care and should be given an opportunity to participate in the decision making process.

Family-centred care requires healthcare professionals to treat patients and families with respect and dignity. Collaboration in rendering healthcare with families shows that families are supported in hospital. The plan of care in hospitals should be family-centric as the literature emphasises.

The plan of care moved from physician opinion to client-centred care, then patient-centred care and now we are on family-centred care. Families should be allowed to be part of care by collaborating with healthcare professionals. Interdisciplinary teams can do this by involving family in the treatment plan for their loved ones and allow full family participation in the decision making process. Families are willing to be part of care and research says they should be allowed but not to be demanded, they should participate voluntarily. Family-centred care has advantages for the patients, family and the healthcare providers. FCC helps healthcare professionals in comprehending family’s needs and expectations in hospitals; however, there are barriers associated with successful implementation of family-centred care.

The barriers to the implementation of family-centred care are unit rules and hospital policies, followed by the healthcare professionals, busy unit schedules, among others.

The family-centred care approach has been supported by several organisations and associations noted from the literature, namely the Association for the Care of Children in Hospital (ACCH), Institute of Medicine (IOM), Association for the Wellbeing of Children in Hospital (AWCH), as well as Critical Care organisations. There is an accompanying legislation to support the movement of family-centred care, as the National Health Act no 61 of 2003 states the user has the right to participate in the decision making process. In Critical Care nursing, where patients are unconscious, this right remains with supporting family members who advocate the patient’s rights.

This chapter has dealt with the literature review for this research topic. Included were a brief discussion of the Family Systems Theory and its application to the study. Family coping during critical illness, the critical illness concept and its impact on the family unit were discussed, and also family needs and perceptions of support provided by healthcare professionals in the Intensive Care Units was described.

In the next chapter, the research methodology will be described in detail.

CHAPTER THREE

RESEARCH METHODS

3.1 INTRODUCTION

This chapter will describe the research design used in this study including the research methodology, the research setting and research methods (population, sampling method, data collection and data analysis). The research design used in this study was explanatory sequential mixed methods.

3.2 RESEARCH PARADIGM

A paradigm refers to how the world is being viewed with its complexities (Polit and Beck, 2012). Pragmatism allows the researcher to look at the practicality of the situation. Researchers can use mixed method to provide better understanding of the phenomenon (Creswell, 2014).

The pragmatic approach believes that the truth about something, person or an object is found through being in contact, searching knowledge and interacting as well as interviewing the person. Pragmatism looks at different methods of collecting data and analysing it rather than using one method and this helps in better comprehending of the research problem (Creswell, 2014). The research is a technique of getting true information about problems encountered in daily living and provides a way of obtaining a deeper understanding about new problems. To study a human`s social life, experiences, feelings and perceptions, needs certain techniques and methods. To obtain this information a mixed method approach was chosen for this study.

Ontology refers to how we view the world, ourselves and other people. It is a study of being and existence (Polit and Beck, 2012). The family exists as a unit structure that cannot be separated from each other; they can be living under same roof or as an extended family structure. The family has good interaction amongst themselves and with the society in which they live, which plays a big role in their lives. The world does not change but changes are brought by human beings in the world.

Epistemology is how knowledge is acquired, as well as the relationship between the researcher and the knowledge to be known. Researchers look at different perspectives when dealing with subjective or practical side of information they require from people (Welford *et al.*, 2012). To get information from the families, the researcher has to interact with them, asking them to participate in the study by answering questions with the aim of working with families to enhance holistic nursing care delivery. This contributes to the knowledge of scientific human research study that is required by the researcher.

Methodology refers to how the researchers find techniques or strategies of studying the knowledge they require for their research topic (Polit and Beck, 2012).The study utilised the explanatory sequential mixed method design, first starting with the quantitative research, analysing the results and explaining more on the qualitative research (Creswell, 2014). The researcher used the quantitative study (Phase 1) to ask survey questions and qualitative study (Phase 2) for the in depth face-to-face interviews using audio tape recording. This allowed the researcher to get answers for the research topic using both approaches.

The mixed method approach in research allows the researcher to obtain a broader view or understanding about the research phenomenon and to generate strong research. Health science research is believed to be more evidence-based practice if the study was conducted in a clinical setting. Human beings are not just objects in nature but are people with dignity and need to be treated with respect by healthcare professionals, with strong adherence to principles of non-maleficence and beneficence in healthcare profession. Evidence-based practice in health science has become the framework in guiding clinical research and practice informed principles in hospitals.

3.3 RESEARCH DESIGN

A research design is a strategy of enquiry used by a researcher to guide him or her in a specific direction on how to achieve the required objectives (Creswell, 2014). The research design utilised in this study was an explanatory sequential mixed methods design; this means the quantitative data results will be further explained with the qualitative data (Creswell, 2014).The use of mixed method research is becoming recognised in the field of research, especially in healthcare, social and behavioural sciences (Collins *et al*., 2006; Plano Clark, 2010).

3.3.1 Mixed Methods

A mixed methods approach is suitable where the single approach may not answer the entire research question. This approach allows the study phenomenon to be examined in both approaches. The quantitative phase included closed-ended questions, which limited the researcher in collecting enough information to address the basic aim of the study. The researcher had the option to elaborate on the problem by adding the qualitative phase, where the open-ended questions were utilised. This allowed the participants to express themselves more fully and yielded new and deeper insights into family-centred care. Mixed methods use has some advantages. It provides a broader view of the study allowing the researcher to get into the phenomenon in both methods and enhances research skills to novice researchers. However, there are also disadvantages associated with a mixed methods approach. It is more expensive, collecting and analysing data takes longer and most of all as a novice, the researcher needed substantial guidance in the conduct of the study.

3.3.2 Explanatory study

For the purpose of this study, the researcher applied the **explanatory sequential design**. The sequential design was found to be more appropriate for a number of reasons. Firstly, the study was conducted in two phases, which enabled the researcher to get back to the participants to collect qualitative data in the second phase after collecting quantitative data in the first phase. The quantitative data provided the general picture of the participant’s perceptions of family-centred care (FCC), barriers to its realisation and possible solutions, while the qualitative phase generated in depth coverage of participants views.

3.3.3 Sequential study

A sequential study was utilised because the researcher did the quantitative and qualitative research methods in two separate phases with regard to data collection and analysis, one type of data collection and analysis occurring after the other type of study had been done (Creswell and Plano Clark, 2011). In this study, the quantitative data **(Phase 1)** was collected and analysed first, followed by qualitative study **(Phase 2)**. The sequential design allows the researcher to probe the question in a way that will best answer the research aim. The researcher was able to put emphasis on findings that arose from the quantitative findings, which could not be answered using the quantitative data. Information that was not clear from quantitative study results was further elaborated in qualitative study during interviews with participants through probing questions (Creswell and Plano Clark, 2011).

This allowed the researcher to explore potential problems and solutions in greater depth and detail. Where more clarity and understanding were required, this was sought during the qualitative phase. The data were collected and at the same time analysed, which made the study more manageable for a single researcher.

3.4 RESEARCH SETTING

The setting in research is a place where data collection for the study takes place (Polit and Beck, 2012). Setting is also called the field. The field is the place in which the subjects of interest live, experience life and a place where data is collected for the study (Streubert and Carpenter, 2011). The study was conducted at a South African private hospital located in Bloemfontein, Free State. This is an acute hospital with 251 beds and different specialities. The study was focused in an adult General Intensive Care Unit with 11 beds. The target for this study was family members of critically ill patients admitted in this unit. This unit uses an open unit style, where all the intensivists and specialist surgeons are responsible for the patients they admitted. The unit has an all nursing skills mix, Intensive Care trained professional nurses, experienced professional nurses, enrolled nurses and assistant nurses. Nurse ratio for the critically ill patients is one is to one .The hospital has a visitor friendly policy with some visiting restrictions that can be changed at the discretion of the nurse looking after the patient. Family members have access to medical staff by individual appointment. The hospital admits patients from different catchment arrears, not only inside Bloemfontein city but also from other towns inside the Province.

3.5 PHASES OF RESEARCH

This study had two phases as explained in the following sections. There was a quantitative phase (step1) and a qualitative phase (step 2).

Table 3.1 Summary of study phases

Objectives	Data collection	Sample and Population	Data analysis	Data integration
Phase 1 – step 1: Describe the perception of family members of patients in general ICU regarding family-centred care.	*Data collection:* survey questionnaire	*Population:* P (n = 87) *Sample:* Random sampling	Statistical software package, STATA version 14 Descriptive statistics	Mixing both Phase One and Phase Two (quantitative and qualitative data)
Phase 2– step 2: To explore the views of family members of patients admitted in a General Intensive Care Unit about family-centred care	*Data collection:* Individual interviews	*Population:* Family members (n = 20) *Sample*: Purposive sample	Thematic analysis by Clarke and Braun (2013)	

3.5.1 Phase 1: Quantitative Study

The first objective of the study was to describe the perceptions of family members of patients admitted to a General Intensive Care Unit regarding FCC (quantitative study).

3.5.1.1 Population

Population refers to the aggregation of participants in which a researcher is interested (Polit and Beck, 2014). In this study, the population involved the family of patients admitted to an adult Intensive Care Unit in one private sector hospital in Free State Province, South Africa. The target population for this study was the family members of patients who were critically ill and admitted in the General Intensive Care Unit of a private hospital in Bloemfontein. These family members were regular visitors for the patients in this unit.

A preliminary record review undertaken in May 2018 indicated there were approximately 112 (N=112) patients who received treatment in this unit in the past three months; that was an average of 37 patients per month.

3.5.1.2 Sample and sampling

Sampling refers to a process of selecting participants to represent the entire population so that inferences about the population can be made (Polit and Beck, 2012). After consultation with the statistician, a sample size of 87 (n = 87) family members of ICU patients was decided upon to ensure good representation of the population from which the sample was drawn, and to ensure a power of 95% with a margin of error of 5% and response rate distribution of 50% for each question. Random sampling was used to select the family member participants provided they were suitable and fit the inclusion criteria of the study. The random sampling was chosen because it gave each individual in the population an equal opportunity to participate in the study. Random sampling was used to provide the ability to generalise the population (Creswell, 2014).

Inclusion criteria for participants included:

- A family member of a patient who stayed in the ICU for more than 3 days;
- Over 18 years of age
- Able to read, understand or communicate in English
- Obtained permission to participate in the study

If more than one family member met the inclusion criteria, the researcher invited the significant other or main caregiver who visited the patient most frequently as the participant for the study.

The exclusion criterion was if the family member of the patient was involved in a medical malpractice dispute, as there might be a risk of bias or conflict of interest.

3.5.1.3 Data collection

Data collection is a process of collecting or gathering of information that will address the research problem (Polit and Beck, 2012).

A survey questionnaire entitled "Family-Centred Care Questionnaire," developed by Mitchell *et al.* (2009), identified in the literature and validated in previously published studies (Wang *et al.,* 2016), was used in data collection to achieve the study objectives.

The questionnaire had two sections. The first section collected demographic data about the family member participant. Included were the reasons for patient's admission, the degree of illness, the age of the patient and family member, gender of the patient and family member, ethnic background, education of the family member, the family member's previous ICU experience and relationship to the patient. The second section had 20 items, which were further divided into three sub-categories: respect (6 items), collaboration (9 items) and support (5 items). All items were questions about how often a stated event occurred; response options ranged from 1 (never) to 4 (always). The 4-point Likert-scale was used for mean subscale scores; higher scores indicated perceptions of higher levels of FCC.

The developers assessed face and content validity of the questionnaire in the sample of the original study (Mitchell *et al.,* 2009). Furthermore, it was tested on a sample of 174 family members of patients in Australian ICUs, where Cronbach's alpha was 0.62 for respect, 0.80 for support and 0.70 for collaboration.

One subsequent study was found that utilised the questionnaire on an independent sample of family members of patients (n = 249) in Taiwan (Wang *et al.,* 2016). The overall Cronbach's alpha for the total scale was 0.88, whereby the average item correlation was 0.69 for respect, 0.82 for support and 0.77 for collaboration (Wang *et al.,* 2016).Thus the questionnaire was deemed suitable for use in the South African study.

3.5.1.4 Pilot testing

Pilot testing was conducted to test if the instrument was applicable to the South African context as it was adapted from studies done in other countries. The pilot study consisted of five questionnaires, but these questionnaires also formed part of the main study since the research topic and the objectives did not change. The questionnaire was handed to these five participants and there was no difficult in answering these questionnaires. Participants were asked if they do understand information document about the research topic and the list of questions on the questionnaire. Minor clarity was provided to participants who asked questions. These five questionnaires were checked if all the questions were answered by participants. All questions were answered and these questionnaires formed part of the study.

3.5.1.5 Data collection process

Permission was sought from the hospital manager to conduct the study in the chosen hospital. Once permission was obtained from the institution, permission from the nursing services manager was sought,and after that, the ICU unit manager was approached for permission. The researcher had visited the Intensive Care Units and observed the unit admission register for selection of potential participants. The respondents who agreed to participate in the study were given an information letter outlining the study and its procedures. This being a researcher-administered questionnaire, written consent was obtained from all the participants. Data collection started after the relatives (patients) of loved ones were discharged from ICU to a general hospital ward. Participants were asked to put the completed questionnaire into a sealed envelope and post it themselves into a sealed box marked for this research study in the unit.

3.5.2 Phase Two: Qualitative Study

The second objective of the study was to explore the views of family members of patients admitted in a General Intensive Care Unit about FCC (qualitative study).

3.5.2.1 Population

The population for this study involved family members of patients admitted to the adult Intensive Care Unit of one private hospital in Free State Province. They were regular visitors for the patient admitted in the adult ICU.

3.5.2.2 Sample and sampling

Purposive sampling was used to recruit study participants. Purposive sampling occurs when an individual is chosen because he or she possesses a component or is knowledgeable about the interest for the particular research study (Creswell, 2014).

This sampling method was chosen because the researcher was required to involve the family members who were willing and able to communicate their views. This was done by conscious selection of family members who met the requirements of the sampling criteria set out by the researcher. A minimum of 15 to 20 participants were interviewed. Data would continue until saturation of information was achieved.

3.5.2.3 Data collection

Data collection refers to collecting information by researchers to address the research question of the study (Polit and Beck, 2012).Interviews are one of dominantly used methods of data gathering in qualitative research studies (Streubert and Carpenter, 2011). In Phase 2 of this study, data was collected with audiotaped semi-structured interviews. This was chosen because (Phase 2) qualitative study explores the perceptions of families and semi-structured interviews are a good choice in perceptions (Botma *et al*., 2010). The researcher is not yet an expert in research and this makes semi-structured interviews a preference. A semi-structured interview is a type of interview used by qualitative researchers to collect data; it uses list of topics to cover rather than a specific series of questions to ask the participants (Polit and Beck, 2012).

3.5.2.4 Data collection process

Data collection of the study was done after receiving clearance to conduct the study from the Post-graduate Committee **(Appendix I),** Ethics Committee of the University of Witwatersrand **(Appendix G)** and approval from the Private Hospital Manager **(Appendix H).** The protocol of the study was presented to the hospital management as a policy requirement. The permission to conduct the study in the unit was obtained from the unit manager after the informative letter was given to her providing all the details of the intended study.

After the unit manager gave permission, the participants were invited to participate in the study post discharge from the General Intensive Care Unit. The information sheet with all the details of the study was given to the participants. Voluntary participation to the study was stressed to the participants and those who intended to participate were given the audio taping informed consent to be signed to show they agreed to do so. One open-ended question was asked during the interview and additional probing questions where necessary. The contact details of participants were taken should a follow up interview be required for clarification purposes.

The first interview was conducted as a pilot interview with the researcher`s supervisors to allow the researcher to clarify questions and his interviewing technique. The interviews were tape-recorded and field notes were taken for all interviews. A convenient time for the interview was agreed upon by the researcher and the participant, and the unit manager was informed of the decision and the approximate time of the interview. At the beginning of the interviews, participants were asked to relax and reminded that participation in the study was voluntary, the study had no intention to harm, and they could withdraw from the interview at anytime. The researcher did not implicate his feelings or interfere with data from the participants; it was taken from participants with no data fabrication done.

An interview guide with one open-ended question and probing questions was used to keep the interview focused. This allowed the researcher to collate detailed data and gave the participants the opportunity to talk about their perceptions as they wished. The interview was aimed at sharing the views of relatives regarding FCC in an adult Intensive Care Unit. Interviews were continued until data saturation was reached.

Semi-structured interview questions were used to explore family member's perceptions of FCC with additional probes if necessary. Interviews were tape-recorded and transcribed using pseudonyms to ensure anonymity and confidentiality, and field notes were made of all the interviews. Interviews were conducted in a small office in the hospital near the ICU, post discharge of the patient from the Intensive Care Unit, except when the family member requested to be interviewed at home, as this was a comfortable atmosphere, emotionally wise, and when the family member could not financially afford to come to the hospital for the interview.

At the end of the interviews, all participants were thanked for their participation, cooperation and for being open during interview. The audio tapes and field notes were kept safe under lock and key, and only accessed by the researcher. In total, 20 interviews were conducted by the researcher and all were audio taped.

3.6 DATA ANALYSIS

This is a process of organising and synthesising research data, and in quantitative research studies, it is where the hypothesis is tested using data (Polit and Beck, 2012). For this study, data analysis included quantitative analysis and qualitative analysis because the study was an explanatory sequential mixed methods approach. It started with the quantitative phase to inform the qualitative phase of the study.

3.6.1 Quantitative Data Analysis

In quantitative studies, the purpose of data analysis is to organise, provide structure and elicit meaning about data (Polit and Beck, 2012). Data analysis, related to the survey study, was captured onto an Excel spreadsheet; this was in preparation for transfer into the statistical software package, STATA version 14.

Descriptive statistics were used to summarise the sample and survey responses. Medians and interquartile ranges (IQRs) were calculated for the total family-centred care (FCC) scale and its three sub-groups (respect, collaboration, information and support). However, on the advice of the statistician median split subgroups were not further explored during data analysis because there was more similarity rather than a difference in the responses of the participants to run a factor analysis and regression analysis.

3.6.2 Qualitative Data Analysis

In qualitative studies, the purpose of data analysis is to organise, provide structure and elicit meaning to the data (Polit and Beck, 2012). Data analysis was initiated after the participants had been interviewed. The interviews were transcribed verbatim and analysed according to the method of Clarke and Braun (2013). This method is preferred for its flexibility in identifying themes in different ways. It uses thematic analysis. Thematic analysis is a significant method to identify and analyse patterns within qualitative data, and can be used to analyse different data, such as media, transcripts and interviews from people`s experiences (Clarke and Braun, 2013).

Thematic analysis has six essential steps in data analysis; these steps will be discussed below and the related practical approach utilised during analysis. These steps were followed:

- Read all transcripts and field notes thoroughly to get an overview. Highlight important ideas.
- Read each interview and question the objective and underlying meaning.
- Distinguish between main, unique and other themes.
- Code themes and highlight themes throughout the text.
- Describe and categorise themes, and identify relationships between them.
- Assemble data from text into identified categories.

The interviews were crosschecked with the original audio-tape recording before data analysis was commenced to ensure accuracy of information. **Table 3.2** displays the steps that were followed in the study.

Table 3.2: Thematic analysis steps by Clarke and Braun (2013)

Steps	**Description of the steps**
1. Reading transcriptions and field notes deeply, noting significant ideas	This step is common to most data analysis methods, where there researcher engages immensely with data collected. The researcher is reading and re reading or transcribing data and noting the significant ideas.
2. Reading each interview, questioning the objective and underlying meaning	To this step, the researcher identifies data with same features and organising it according to relevance with ideas. In this phase, data analysis continues, it is not phase of data reduction.

3. Distinguishing the different types of themes	The process of identifying similar codes of data available takes place in this phase. This phase concludes by relating all coded data significant for each theme.
4. Coding themes and highlighting them throughout the text	Thematic map of data analysis is being generated in this phase. The researcher provides description about the themes and state whether the themes are giving a concrete story about the data and relationship in themes.
5. Describing, categorising and identifying relationships of themes	This is a continued process of identifying the specifications of each theme and naming themes. It is all about getting the essence of specific theme for the researcher to name it.
6. Report writing	The researcher looks at the whole analysis, relating it back to the main research question and the literature review of the study, then produce the report.

3.6.3 Interpretation of Results and Integration of Data

In this sequential explanatory mixed methods study, the qualitative data (Phase 2) was used to explain the quantitative (Phase 1) data. The researcher compiled and drafted recommendations for promoting FCC in the adult Intensive Care Units based on data collected in the study. The recommendations were guided by the framework of FCC (Mitchell *et al*., 2009) and the literature review.

3.7 ACADEMIC RIGOUR

Academic rigour of the study refers to the criterion that the researcher utilised to align himself with quality of the study findings. In mixed methods, it comprises validity and reliability, as well trustworthiness (Polit and Beck, 2012).

3.7.1 Validity and Reliability

Validity and reliability is a criterion of aligning the quantitative study with the quality of findings. It measures the scales or instruments that were used for data collection and if they can be used in human research study.

3.7.1.1 Validity

Validity is a criterion to assess methods for measuring variables (Polit and Beck, 2012).The FCC instrument or tool for data collection was developed by Mitchell *et al.* (2009) for FCC study in the Intensive Care Units. This instrument has been used in several research studies successfully. It was checked with the supervisor if it could be a valid instrument for this study and permission to use it was then obtained from the owner.

3.7.1.2 Reliability

Reliability refers to the consistency and reliability of research data as it was obtained, and it incorporates the reliability of the scales or instruments utilised to gather information (Polit and Beck, 2012). The information was collected from the participants using questionnaires. The questionnaire used was developed by the previous researcher for a study on FCC, and permission to use it was obtained from her. The questionnaire went to the Ethics Committee for review to be used in this study and it was approved.

3.7.2 Measures of Trustworthiness

The term trustworthiness refers to the degree of confidence qualitative researchers have in their data, assessed using the criteria of credibility, transferability, dependability and Confirmability (Polit and Beck, 2012).Trustworthiness forms part of qualitative research validity, and is about aligning the study according to the four concepts below.

3.7.2.1Credibility

The term credibility refers to confidence in the truth of data and interpretation as the researcher attempts to demonstrate that a true picture of the phenomenon under study is being presented (Polit and Beck, 2012). The researcher is a qualified Intensive Care nurse who has first-hand experience of caring for a wide range of critically ill patients in Intensive Care Units.

3.7.2.2 Transferability

This refers to the degree to which the research findings can be applied to different contexts or groups, and large population. It incorporates the demographic sample comparisons and the sources of data sampling as well as data saturation.

3.7.2.3 Dependability

The term refers to the stability or reliability of data over time and conditions (Polit and Beck, 2012). The researcher ensured this criterion was achieved by enabling other researchers to repeat the study by reporting processes in detail, although not necessarily yielding the same results. This was achieved through individual interviews and member checking soon after the interview.

3.7.2.4 Confirmability

This term refers to the potential for extrapolation or the extent to which the findings can be transferred or have applicability in other settings (Polit and Beck, 2012). The researcher ensured this criterion was achieved by the use of rich and thick description of participants experiences obtained in the audiotaped interviews. The audiotape recordings of interviews with participants were done to show that interviews were from participants and field notes were kept for verification purposes.

3.8 ETHICAL CONSIDERATIONS

Ethical considerations in research refers to compliance with the principles of respect, beneficence and honouring justice throughout the research process, this manifests from the following headings: obtaining permission to conduct research, the informed consent, and ensuring anonymity and confidentiality in research study (Streubert and Carpenter, 2011).

3.8.1 Permission to Conduct Research

The research proposal was written and presented for peer review to the Department of Nursing Education, where it was refined. The refined research protocol was submitted to the University Postgraduate Committee for assessment of feasibility of the study. The protocol was assessed and corrections made. The protocol was further submitted for review and clearance to Ethics Committee for Research on Human Subjects of the University of the Witwatersrand. Approval to conduct the study was received. After the receipt of ethics permission to conduct the study, approval was sought from the hospital authorities where the study was done. The permission to conduct research in the Intensive Care Unit was obtained from the Unit Manager in order to gain access to the study participants.

3.8.2 Informed Consent

After the researcher has obtained approval to conduct the study from authorities, the participants were invited and given a brief overview of the study. The inclusion and exclusion criterion of the study were explained. Those who met the inclusion criteria were given the information letter, which explained all the study details. A written informed consent was obtained from those who met the inclusion criteria and expressed the willingness to participate in the study. The separate consent to audio-tape the interview was received from the participants. Their right to withdraw from the study at anytime they felt uncomfortable in the study was emphasised.

3.8.3 Anonymity and Confidentiality

Anonymity in research refers to safe keeping of participant’s private, confidential matter and preventing the divulging of participants information (Polit and Beck, 2012). Confidentiality in qualitative research studies means protection of participant’s identification details to avoid it coming into public (Polit and Beck, 2012).In this study, anonymity was done using data codes instead of names during data collection, which in doing so maintained confidentiality.

3.8.4 Management of Data and Security

Management of all research material was ensured by safe keeping in a locked private place by the research supervisor at the university. A backup copy was available and kept on the computer, and accessible through a password, which was available only to the researcher and supervisor. After (5) five years, the stored data was to be destroyed by shredding hard copy documents and permanently deleting all electronic data from the computer and backup hard drives. The raw data was only known to the researcher.

3.9 SUMMARY

This chapter has provided a detailed discussion about the research setting, paradigm, design and methods, the population, sample and sampling methods, data collection and data analysis procedures followed. The reliability and validity, as well as the trustworthiness and ethical considerations of the study were discussed.

The next chapter will address the results about perceptions of patient’s relatives regarding FCC in an adult Intensive Care Unit.

CHAPTER FOUR

FINDINGS OF THE STUDY

4.1 INTRODUCTION

This chapter outlines the findings of the study, which have been presented in two sections, namely quantitative findings and qualitative findings. The quantitative findings, Phase 1, are illustrated by descriptive statistics and followed by inferential statistics. The qualitative findings, Phase 2, were explained by thematic analysis. Qualitative findings are explained after the quantitative findings.

4.2 PHASE ONE: QUANTIATIVE FINDINGS

4.2.1 Demographic Data of the Relatives

This section related to participants demographic data, which comprised seven items. Items included age, gender, ethnic background, relationship to the patient, level of education, distance to the hospital and the reason for admission.

Eighty (n=80) relatives or significant others made up the sample size. **Table 4.1** provides an overview of the results. Items were grouped together for ease of discussion.

Table 4.1: Demographic characteristics of the study sample

Item	Variable	Frequency	Percentage
1	Age		
	18 to 25 years	7	8.75%
	26 to 35 years	15	18.75%
	36 to 55 years	37	**46.25%**
	56 to 70 years	18	22.50%
	71 to 80 years	3	3.75%
	Over 80 years	-	-
2	Gender		
	Male	28	33.00%
	Female	51	**63.75%**
	Unspecified	1	1.25%
3	Ethnic background		
	Black	17	21.25%
	White	59	**73.75%**
	Asian	1	1.25%
	Indian	3	3.75%
	Other	-	-
4	Relationship to the patient		
	Partner	27	**33.75%**
	Daughter/Son	27	**33.75%**
	Sister/Brother	8	10.00%
	Other	18	22.50%
5	Level of Education		
	Completed primary school	1	1.25%
	Completed secondary school	24	30.00%
	Tertiary certificate/diploma	31	38.75%
	Undergraduate degree	7	8.75%
	Postgraduate qualification	17	21.25%
6	Distance to the hospital		
	< 5min	17	21.25%
	>5 to 10min	20	25.00%
	30 to <60min	6	20.00%
	60 to <120min	9	11.25%
	>120min	8	10.0%
	180min	5	6.25%
	190min	-	-
	240min	3	3.75%
	360min	2	2.50%
7	Reason for patients' admission to hospital		
	Medical	34	42.50%
	Surgical – elective	31	38.75%
	Surgical – emergency	15	18.75%

Females accounted for 63.5% (n = 51) and males 33.0% (n = 28) of the total sample (n = 80). The highest responses (46.25%; n = 37) were between the ages of 36 to 55 years, followed by 22.50% (n = 18) and 18.75% (n = 15) in the 56 to 70 and 26 to 35 age categories, respectively. **Figure 4.1** presents the results of this study.

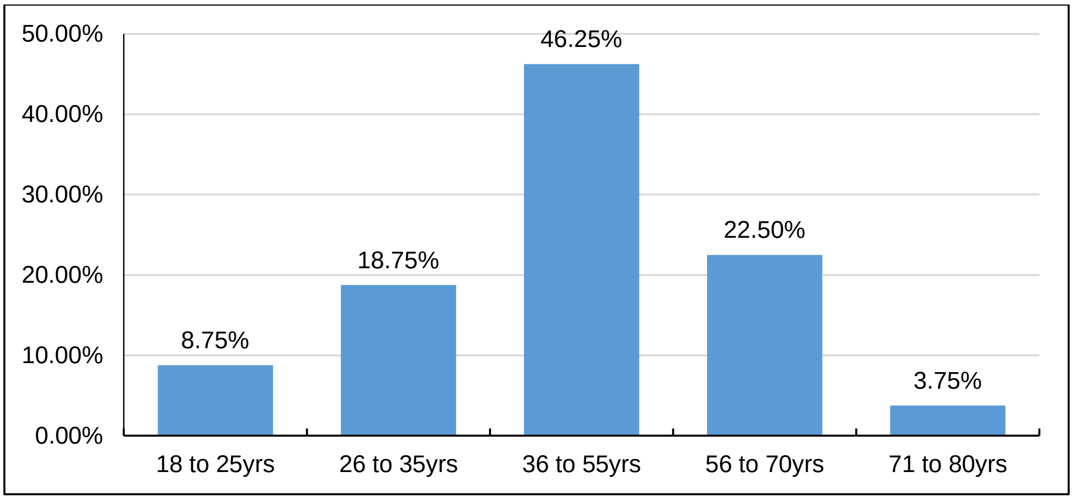


Figure 4.1: Age distribution of the participants

The ethnic background of the participants was highest (73.75%; n = 59) in the White category, followed by the Black (21.25%; n = 17) Indian (3.75%; n = 3) and Asian (1.25%; n = 1) population groups. **Figure 4.2** presents the results of this study.

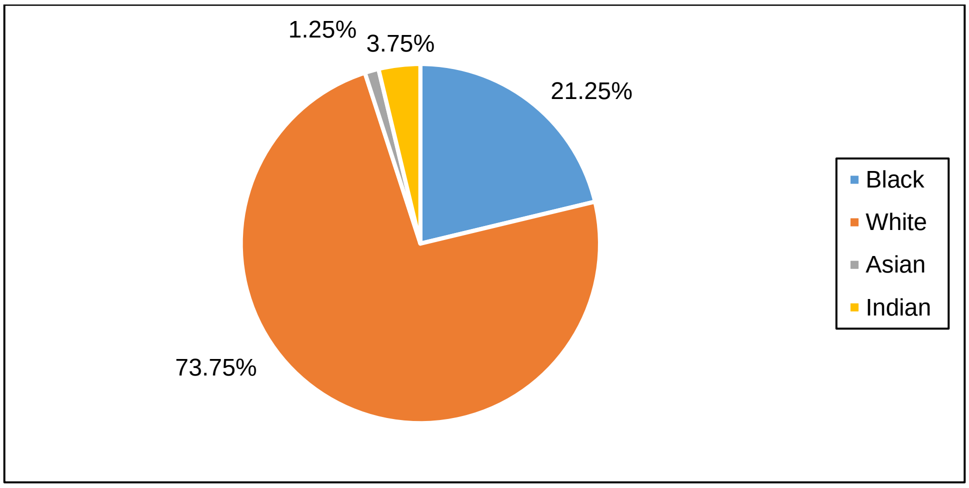


Figure 4.2: Ethnic background of the participants

The participants' relationship to the patient was slightly higher (33.75%; n = 27) in either partner or daughter and son respectively, followed by significant other

(22.50%; n = 18) and sister or brother (10.0%; n = 8). **Figure 4.3** presents the results of this study.

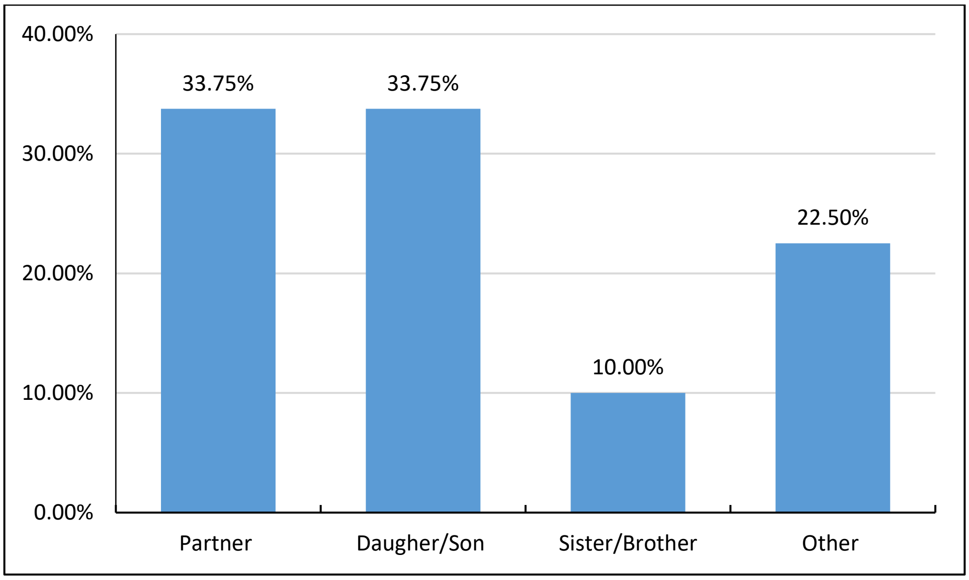


Figure 4.3: Participants relationship to patients

The largest group (38.75%; n = 31) of participants in this study had completed a tertiary certificate or diploma, followed by secondary school (30.00%; n = 24) and postgraduate qualification (21.25%; n = 17). **Figure 4.4** presents the results of this study.

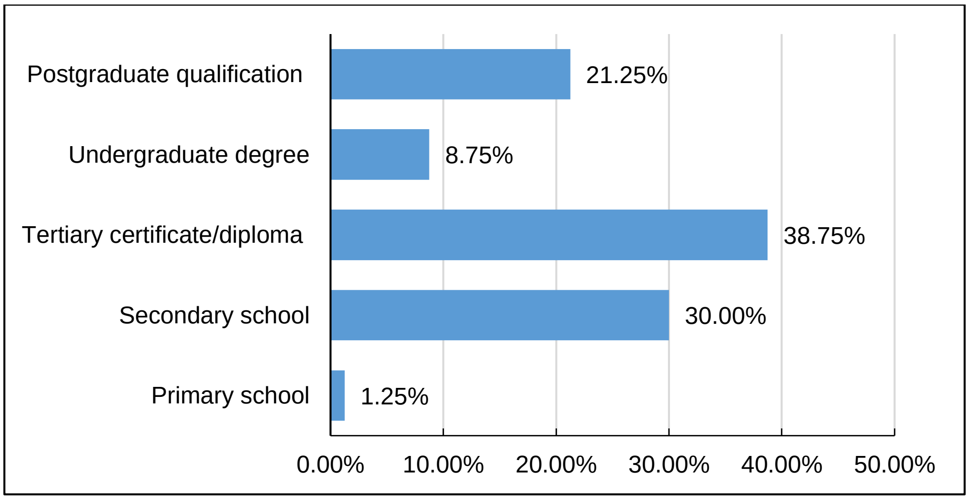


Figure 4.4: Level of education of the participants

In this study, an analysis between participants' travelling distance to the hospital revealed the largest group 25% (n = 20) were in the >5 to 10 minutes category, followed closely by 21.25% (n = 17) and 20% (n = 16) in the <5 minutes and 30 to <60 minutes distance categories respectively. **Figure 4.5** presents the results of this study.

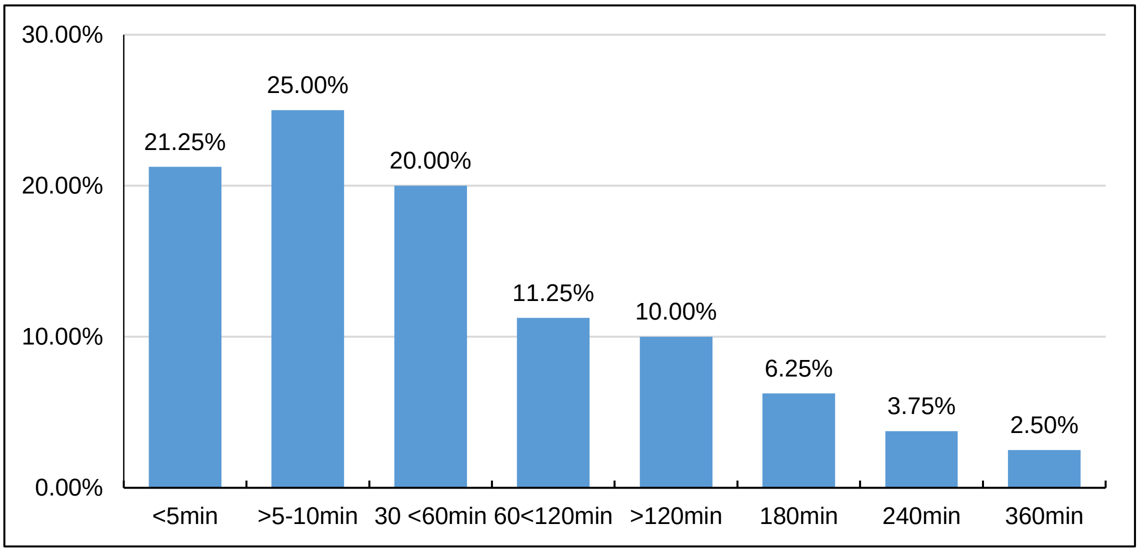


Figure 4.5: Distance to the hospital

In this study, an analysis between patients' reason for admission to ICU revealed that the largest group (42.50%; n = 34) were medical cases, followed by 38.75% (n = 31) and 18.75% (n = 15) as surgical elective and surgical emergency cases respectively. **Figure 4.6** presents the results of this study.

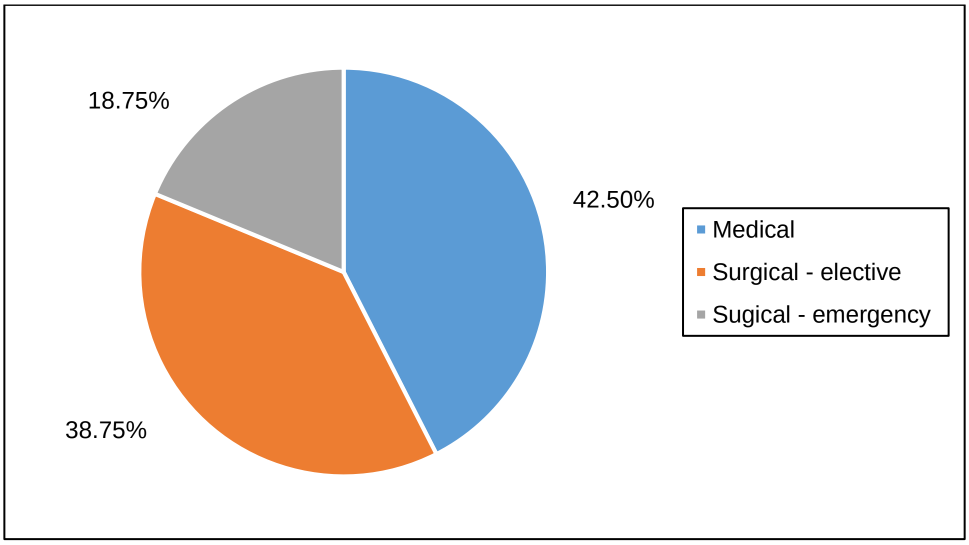


Figure: 4.6: Reason for patient's admission to ICU

4.2.2 Demographic Data of Patients in the ICU

This section of the questionnaire comprised of three items related to the patients in the ICU. Included were severities of illness, as determined by the TISS score, length of stay in ICU and patient's re-admission to ICU.

In terms of severity of illness, the majority of the respondents had a TISS score between 20 to 25 points, followed by 41.25% (n = 33) and 3.75% (n = 3) in 26 to 30 and 31 to 34 points respectively. **Figure 4.7** presents the results of this study.

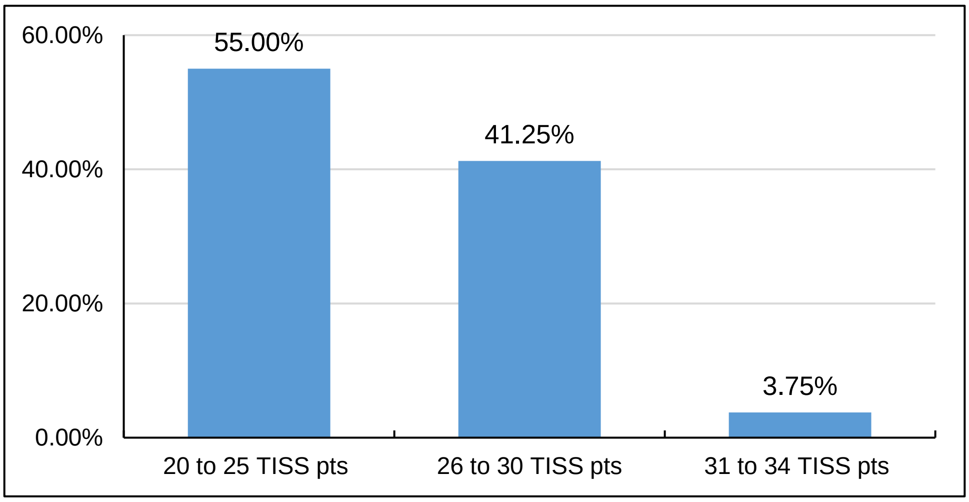


Figure 4.7: Patients severity of illness (TISS score) in ICU

In terms of the patients duration of stay in ICU, the largest group 36.25% (n = 29) were between >7 to 14 and >14 to 21 days categories respectively, followed by 15.00% (n = 12) and 12.50% (n = 12) days categories respectively. **Figure 4.8** presents the results of this study.

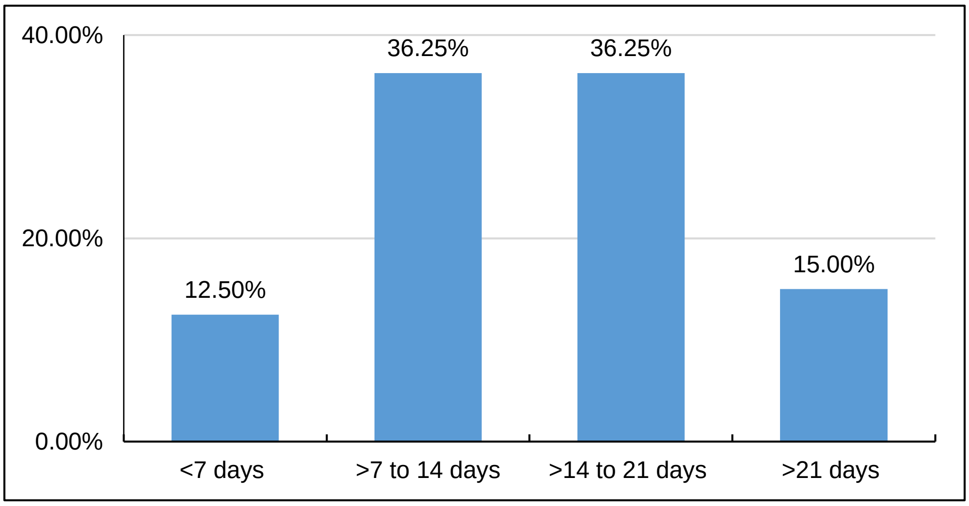


Figure 4.8: Patients length of stay in ICU

The results of the Shapiro Wilk test for normality showed the data on the patients' TSS score to be normally distributed (p<0.016) and data of their length of stay to be skewed (p<0.001).

The mean (SD) TISS score of the patients was 25 (3.41), while their median (IQR) length of ICU stay was 15 (10-19) days.

4.2.3 Relatives perceptions of Family-Centred Care in ICU

This section comprised 20 items. Responses were obtained from the participants by the researcher through a structured interview process, specifically after the patient was discharged from the ICU, to determine relatives' perceptions of family-centred care provided by healthcare professionals in the ICU. Descriptive and comparative statistics were used to analyse the data.

The sample comprised 80 (n = 80) participants, who were family or significant others of adult patients admitted to one General Intensive Care Unit. The instrument used in the study was the "Family-Centred Care Survey – Adult Scale". This questionnaire measures family members' of critically ill patients perceptions of family- centred care in ICU, inclusive of three subscales, namely (i) respect, (ii) collaboration and (iii) support, on a four point Likert-type scale, with the rating option of 1, 2, 3, or 4 reflected as never, sometimes, usually and always, respectively.

Table 4.2: Descriptive statistics of perceptions of relatives regarding **respect** in family-centred care

Item	Subscale 1: Respect Cronbach alpha=0.65 KMO=0.72	Median	IQR	No response n (%)	Never n (%)	Sometimes n (%)	Usually n (%)	Always n (%)
	Respect	3	2-4	16 (20.00)	16 (20.00)	17 (21.25)	18 (22.50)	13 (16.25)
1	When I come, I feel I am welcome to be there.	3	2-4	1 (1.25)	-	5 (6.25)	18 (22.50)	56 (70.00)
2	Other members of my family are welcome to attend with me in the unit.	2	1-2	1 (1.25)	-	10 (12.50)	12 (15.00)	57 (72.25)
3	I am able to be with my relative through some procedures	2	2-2	3 (3.75)	17 (21.25)	22 (27.50)	21 (26.25)	17 (21.25)
4	I have a right to question medical and allied health recommendations about my relative as much as I want.	2	1-3	3 (3.75)	2 (2.50)	9 (11.25)	18 (22.50)	48 (60.00)
5	I feel like a visitor rather than a relative when I attend the unit.	3	2-4	4 (5.00)	38 (47.50)	18 (22.50)	6 (7.50)	14 (17.50)
6	Did you feel your relative’s procedures were carried out with privacy and confidentiality?	3	2-4	3 (3.75)	1 (1.25)	3 (3.75)	12 (15.00)	61 (76.25)

4.2.3.1 Perceptions of relatives regarding respect in family-centred care

Table 4.2 shows the descriptive statistics of perceptions of relatives regarding **respect** in family-centred care.

The Cronbach alpha statistic to measure internal consistency of the size items (items 1-6) for the **respect** subscale was 0.65, which was below the accepted threshold of ≥0.70, showing poor internal consistency. The KMO measure was 0.72, which was above the accepted threshold of ≥0.6; hence, the items in the **respect** subscale were suitable for factor analysis.

The median response for the *respect* subscale was 3 (IQR 2-4), showing the relatives were <u>on average, in agreement with adequate **respect** </u>in family-centred care at the ICU unit of the South African private hospital.

Of the 80 relatives who participated in the study, 60% (n = 48) gave the response “sometimes,” “usually” and “always” to questions regarding the existence of **respect** in family-centred care.

In this study, 70% (n = 56) of the participants answered they “always” felt welcome when they came to the Intensive Care Unit (item 1).

More than 70% (72.25%; n = 57) of the participants answered “always” to other members of my family being welcome to attend with them in the unit (item 2).

More than three quarters (76.25%; n = 61) of the study participants said they “always” felt relative’s procedures were carried out with privacy and confidentiality (item 6).

Table 4.3: Descriptive statistics of perceptions of relatives regarding **collaboration** in family-centred care

Item	Subscale 2: Collaboration Cronbach alpha=0.83 KMO=0.75	Median	IQR	No response n (%)	Never n (%)	Sometimes n (%)	Usually n (%)	Always n (%)
	Collaboration	3	2-4	16 (20.00)	16 (20.00)	17 (21.25)	18 (22.50)	13 (16.25)
7	I feel prepared for discharge to the ward	3	1-4	8 (10.00)	13 (16.25)	9 (11.25)	19 (23.75)	31 (38.75)
8	The staff give me honest information about the care that my relative may need	4	3-4	4 (5.00)	1 (1.25)	9 (11.25)	15 (18.75)	51 (63.75)
9	I know whom to call after I get home if I need help or reassurance	4	2-4	3 (3.75)	8 (10.00)	10 (12.50)	15 (18.75)	44 (55.00)
10	When decisions are being made about care the staff include me	3	2-4	3 (3.75)	10 (12.50)	18 (22.50)	17 (21.25)	32 (40.00)
11	I am being taught what I need to know about the care my relative may need	3	2-4	3 (3.75)	10 (12.50)	11 (13.75)	20 (25.00)	36 (45.00)
12	I know the name of the doctor with primary responsibility for my relative's care	4	3-4	1 (1.25)	1 (1.25)	5 (6.25)	15 (18.75)	58 (72.50)

13	I can easily understand the written material that has been given to me	4	3-4	4 (5.00)	4 (5.00)	7 (8.75)	18 (22.50)	47 (58.75)
14	The staff include family members in the care of my relative	3	2-4	4 (5.00)	10 (12.50)	11 (13.75)	23 (28.75)	32 (40.00)
15	I feel overwhelmed by the information given to me about the relative	2	1-3	2 (2.50)	24 (30.00)	23 (28.75)	16 (20.00)	15 (18.75)

4.2.3.2 Perceptions of relatives regarding collaboration in family-centred care

Table 4.3 shows the descriptive statistics of perceptions of relatives regarding **collaboration** in family-centred care.

The Cronbach alpha statistic to measure internal consistency of the size items (items 7-15) for the **collaboration** subscale was 0.83, which was above the accepted threshold of ≥0.70, showing good internal consistency. The KMO measure was 0.75, which was above the accepted threshold of ≥0.6; hence, the items in the **collaboration** subscale were suitable for factor analysis.

The median response for the **collaboration** subscale was 3 (IQR 2-4) showing that the relatives were, <u>on average, in agreement with adequate **collaboration**</u> in family-centred care in the ICU unit of the South African private hospital.

Of the 80 relatives who participated in the study, 48 (60.00%) participants gave the response “sometimes,” “usually” and “always” to questions regarding the existence of **collaboration** in family-centred care.

In this study, 63.75% (n = 51) of the study participants reported that the staff “always” gave them honest information about the care their relative needed (item 8).

More than half (55.00%; n = 44) of the study participants said they “always” know who to call after they get home if they needed help or reassurance (item 9).

In this study, 72.50% (n = 58) of the participants said they “always” know the name of the doctor with primary responsibility for my relative’s care (item 12).

Table 4.4: Descriptive statistics of perceptions of relatives regarding **support** in family-centred care

Item	Subscale 3: Support Cronbach alpha=0.81 KMO=0.63	Median	IQR	No response n (%)	Never n (%)	Sometimes n (%)	Usually n (%)	Always n (%)
	Support	3	2-4	16 (20.00)	16 (20.00)	16 (20.00)	17 (21.25)	15 (18.75)
16	All team members are familiar with my relative's special needs.	4	3-4	3 (3.75)	1 (1.25)	7 (8.75)	24 (30.00)	45 (56.25)
17	All team members listen to my concerns.	4	3-4	3 (3.75)	1 (1.25)	9 (11.25)	22 (27.50)	45 (56.25)
18	Whenever possible I get to see the same team member for each area of care.	3	3-4	4 (5.00)	6 (7.50)	14 (17.50)	30 (37.50)	26 (32.50)
19	The staff know who my important support people are.	3	2-4	3 (3.75)	6 (7.50)	13 (16.25)	27 (33.75)	31 (38.75)
20	The staff understand what my family and I are going through.	4	2-4	1 (1.25)	1 (1.25)	11 (13.75)	19 (23.75)	48 (60.00)

4.2.3.3 Perceptions of relatives regarding support in family-centred care

Table 4.4 shows the descriptive statistics of perceptions of relatives regarding **support** in family-centred care.

The Cronbach alpha statistic to measure internal consistency of the size items (items 16-20) for the **support** subscale was 0.81, which was above the accepted threshold of ≥0.70, showing good internal consistency. The KMO measure was 0.63, which was below the accepted threshold of ≥0.6; hence, the items in the **support** subscale were suitable for factor analysis.

The median response for the **support** subscale was 3 (IQR 2-4) showing that the relatives were on average in agreement with adequate **support** in family-centred care in the ICU unit of the South African Private hospital.

Of the 80 relatives who participated in the study, 48 (60.00%) participants gave the response “sometimes”, “usually” and “always” to questions regarding the existence of **suppor***t* in family centred care.

In this study, 60.00% (n = 48) of the participants reported that staff “always” understand what my family and I are going through (item 20).

More than half (56.25%; n = 45) of the study participants said they “always” felt all team members listen to my concerns (item 17).

In this study, 56.25% (n = 45) of the participants said they “always” know all team members are familiar with my relatives special needs (item 16).

4.3 PHASE TWO: QUALITATIVE FINDINGS

This section presents qualitative findings from interviews with family members of patients admitted into the ICU at the selected study site.

4.3.1 Demographic Data of the Participants

Participants in this study were relatives who visited patients most during admission in the South African private adult ICU. This was the second phase (Qualitative phase) of the study, and those who participated in Phase 1 (Quantitative phase) and were willing to be part of Phase 2 were allowed. The research question and the study objectives remained the same. Participants were males and females, aged 18 years and above.

Participants were family members living under same roof or extended family members with direct contact with the patient. For the purpose of this study, 20 participants, visiting critically ill patients who had been in the ICU for more than three days, were interviewed during data collection. Most participants were from the Free State, Bloemfontein and other small towns, and some from Lesotho, a small country that borders Free State Province. There were also a few participants visiting patients from other provinces, namely Northern Cape and Eastern Cape. These participants were regular visitors for patients in ICU.

4.3.2 Emergent Themes

The study collected data about perceptions of patient’s relatives regarding family-centred care at a South African private adult ICU. Data was collected using an audiotape recorder. The participants signed consent forms to participate in the study. A quiet private room in the hospital was used for the interviews with the participants. Permission to conduct interviews was sought from the Unit Manager and Chief leader in the ICU during the selection process of asking families to participate in the study. Data was collected through a semi-structured questionnaire with one main research question and following questions. Emergent themes that arose from the interviews were communication, partnership, caring environment, proximity need, religion and cultural practices. There were 14 subthemes with the following prevailing issues: lack of updates; healthcare providers’ attitude; communication technology; incomplete handover; involvement in activities; learning opportunities; feeling of relief; respect; dignity; family support; fair treatment; visiting hours; family bonding; cultural and religious inclusion.

The data regarding these themes and subthemes from participants was analysed using thematic analysis by Clarke and Braun (2013). There were two statements attached as quotes from the participants to support the statement from the themes. The quotes were given codes during data coding, (PN) meaning participant number, for example if the quote was for participant number 4(PN4). Table 4.5 provides an overview of themes and subthemes that arose from the interviews of the participants.

The transcribed interviews were reviewed by the supervisors after the coding of each participants interview as (PN) meaning participant number with a digit value next to PN. Supervisors verified the transcribed interviews and did the co coding of the interviews. The consensus was reached with the supervisors on emergent themes after coding of data.

Table 4.5: Themes emerging from the qualitative interviews

THEMES	**SUBTHEMES**
4.3.2.1Communication	4.3.2.1.1 Lack of updates 4.3.2.1.2 Healthcare providers attitudes 4.3.2.1.3 Communication technology 4.3.2.1.4 Incomplete handover
4.3.2.2 Partnership	4.3.2.2.1 Involvement in activities 4.3.2.2.2 Learning opportunities 4.3.2.2.3 Feeling of relief and helping
4.3.3.3 Caring environment	4.3.3.3.1 Respect and dignity 4.3.3.3.2 Unfair/unequal treatment 4.3.3.3.3 Family support
4.3.3.4 Proximity feeling	4.3.3.4.1 Visiting hours 4.3.3.4.2 Family bonding
4.3.3.5 Religion and culture	4.3.3.5.1 Different cultural inclusion 4.3.3.6.2 Religious affiliation

4.3.2.1 Theme One: Communication

4.3.2.1.1 Lack of updates

Participants stated they did not get information from the doctors to keep them updated; information was only received from the nurses. At times, the nurses could not explain some of the things that required the treating doctor to explain. The following quotes from participants support these statements:

"…*For my family not to hear from the Doctor for these four days was a negative experience we had in hospital. It showed that there is no good communication with Doctors. The support was fine that we received from the nurses. They tried to explain things but some of the things you can see that a doctor has to explain them. In this way there was not enough support from the medical doctor's side." (PN 2)*

Other participants added to this statement:

"*The nurses will be talking to my granny although she was writing down if she wants to say something and the nurses will be reading her lips when she talks, and interprets to us what is she saying." (PN 6).*

"Doctor that left without giving us proper complete information. We did not get updates from the Doctor at all." (PN7)

4.3.2.1.2 Healthcare providers' attitudes

Participants stated the attitude of healthcare providers affected communication with families. The following quotes substantiate this statement:

"*The surgeon Doctor that operated my husband did not have time for me and no time to even answer my questions. You will see, she will be saying I am going out I am on my way out now as if other patients are more important to her than my* *husband. The communication between the doctors and us as family was very rushed*.**"** *(PN 3)*

"….I saw him coughing and I went to report to the sister and the sister rolled the eyes showing to be not pleased at all with me, it was like I am irritating." (PN9)

4.3.2.1.3 Communication strategies

Family members were unhappy about not getting updates. Other families suggested that health care providers should utilize other means to communicate with them like technology. Families do understand that at times healthcare providers are extremely busy and there is no time to meet families and explain to them but there should be a way to communicate with the families. The following quotes states suggestions from family members:

"….now we also have technology where we can get emails about feedback if the Doctor is too busy or even get a call". (PN13)

Other family members perceived that, the best time to communicate with families should be at the bedside, during interdisciplinary rounds. This would allow families to ask questions and for the doctor to explain.

"Encourage families to be part of Doctors rounds that also reduces time to Doctors to seat down and explain." (PN 8)

4.3.2.1.4 Incomplete handover

Handover in clinical setting comprises of giving or passing vital information about the patient amongst healthcare professionals. This information might be regarding the condition, treatment plan and changes to be implemented.

Participants perceived there was incomplete handover in the unit between healthcare professionals. This affected the way the healthcare service should be rendered to patients in the Intensive Care Unit. The statement from the participant supports this:

“The other day the other nurse realised that the medication has been stopped two days ago but it was not supposed to be stopped but that happened because of poor handover.” (PN 3)

The participant continued by stating that especially in ICU, things should be taken as crucial and everything is vital, as said in the following quote:

“You must remember this is critical care meaning if you work in ICU you should not take things light, every bit of medication and instruction is vital. At some point you can see that there is no proper flow of information amongst the healthcare providers.” (PN 3)

Another participant also stated that the poor handover resulted in lack of proper updates to the family. If one healthcare professional stands in for another, they should at least be given enough information about the patient to ensure the same consistent updates to family.

“…we were in the dark is because the Doctor who treated my father at times will be gone to somewhere like we going to hear that he is out of the country and the nurses will give us little information about what is happening to my dad. The other Doctor who will be standing in will only give us limited information. At a later stage we found that he is having failure of one organ at once.” (PN 7)

4.3.2.2 Theme Two: Partnerships

4.3.2.2.1 Involvement in activities

The interviews showed there were more participants willing to be involved in performing daily activities for their loved ones while admitted in hospital.

"…Promote family involvement in terms of self-care like bathing, cutting nails and brushing teeth." (PN8)

Another participant added to this statement of allowing family to help during activities and suggested family supervision by nurses. The following interview quotes support this statement:

"…allow family members to help if they want to but please they should be under supervision." (PN13)

"I would love to be part of small procedures like combing the hair and cutting nails I would not say its nurses' job, the family should contribute as well." (PN14)

A few participants stated they would not like to be present during activities because of fear. Other participants stated that they trust healthcare providers and they did not want to interfere in their job. Involvement in activities brought mixed perceptions from different family members, because some were happy to be involved and would like to see that happening, whilst other participants did not like to be involved in activities. The interview quotes below are in support of this statement:

"I wouldn't love to be involved during activities or certain procedures done to him because it will traumatise me more and I will be scared, but it is good for us as family that nurses are helping with all those activities and procedures. We also don't want to interfere with the hospital procedures." (PN 4)

Another participant added on this same perception:

"I personally feel that being around with big procedures that Doctors are doing like a big drip on the neck can be very too much and healthcare professional might struggle even more. I will also feel the pain myself as well." (PN 18)

4.3.2.2.2 Feeling of relief and helping

Participants felt the feeling of relief by collaborating with healthcare providers in rendering healthcare to their loved ones. The feeling of relief to family members came from the point of being a helper even in hospital. Other participants felt that when a family member is sick you must continue to look after them in hospital. This feeling is worse if the loved one in ICU is a parent, because you must give back to your parents by doing good things for them. One participant responded accordingly:

"I felt that being there and doing minor things for my daughter gave me a sense of belonging and I felt that I did not abandon my daughter I am still caring for her." (PN18)

One participant added that the admitted family member was her father, who had done great things for them back at home:

"…...I always thought of my dad doing great things for us now it is our time to give back to my dad by doing that." (PN8)

Partnership between healthcare providers and family members also promotes the relationship of trust as families start to trust healthcare providers. One participant stated that through collaborating with nurses in ICU, she ended up developing trust from them and knowing that her husband was in 'good hands.' The following quote is from her interview:

"I ended developing relationship of trust with four staff members that I knew that if there is a problem I should come to talk to. That for me made the burden bearable because I know they got my back even if I go home." (PN3)

4.3.2.2.3 Learning opportunities

Partnership in rendering healthcare services does not only strengthen relationship of trust between healthcare providers and family members, it was found to promote opportunities for family members. This partnership occurred during minor activities at the bedside in the presence of family members. Family members got opportunities to ask questions about the condition and expectations, and the nurses were teaching the family members when they answered the questions. The following responses from different participants support this statement:

"I want to be part of care like when they clean the wound I want to be there and see, it is important to get family involved and you get chance to ask questions and learn about other ICU things." (PN3)

"The most positive thing is that I learned a lot about patient admitted in ICU and the way patient's behaviour changes in ICU." (PN16)

Another participant said they also want to know the medication's effects and the response of the human body to the medication. This participant had a little bit of medical background, being a paramedic, which influenced his learning needs at the bedside. The participant stated that they wanted to know everything about the medication but no one taught them and he was not happy about that:

"*She is already in a bad state and now I don't know the effects of the medicine. I also don't understand how the human body responds to certain medication, she is always sleeping and I want to interact with her but I can't (look of emotion on his face) because of all these medications." (PN 1)*

Learning opportunities expanded further for other participants as they continued to learn at home. Families discussed with their relatives overseas and they were reading articles based on what they heard in the ICU from the nurses. Another participant learned about the infection, how it should be prevented, how a person gets the infection and the new related research. The responses below are in support of these views from families:

"My daughter is a physiotherapist and she sends me things that you can read as a result I learned about delirium and my husband was once delirious as well and not talking sense at some stage seeing things. I really feel sorry for the people who do

not have this information because they don’t understand what is going on with their loved ones.” (PN16)

Another family member added to this by stating that nurses quote some research work done about infection for the family to understand:

“The nurses some of them you can see that they are highly knowledgeable as they explain to us and teach us about infection and they quote research and studies that has been done.” (PN 3)

4.3.3.3 Theme Three: Caring Environment

4.3.3.3.1 Respect and dignity

Family members perceived they were treated with respect and dignity in the unit. The politeness, humbleness and good communication from the healthcare professionals brought a sense of respect to families. Participants reported that as they went through the door, a nurse would greet them and walk them to the cubicles where their loved ones were lying. A family member saw the nurse talking to the patient who was unconscious and mechanically ventilated. The responses below came from participants about treating someone with respect and dignity:

“Nurses are always there for us and they talk to my father even though he is on the machine and sedated they still talk to him, that shows respect to us as family as we see that he is in good hands.” (PN4)

“The staff talks polite to my husband I feel like they have respect in this unit.” (PN16)

A different family member added on this statement:

“The first day I came in I was treated with respect and warm welcome….” (PN12)

The participants perceived that respecting someone’s dignity in ICU was vital because during that time the patient is vulnerable. One participant stated that even during suctioning of the phlegm, the nurses talked to her father informing him what they were going to do. To her that was part of respecting someone:

“They treat him like he can see and talk because he was sedated they would say “Sir we are now going to suction” if they want to suction the phlegm. He is treated like he can hear everything they are gentle with my father.” (PN4)

4.3.3.3.2 Unfair/Unequal treatment

Participants expressed feelings of being happy and satisfied about the treatment they received in the ICU, however there were those who perceived the treatment as both negative and positive experiences. Other participants felt that family members of other patients were getting special treatment, unique from that received by other families. These different views resulted in different feelings expressed by participants, stating that maybe this was because of their skin colour. The interview quotes attest these perceptions:

“As far as I am concerned the families are being treated well and we did get updates where it was needed. We got a priority the first day we come in through the door and we do get support at times.” (PN17)

Another participant from the families who were happy and satisfied added to the above statement:

“I am satisfied that my husband is in good hands according to what I see with my eyes.” (PN16)

The lack of consistency in addressing families in the Intensive Care Unit resulted in many complaints from families. Some family members perceived the care as unfair and influenced by skin colour. This was related to the number of visitors per patient in ICU and the reaction from nurses when visiting hours were over. These participants concluded that they were unfairly treated in ICU.

“…..I thought we are all visitors for patients that are paying in the hospital. I noted that we were not treated equal with visiting times the Whites will be allowed to be more than two at the bed side per patients but when it comes to us as Blacks they will be strict telling us that only two visitors per patient but we can see that we are not treated fairly and equal.” (PN17)

The same participant continued to express concerns of not being satisfied about the situation she observed happening in ICU, by adding that the reactions of nurses was not the same to all visitors when visiting time is over. The quote below was extracted from the interview*:*

“The other thing will be that when visiting time is over the Blacks will be told that visiting time is over but Whites will remain sitting inside so that created a lot of questioning to us as visitors.” (PN17)

Another participant also raised concerns about the issue of unfair treatment by healthcare providers. The views of this participant attest to what was perceived by PN17 above.

“One day I saw that the patient was not that critical ill but there were more family members I asked myself is it because I am Black or what is happening? They must try to treat us the same way please.” (PN19)

4.3.3.3.3 Family support

Family members who received support from the healthcare providers of Intensive Care Unit coped well during the critical illness of their loved ones. Communication with families by healthcare providers was found to be a key factor in promoting support. Most participants who communicated more with nurses ended up perceiving the ICU environment as being supportive to them. Nurses allowed family members to be at the bedside close to their loved ones, answered their questions and offered tea. All this led families to feel supported by nurses. Participants perceived support as critically important in the ICU context.

“Hospitals and ICU need to look closer to supporting families especial in ICU, really this needs to be addressed. In ICU at times you need someone to assure you. You might perceive yourself as strong but few days your loved one continues to deteriorate in ICU, your mental state also go down very fast trust me (making cross with his fingers).” (PN1)

“The other good thing that was done to me, I was tired from work a male nurse brought me a cup of coffee and that was good and the other sister provided health talk to my husband about smoking cessation that showed more caring.” (PN3)

Another participant continued to talk further about the support she received from nurses and from extended family members. The participant reported that she was working, and having to cope with all this was not an easy thing for her. The routine at home changed because her husband was hospitalised in ICU and now she has to do extra duties. At times, she has to travel with her work and leave her children at home. She managed all this through the support she received in ICU.

“Now I had to change the whole routine of mine and I had to travel to head office at times with my work. It was chaotic but the support from the nurses and my extended family members helped me to cope.” (PN3)

Participants stated that additional support systems, if available, should be utilised effectively to ensure family support in ICU. Families suggested there should be a psychologist or a counsellor that might help to communicate with families. This is to see if they are coping and not suffering psychological effects due to the critical illness of their loved one. The following interview quote supports this statement:

“ …Even me I worked in the prison. I am strong and hard type of person but these days we struggled to cope with my daughter we had to get the therapist to tell her our story because if we tell our story the burden becomes lighter. This was because we needed help with the mental fight that we had, in the ICU the mental war in your mind continues to play in your head.” (PN1)

“The ICU did send a counsellor to talk to us but my mom did not want to talk, so that way support was provided by the unit.”(PN4)

Another participant added to this statement. She talked about getting a middleman to promote family support. The figure of a social worker came to mind to promote family support. The participant said that the reason for bringing in the middleman was to prevent the family from being in the dark about the situation. Communication between family members and healthcare providers still plays a big role in supporting family.

“There should be a component to bring psychologist and social worker on board to talk to family and be a middle man between family and the Doctor this will prevent family being kept in the dark. For me if nursing staff cannot talk to family someone should be used to do such function for family support.” (PN 7)

4.3.3.4 Theme Four: Proximity Feeling/Need

4.3.3.4.1 Visiting hours

Family members had mixed perceptions or views regarding the visiting times. Some participants were satisfied, while others were not, about the current visiting times. The reason they felt satisfied about these current visiting hours was that, they want to allow time for the healthcare providers to do their work and to allow healing to their loved ones. The participants who felt satisfied about visiting hours received clarity from healthcare providers. The clarification they received was about the need for visiting hours in ICU. The following responses came from participants:

“They explained well why they have specific visiting hours to allow time for patients to rest and other healthcare team members can perform certain procedures. I did not have a problem with that.” (PN18)

Many participants added to this by saying why they were satisfied about the currently existing visiting hours in the unit.

"I believe the visiting hours here are more than enough because people are very sick needs to rest and people should adhere to these hours." (PN 15)

"I am satisfied about the visiting hours and believe that she is here to get better then she needs to rest and not make visiting hours longer." (PN 14)

Other participants felt that visiting times should be increased to allow more time for them to be around their loved ones. These participants felt that visiting hours interfered with their work times; others reported traffic on the road when driving to the hospital. These emerging reasons resulted in requests to increase the visiting hours. The following extracts are from the interviews:

"The visiting times are a bit shorter sometimes although they did allow us if we request the staff was understanding. The visiting times might need to be increased a bit I think." (PN5)

Two other participants also supported this view of increasing the visiting hours:

"I think they should expand on the visiting hours a bit because at times you want to go somewhere now the visiting times will restrict you." (PN17)

"They should increase number of visitors for the patient and they should try to extend the visiting hours." (PN 20)

Family members still perceived the visiting hours as not necessary in the ICU setting. Some participants attested that visiting hours should be removed completely. Participants believed that as the people in ICU were critically ill family members they needed to be close to their loved ones; while some said long distance travelling to visit patients makes visiting times impractical. The following interview quotes support this statement:

"…..Allow visitors to come any time because this is ICU patients are critically ill…" (PN8)

“…..I think removing the visiting times to make visiting in ICU convenient to everybody I am not sure if it is possible…..” (PN 6)

Another participant agreed with visiting times accommodating people travelling from afar and those who were working.

“The visiting hours should be considerate to people travelling from far.” (PN 10)
Family members were aware that visiting times were not being used in other dimensions of nursing. One participant even mentioned that in maternity, families are allowed at anytime. The reasons of removing visiting times were that family members want to be around their loved ones while they are hospitalised. Other participants verbalised that at times they want to come at night to see their loved ones because they are stressed and concerned, but they cannot due to visiting times that are in place. The following interview quotes supports these statements:

“They should at least allow close family to stay as much as they want like it happens in maternity.” (PN20)

Another participant added to this response:

“The other times I felt like going there at night to see him but then I will think about visiting hours that it is out of visiting hours they will not allow me in. I feel like in ICU we should just be allowed to come in any time because patients are very sick there.” (PN8)

Participants did mention that during times when the hospitalised family member became critically ill or deteriorated in condition, family were allowed to stay longer in ICU. The ICU did this to allow family time around the sick person and this special consideration was only given to families with critically ill patients who were deteriorating clinically. Participants also stated that special requests were considered if you came late due to work, or you asked from the nurses. The following interview quotes are in support of this statement:

“….although they did allow us if we request the staff was understanding.” (PN5)

“……..I think in ICU the family should be given access anytime because patients are very sick. Although I know the staff allows you if your family member is very sick.” (PN1)

“The nurses did allow us to come in even if it was not visiting time because I am working I could not get there in time that was a good thing they did.” (PN5)

4.3.3.4.2 Family bonding

Participants felt the need to continue bonding with their relatives or family members even in ICU. Family members stated that through collaboration with healthcare providers, they managed to learn other things to help their loved ones, such as small activities, massages, combing hair, cutting nails. These activities allowed relatives to bond with their loved ones during hospitalisation. Participants also felt the need of allowing more visitors at a patient’s bedside for enough support and bonding with the sick family member; the number of visitors per patient at present is limited to two people. The following quotes were from participants interviews:

“...Increase the number of people to visit in the ICU not only limited to two people.” (PN8)

Another participant added to this point:

“They should increase number of visitors for the patient and they should try to extend the visiting hours.” (PN20)

Participants responded with a need of increasing time for them to be around their sick relatives. Family members did raise concerns about insufficient time for them to bond with their loved ones. There were a few aspects mentioned that resulted in limited time for family bonding in hospital, short visiting times, visiting times utilised by healthcare providers with procedures, pain medication causing patients to sleep before visitors came, and number of visitors limited to two people; participants also mentioned that cleaners at times would be busy cleaning the floor and the visitors had to wait to allow floor to dry.

The participants mentioned there should be a way to synchronise the visiting times with the pain medication. The reason for this was to allow time for visitors to communicate with their loved ones while they were awake. Participants stated that when they visited their loved ones they would often be sleeping and the nurses would tell them that it was because of pain medication.

"The visiting times should at least be before patient gets medication so that family can interact with their loved ones because some medication makes patients' sleep. I could not speak to my wife due to certain medication that was given making her sleepy." (PN1)

"The family members must sit there while they are not communicating with their loved one because they are sleepy there should be a right way of synchronising care with hospital routines, medications and activities with visiting times." (PN3)

The healthcare providers were also seen to be utilising the visiting hours; participants noted that physiotherapists would be busy with patients while visitors were waiting to visit the patient.

"At times I feel like the visiting times are utilised by physiotherapists because they do their work just before visiting hours and now the patients are tired wants to sleep." (PN3)

The cleaning teams at times delayed the visitors from entering the ICU because they were scared of stepping on and falling on the wet floors.

"The bad experience was when we come to visit then we had to wait while it's already visiting hours because the cleaners were still busy at the entrance. I feel like during visiting hours they should give us a chance because I know hospitals are very strict about visiting hours." (PN14)

Family members who drove long distances to visit family members in hospital complained that visiting times were too short. This happened because as they came to hospital there would be traffic on the road, and their stay was too short with their loved one.

"We came to ICU to visit the other day the visiting hours were finish so assumed that we have to stay shorter like greeting my husband." (PN10)

"There is an issue of visiting hours of which they should think about people who are driving from far. Remember you may leave your house in time but traffic on the road, this delay you to arrive on time. We are driving from Lesotho so the hours are always not convenient on our side." (PN 13)

4.3.3.5 Theme Five: Religion and Culture

4.3.3.5.1 Cultural inclusion

Cultural practices were noted as vital to some participants although not to others. This was because of living a western life; the complete family attends church with no cultural practices needed in the family. Participants did mention that cultural and traditional values of families should be accommodated in ICU. Families were scared to ask or to perform certain cultural relevant practices because they were not sure it was allowed. The suggestion from participants was that it should be addressed in the orientation part of the unit. The quotes below were extracted from the interviews of the participants:

"We also have traditional values that are very important. At some point we wanted to burn ashes but we did not know if we can do that because we thought ICU is a very clean environment." (PN3)

The response of participant PN3 was seconded by the response of PN8 below, which also suggested inclusion of cultural practices in treating patients in ICU.

"Allow people to perform rituals or cultural practices and that should be in the booklet stating that you are allowed to perform that." (PN8)

Participants demonstrated understanding of their cultural and traditional values. Family members did this by providing explanations of their cultural practices about what the practice meant or did for them. Healthcare providers should note even small things because it serves a certain purpose to someone’s culture. This came through from participants responses. Some participants saw the unit as accommodative to cultural practice, whereas others viewed the unit as not accommodative.

“*We believe in talking to our elders when someone is sick at home, we do believe in ancestors in my family*.” (PN17)

One participant was not happy about cultural inclusivity because of the rope that was removed from the hand of her family member for insertion of intravenous infusion line. She provided the meaning and significance of this rope on the hand:

“I am not happy about cultural inclusivity because my family member had a rope on the hand, we are Zulus, we believe that rope provides protection against evil spirits but then she was told to cut it off in casualties because they wanted to insert a drip on that hand. Now we had to keep it in her bag.” (PN17)

4.3.3.6.2 Religious practices

Participants described religious practice inclusion in the ICU as being allowed, but they were unsure about it initially until they did it themselves. This happened because participants did not receive any information booklet to inform them if religious practice was allowed or not in the unit. Family members stated that they asked nurses if they could pray in the unit for their loved ones and the nurses allowed them to do so.

“As a family we were allowed to bring in the picture of our religious teacher that we believe into. And we used ashes on his face that brings the sense of protection.” (PN3)

The views of the above participant we attested by PN8:

"I liked it when we request to pray and they did allow us, they said we can just close the curtain and pray for my dad…"

Participants prayed using their religious instruments and meditating beads. The critical illness of the family member caused the whole family to be serious and scared. Family members had to consult the seniors at church and in the family to strengthen the way they prayed, which was why they prayed using rosaries and why they brought water from church. Other family members brought their senior pastors from church to help them with prayer.

"The other night I prayed using a Mantra which is very good in healing people, it is a Hindu culture although there are different religions in the family. The Holy Rosary plays a very big psychological role. It's like the ashes meaning that I have done the prayer therefore this is Gods protection and the Holy Rosary also declares that God is nearer to you and protecting you." (PN3)

Another participant brought water from church because it is used when praying for a sick person, as well believing it is Holy Water.

"Sometimes we got water that we bring from church….." (PN 17)

Participants mentioned that they consulted the senior pastors in their church to come and do a big prayer.

"The priest came on Monday to pray because we are Christians at home. The nurses did allow him to do the prayer. We are the Roman Catholics so the priest also came with sacraments." (PN12)

Family members mentioned that they were unsure if they were allowed to pray or to bring religious items with them along with prayer. The two following quotes support this statement:

“Sometimes we got water that we bring from church we are not sure if we are allowed to use it or not and we were scared to ask thinking that the rope was cut off.” (PN17)

“At some point we wanted to burn ashes but we did not know if we can do that because we thought ICU is a very clean environment.” (PN3)

4.4 SUMMARY

This chapter presented and analysed the findings of the study, which were broken down into themes and sub-themes for the qualitative phase. The findings of the quantitative phase, where the data were collected from questionnaires, were presented in the form of tables.

Chapter Five will discuss the findings of the quantitative and qualitative data analysis in relation to relevant studies.

CHAPTER FIVE

DISCUSSION OF FINDINGS

5.1 INTRODUCTION

This chapter discusses the findings of the study in relation to the supporting literature. The discussion has been aligned with the analysis of the study. The discussion has been organised in line with the findings, i.e. Phase 1 – quantitative, Phase 2 – qualitative.

5.2. PHASE ONE: DISCUSSION OF QUANTITATIVE FINDINGS

The study collected data from the family members of patients who were admitted in the General ICUs of a South African private hospital in Bloemfontein. Most of the participants in this study were female, aged from 36 to 55 years. One-third of the participants were related to the patient as a partner (spouse) or a child (daughter/son). A close three-quarter of the participants were White, 38.75% had completed a tertiary certificate or diploma, and a close half (46.25%) lived within a 10-minute travelling distance from the hospital. Most patients had a medical diagnosis on admission to ICU, mean TISS score of the patients was 25 (3.51), while their median length of stay was 15 (IQR 10-19).

Phase 1 (quantitative study) collected data using a semi-structured questionnaire. The questionnaire collected data from participants about perceptions of patient’s relatives regarding family-centred care under the following headings: respect, collaboration, and support. These headings are discussed below.

5.2.1 Respect in family-centred care

Findings in this study demonstrated that the participants were on average in agreement with adequate respect in family-centred care (Median 3; IQR 2-3). Most of the participants gave the response “sometimes”, “usually” and “always” to questions about the existence of respect in family-centred care. Similarly, most participants reported that they always felt welcome (70%) when they come into the ICU, and their extended family members also felt welcome to attend to their relatives (patients) (72%). These findings are supported by one study by Mitchell et al. (2009) which showed a median score of 3.7 of participants who felt respected compared to a lower score of 3.5 from the control group of participants.

In this current study, findings showed that family members felt respected in the unit. Findings in this study revealed that there was an increase in the percentage of family members who disagreed on being allowed to be present during their relative's procedures. The findings showed that 21.25% (n = 17) gave the response “never”, contrasted by, “sometimes”, “usually” and “always” (28%; 26%; 21%), respectively.

Although participants perceived respect in the unit and felt welcome, some of the participants also gave responses that they “sometimes”, “usually” or “often” felt like a visitor when they attended the ICU. Findings in this study revealed a close majority (48%) disagreed to this statement.

5.2.2 Collaboration in family-centred care

Findings in this study revealed that there was a high level of collaboration between healthcare providers and family members (Median 3; IQR 2-4).Collaboration occurs when healthcare providers start working together with family members and the patient.

Most (74%; n = 59) of the participants in this study gave the response “sometimes”, “usually” and “always” to questions regarding the existence of collaboration in family centred care. In this study, some (40%) of the participants reported that the staff always involved them when decisions had been taken, and about 45% of the study participants reported that the staff always taught them about the care needed by their relatives. These findings are supported by the results of a study by Ciufo, Hader and Holly (2011), which indicated a high percentage (95%) of participants who wanted to participate in the care their loved ones.

Based on these findings, the majority of participants experienced collaboration in the unit with healthcare providers. Collaboration improves communication, relationships and enhances learning at the bedside. The findings of this study showed that 67.5% to 93.8% of participants “sometimes”, “usually” and “always” agreed that they perceived collaboration compared to participants who disagreed (2.5%-32.5%). The total subscales of 40% for participants who disagreed on collaboration in the unit and a 60% subscale of participants who agreed on collaboration. This is in congruence with the findings of the study by Mitchell et al.(2009), which discovered the higher median score (3.4) of collaboration with the intervention group compared to a lower score (3.0) of the control group. The results of the study are also supported by the findings of the study done by Garrouste-Orgeas et al. *(*2010), which indicated that 96% of family members were in support of collaboration in patient care with healthcare providers. Through collaboration between healthcare providers and family members, there is good information sharing during communication and enhancing of patient satisfaction with care.

The results of the study by Garrouste-Orgeas et al. (2010), further elaborates that 70% of patients were satisfied with family members contribution to rendering healthcare to them; however, 30% of patients did not want to receive care from family members. The findings of this study showed a majority of participants agreed “sometimes”, “usually” and “often” on being overwhelmed by the information they received about their loved one and 30% disagreed.

This provides evidence that collaboration allows information sharing between family and healthcare providers. These findings are similar to those reported in a study by Ciufo et al.(2011), who found that family involvement was noted to be increasing as it moved from 51% to 80%. This study further elaborates that collaboration enhanced patient satisfaction and strengthened relationships between family and healthcare providers.

5.2.3 Support in family-centred care

Findings in this study revealed that there was on average a level of agreement among family members related to support in family-centred care (Median 3; IQR 2-

4).The findings demonstrated that participants in this study displayed a high degree of support they perceived in the unit during the stay of their loved one.

The study found that a majority (95%) of participants responded to the question “sometimes”, “usually” and “always” that healthcare providers were familiar with the needs of their loved ones and they listened to the family, respectively. In addition, 87.5% responded “sometimes”, “usually” and “always” that they saw the same team member for each area of care and 12.5% disagreed. These findings are supported by the results of the study by Andershed *et al.* (2011), which reported that participants showed high perceptions of support concerning information and communication received from healthcare providers and the whole overall stay in the unit. Participants perceived support as present in family-centred care, as the median ranged from 4-5, and the scale ranged from 1 very dissatisfied to 5 very satisfied.

Healthcare providers, through communicating and collaboration with families, can identify families who need help and support. Most families perceived that healthcare providers “sometimes”, “usually” and “always” knew their family support systems. The study results showed respectively about 39%, 33% and 16% agreed on this, and 11.3% disagreed. Overall, participants perceived support in the unit. These findings are in congruence with the findings of the study by Mitchell et al.(2009), which discovered high median score of 3.6 in the intervention group compared to a lower median score of 3.2 from the control group.

Participants felt supported in the ICU if their questions about their loved ones were answered and other support needs were met in the unit. Participants perceived the sharing of honest consistent information about the patient as one of the things that enhanced support to families. In this study, 95% of participants agreed “sometimes”, “usually” and “always” that family members understood their needs and their concerns, and only 5% disagreed on these aspects. These findings were supported by the results of the study by Baileyet al. (2010), which discovered that families were satisfied with support if their informational support needs were met; this was seen with scores ranging from 29 to 80, and the high mean of 55.4.

5.3 PHASE TWO: DISCUSSION OF QUALITATIVE FINDINGS

This section discusses the findings of phase two (qualitative study). The study explains the perceptions of patient's relatives regarding family-centred care at the South African private hospital adult ICU. The themes that emerged from this study are communication, caring environment, proximity need, family involvement and cultural practices with religion.

Communication was the most common theme amongst participants and had four sub themes; lack of information updates, healthcare provider's attitude, use of technology and incomplete handover. Participants were not satisfied with communication in the unit, especially from the medical doctors. Poor communication was pertaining to the lack of updates from the doctors. Family members wanted to get these updates to keep themselves informed about the patient's condition, treatment plan and expected outcomes. Davidson (2009) stated that clear communication with family was vital to identify their needs and components to meet these needs in the ICU.

Poor communication between healthcare providers and family members poses challenges. This supports the statement that nurses were not always informed about the explanations and progress from doctors to family, and that worsened the communication problem, as nurses did not know what to tell family members (Brysiewicz and Bhengu, 2010). Good communication between healthcare providers and family members is significant because it gives assurance and support. Family members also felt they were part of care for their loved ones (Obringer et al., 2012).

The information that was given to participants was only from the nurse's side, but some of the things required the treating doctors to explain. This was perceived by participants as incomplete information and stressful to families as they wanted complete information. Communication is one of the important needs of family members as they enter the Critical Care Unit. Family members want to get as much information about their loved one as they can, and they want healthcare providers to address them with this information. A study done by Schmollgruber (2019) discovered that attending to family members’ needs does not only decrease anxiety and stress, it also improves the patient’s level of satisfaction with the care. Communication was a theme that needs to be addressed by healthcare providers because it fulfils the satisfaction of informational needs of family members.

Participants suggested that technology was there to be utilised; the hospital could even use it to communicate with families. The participants suggested emails and cell phones; a phone call should be used to communicate with the family to provide updates, and this is even more vital if the doctor is too busy in the hospital. A phone call enhances communication and satisfaction with care to family members. Family members also felt that their informational needs were met in the ICU (Bailey *et al.*, 2010).

Other participants suggested the use of informative pamphlets by ICUs to give them information on what to expect and what to bring to the unit. These leaflets could be kept in the waiting room outside the ICU and family members can read them while waiting to enter the ICU. There is literature that supports the use of information leaflets to educate the family about the ICU, diagnosis, and to orientate family members about the hospital rules and policies. These leaflets help in meeting the informational needs of patients (Bailey *et al.*, 2010).

Communication with family members should be educational, providing them with literature or sources where they can get information. Participants were happy to get information about delirium in the ICU, as nurses were teaching them in the unit and the online sources were shared with the family. Family members also learned about infection and sources of infection, and measures to prevent transmission; these sources were provided to the family for this information. A study by De Beer and Brysiewicz (2016) discovered that information shared by healthcare providers to family members should also provide sources where it is found and family members should be able to access that information on their own.

The attitude of healthcare providers also affects the communication process. Healthcare providers should communicate with families politely and professionally. Participants verbalised that information sharing was rushed between them and the surgeon doctor. The surgeon did not want to communicate due to going into theatre, but the family member felt she wanted to ask something from the doctor, however, there was no chance for that. Participants described communication as “rushed.” Nurses at times considered themselves as not capable of providing information to families and told families that the doctor will come and explain all the concerns of the family. Healthcare providers are not taking the information needed by the families seriously (Koukouli *et al.*, 2018). Healthcare providers’ attitudes need to be addressed in order to promote family-centric approach in the unit.

Healthcare providers should give comprehensive handover about patients. This ensures that all information about the patient is carried over from shift to shift amongst nurses. Doctor’s clinical notes should provide complete information about the patient. Information sharing to families by healthcare providers should be consistent at all times (Bailey *et al.*, 2010). Participants stated that certain medications were stopped, but still given to the patients due to poor handover.

The attending doctor did not hand over his patients to a doctor working the weekend, and the family did not get complete updates. These findings were supported by results of the study by Brysiewicz and Bhengu (2010), which discovered that communication is often a problem in private hospitals because the patient has multiple doctors looking after different conditions and that worsens the already poor communication. Family members want to hear precise information about the diagnosis, treatment and prognosis from doctors and nurses; they want to hear about the daily care and reasons for certain treatments and ICU equipment (van Mol et al., 2017).

Participants also stated that information about the patient was not given to doctors who would be standing in for the weekend, and at times incomplete handover was noted amongst healthcare providers, including nurses. The new doctor would speak to the family in medical terms and this was a concern to family members because they did not understand. A study by Baas (2012) stated that families should be given information that is not biased, and this information should be comprehended by the family and the patient at their understanding level. Family members require information sharing to be the same information from all professionals. This information should be provided in common English terms, not medical terms (Wetzig and Mitchell, 2017). Families require communication to be uniform in all spheres as it promotes partnerships between healthcare providers and family members.

Participants in this study were satisfied to be involved in activities of caring for their loved ones. Families are not only significant in the patient's life; they form part of the healthcare team (Jones and Khan, 2017). This partnership between healthcare providers and family members allowed interaction, learning opportunities, information sharing and enhanced satisfaction. Family members also reported they felt they were part of the care for the patient.

Partnership provides the feeling that family members continue to provide care even in hospital; they did not abandon their loved one. Family participation has benefits for the patient and the family, feeling closeness, continuity of life before ICU, relief of guilt feelings and information sharing with healthcare providers (Soury-Lavergne *et al.*, 2011). Family-centred care promotes partnerships in rendering healthcare to patients. Family-centred care provides expansion of partnerships in rendering negotiated healthcare to relatives and close family members (Shields, 2010).

A partnership between healthcare providers and families not only allows family members to participate in activities, but it also promotes feelings of closeness and enhances patient satisfaction with care. Family members get to understand the complexity of the situation and feel relief that they were part of care as their loved one recovers (Wetzig and Mitchell, 2017). Participants in this study were interested in being involved in activities of caring for the patient and wanted to be part of the care.

Participants suggested that it would be more comfortable to be part of the care or doing activities under the supervision of the nurses. Families should be asked if they want to participate in daily activities, such as bed baths, combing hair and cutting nails, they should not be forced to participate (Mitchell et al., 2009). The same study done by Mitchell et al. (2009) discovered that family members who participated in patient care were optimistic and were linking the patient with the environment outside the hospital. Partnership also promotes relationships between healthcare professionals and the family while the patient is in ICU.

The relationship of trust that develops from the family members of the patient is from good interaction between healthcare professionals and family members. Participants started to trust healthcare providers after they received more health talks and they realised the healthcare professionals were knowledgeable. Partnership at the bedside allows families and healthcare providers to know each other better (Mitchell and Chaboyer, 2010).

During partnership at the bedside, while washing the patient, participants were asking questions. Health talk continued through good communication with the nurses. Literature suggests involving family members at the bedside as this will improve satisfaction and allows learning about different cultures, preferences, health literacy, and enhances family satisfaction (Clay &Parsh, 2016). Learning was found to be in two directions, as healthcare provider' learned and the family members gained information.

Family members should be allowed to be part of care and to partner healthcare providers because they are a source of information and help about the patient. These patients at times are sedated and ventilated and family members act as advocates for them (Almaze and De Beer, 2017). Family members can assist in the care of difficult patients and help healthcare providers.

Participants felt involved when they received calls requesting consent for procedures and had the opportunity to discuss this with other family members. Critically ill patients are mechanically ventilated and mentally unfit to make decisions on their own due to sedative medications. Family members come to be the surrogates or decision-makers on behalf of the patient, and represent the vulnerable patient at that time (van Mol *et al.*, 2017).

Participants mentioned that their family members were often confused, and nurses kept orientating them, and immediately family members arrived, they helped the nurses by calming the patient. Patients refused to eat when nurses tried to feed them, but they ate when their family members fed them. This demonstrates a good partnership between the patient, healthcare providers and family members. Family members should be part of interdisciplinary rounds, healthcare plans and progress, and be encouraged to participate (Clay and Parsh, 2016). This improves the healthcare rendered to patients in the ICU.

Study participants reported the good caring environment they encountered in the unit. Participants mentioned that nurses greeted them as they entered the ICU, accompanied them to the bedside of their loved one and communicated with them. Many participants perceived the whole ICU as a caring environment because they felt comfortable inside the unit. When at home, they felt assured their loved one was safe and in ‘good hands’. The Intensive Care Unit does not only render healthcare to patients as the role has expanded to caring about family members as well who are stressed by the admission of their loved one (Latour and Coombs, 2017).

Some participants stated that the ICU environment was scary, and during admission of a family member, they rushed to the hospital. The biggest fear from family members was death and this fear was often worsened by previous experiences or re-living the ICU experience. Family members who had lost other family members in ICU were more scared of the environment. The ICU environment is intimidating, not a common environment and families are thinking that their loved ones could die in ICU (Brysiewicz and Bhengu, 2010). Healthcare providers can change all these perceptions by proving good care to families.

Families verbalised that nurses were communicating with them, allowed them to ask questions and allowed them to be part of care if they wanted to participate. The unit did suggest counsellors to talk to families who were struggling to cope. At times nurses would make tea and chat with the family to hear how they were coping and to identify their needs. The ICU environment has been noted to increase the anxiety and post-traumatic stress disorder in family members (Obringer et al., 2012). Participants further elaborated that they received emotional support when they were in tears. Family members need both internal and external support resources to help them with coping during the difficult time of admission of their loved one in ICU.

Family members achieved this through the care and relationship of trust with healthcare providers (Brysiewicz and Chipps, 2006).

The relationship between family members and healthcare providers was built on mutual respect for each other's dignity. A good relationship occurred when nurses respected the patient and family members who came to visit the patient. Family members felt their loved one was in 'good hands.' Participants noticed healthcare providers talking to patients who were sedated, intubated and unconscious. Families were listening to nurses as they explained to sedated patients the procedures they were performing. This demonstrated caring for patients with respect and dignity. To treat someone with respect means you accept the individual as he or she is, and the accompanying values of that person (Mitchell and Chaboyer, 2010).

Healthcare providers should be cultural and religious sensitive in order to practice family-centric approach in ICU's. To be cultural and religious sensitive means you acknowledge diverse cultural and religious practices (De Beer and Brysiewicz, 2016). Participants brought some cultural and religious practices from home, but they were not sure if they could do use them in the ICU. Others conducted their practices but were uncomfortable because they were not given authority by nurses. The Indian families came in large numbers to pray and left pictures of their religious teacher to whom they pray.

Other family members brought Holy Water from church to pray with and they had a cultural rope that was kept in the bag of the patient. Diverse cultural and religious practices offer hope and support to patients and allow the family to cope with the situation (Brysiewicz and Bhengu, 2010). Healthcare providers showed fair and equal treatment to all families and patients by allowing diverse cultural practices and religion. Participants were satisfied with the opportunity they had to pray for their loved ones in ICU.

Participants stated that when someone is sick at home rituals are done, which includes cultural and religious practices. Families believe in trying everything they can to help their family member to recover. The biggest concern for them when the sick person is hospitalised, especially in the ICU, which is perceived as highly clean by families, is whether their cultural practices can be taken into the ICU. The findings of the study by De Beer and Brysiewicz (2016) found that these cultural and religious practices were believed by families to be improving the outcome, give a sense of control to the family and were a source of comfort since the family wanted to try everything they could to help their loved one. A cultural and religious practice brings the feeling of togetherness and the whole family supporting each other, aiming for recovery of their loved one.

Participants reported the proximity need as significant to them. Family members in this study had a need to be close to their loved ones. The closeness feeling provides relief emotionally, and they felt they were support sources. Participants wanted to spend more time with their loved ones, socialise with them and see how they were recovering in ICU. These findings are congruent to findings of the study done by Al-Mutair *et al.* (2013), which discovered that family members who were stressed by critical illness had a need to be close to their sick relative. To address the psychological suffering of family members, healthcare providers should allow families to be around their sick relatives. Families feel the sense of contributing to a patient’s recovery and wellbeing by being present at the bedside bonding with their loved one (Wong *et al.*, 2017).

In this study, the majority of participants were not happy about visiting times in the ICU, as they reported visiting times were too short. Other participants stated that ICU visiting times did not allow them enough time to bond with their sick relatives. This statement was attested by the findings of Soury-Lavergne *et al.* (2011), which found that visiting times were short, especially in the afternoon. Participants suggested that visiting times should be completely removed in ICU, making visiting more conducive for families. It is vital to allow family members to visit their loved ones in ICU more often and to allow them to visit anytime (Karlsson et al., 2011). In the ICU setting, patients are critically ill, and families should be allowed to be around their loved ones and to visit anytime.

Participants want to be close to their loved ones because they want to show love, massage them, and socialise. These interventions by family members bring support to the critically ill patient and enhance patient satisfaction. The open visitation policy improves family satisfaction on their proximity need and enhances cardiovascular function for the patient (Chapmanet al., 2016). Healthcare providers should support family members by giving them information and allow them to be close to their loved ones (Soury-Lavergne et al., 2011).

5.4 INTERPRETATION OF RESULTS AND INTEGRATION OF DATA

The explanatory sequential mixed methods design was used to achieve the study objectives. This two-phase design analysed quantitative data findings, which was followed and informed by qualitative data collection and analysis. The purpose of this design was to use quantitative data to explain in more detail in qualitative results (Creswell, J.W. and Creswell, J.D., 2018).

The study findings reveal that participants (family members) were not satisfied with the communication with the doctors in the ICU. Poor communication can result in dissatisfaction and poor patient outcomes. Family members reported a lack of updates from the medical doctors treating their loved ones (patients). Healthcare providers should at least update family members about the progress of patients once per day. If the hospital unit is busy, available technology should be utilised to communicate with families. Participants can receive calls from the hospital, and emails from the medical doctors about updates.

Hospital rounds, or doctor's rounds, should be utilised to facilitate communication with the family members at bedside; this reduces the time of having to sit and communicate with family members giving updates about the patient. Family members also get a chance to ask questions at bedside. Appointments to see the treating doctor can still be made if necessary. To promote a family-centred care approach in the unit, healthcare providers should be transparent to relatives about patient's information and keep the family updated. Updates from healthcare providers about sick family members reduce stress to family members at home and allow them to cope during this critical period (Bailey et al., 2010).

Healthcare providers should be trained in providing communication to the patient's relatives. The attitude of healthcare providers during communication with families should display the family-centric approach. Training of healthcare providers should provide a background understanding of a family member visiting the ICU in a devastated state. Family members come with anxiety and feelings of uncertainty to ICU when they visit their loved ones. All this could be due to reliving the ICU experience or the alien ICU environment (Karlsson et al., 2011). Healthcare providers should connect with family members during this time to reduce anxiety and uncertainties.

The understanding of family-centred care goes hand-in-hand with respecting the needs of family members as they come to ICU. Healthcare providers during this time of connecting with family members should communicate and find ways of collaborating with family members in rendering healthcare. Patient`s relatives should be allowed to participate in minor activities, as they want to be part of care, but not be forced to participate. Family members can collaborate by combing hair, brushing teeth, helping during bed baths and doing massages to the patient (Mitchell *et al.*, 2009). Collaboration between healthcare providers and family members enhances patient satisfaction and builds a relationship of trust between healthcare providers and families. Nurses get an opportunity to identify and prioritise family needs during communication at bedside, as they can start to identify the support needed by the family during critical illness.

Family member’s support systems might be from a cultural perspective, where rituals may need to be performed for the patient while in ICU. Families get a chance to enquire about all this at bedside from the nurses. Religious and cultural practices should be involved in the plan of care and be accommodated in the ICU. This brings sense of security, belonging, support and togetherness to family (De Beer and Brysiewicz, 2016b). The values of different cultures should be respected and be treated with dignity by healthcare professionals. All patients’ relatives regardless of the race, gender, culture, or religious affiliation should be treated equal, with respect and dignity without any discrimination in order to promote a family-centric approach.

Family-centric approach should be promoted in all the Intensive Care Units and measures to enhance it should be in place. To promote a family-centric approach the Intensive Care Unit should be a friendly environment. Family members should feel welcome in the ICU, and all the ICU stressors should be minimised to make patients and families feel at home. There should be a written information document provided in the form of pamphlet with all the information about the unit and contact details.

The staff in the unit should greet families at the entrance and orientate them at bedside. Healthcare providers should identify struggling families and those who need support. The visitor's room should be informative and be welcoming to families of ICU patients. Promoting the family presence at bedside is also therapeutic for the patient, as it provides a connection between the patient, relatives and also connects the patient with the outside world as the family talks about the things happening back at home (Mitchell and Chaboyer, 2010).

The family should be encouraged to stimulate and rehabilitate the patient at bedside. . In rendering holistic care to patients in ICU, family members should be allowed to be present at bedside (Mitchell *et al.*, 2009). Findings in this study suggest that visiting hours should be removed in order to promote family-centred care approach in the unit. Participants who drove long distances coming to hospital did not bond with their loved ones due to shortened visiting hours and to traffic affecting travelling times. Elimination of visiting hours enhances client satisfaction and reduces crowding of visitors' rooms (Chapman *et al.*, 2016).

5.5 SUMMARY

This chapter discussed significant findings from both quantitative and qualitative investigation, in line with current literature and the purpose of the study.

In the final chapter, the summary of the study, main findings recommendations and conclusion will be discussed.

CHAPTER SIX

SUMMARY OF THE STUDY, MAIN FINDINGS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION

6.1 INTRODUCTION

This chapter provides a summary of the study's main findings. The study's justifications are presented together with limitations, and the chapter concludes with recommendations for nursing practice, education, management and future research.

6.2 SUMMARY OF THE STUDY

6.2.1 Aim of the Study

The aim of the study was to describe the perceptions of family members of patients admitted in the adult ICU regarding family-centred care.

6.2.2 Objectives

The objectives of the study were to:

- Describe the perceptions of family members of patients admitted to a General ICU regarding family-centred care (quantitative study).
- Explore the views of family members of patients admitted to a General Intensive Care Unit regarding family-centred care (qualitative study).

6.2.3 Methodology

Prior to commencing the study, ethical clearance was granted by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, as was approval from the Faculty of Health Sciences Post Graduate Committee and the Chief Executive Officer, Intensive Care Medical and Nurse Unit management on behalf of the hospital.

A General Intensive Care Unit in a South African private hospital was used to conduct the study. Family members of patients who were admitted to the Intensive Care Unit were selected to participate in the study using the convenient sampling method. Survey data was collected using a validated instrument with permission from the main developing author. A semi-structured interview guide was developed by the researcher and pre-tested with the first participant prior to collecting data to clarify questions.

To achieve the study objectives, a sequential explanatory mixed method design was used. The study was conducted in two phases. In Phase 1, data was collected from 80 (n = 80) participants over a period of 12 weeks. Findings were described using descriptive statistics. In Phase 2, data was collected from 20 (n=20) participants over a 10 weeks period. Findings were discussed using Clarke and Braun's (2013) qualitative thematic analysis.

6.3 SUMMARY OF MAIN FINDINGS

The perceptions of family members of patients regarding family-centred care were established from the survey component of the study, which revealed that on average, they were in agreement with respect, collaboration and support of family-centred care at the ICU unit of a South African private hospital.

Findings revealed that of 80 family members who participated in the study, 60% gave the response "sometimes," "usually" and "always" to questions regarding the existence of respect in family-centred care. More than 70% of the participants answered, they 'always feel welcome when they come into ICU,' and 'family members were welcome to accompany them into the ICU.' In this current study, 59 (74%) participants gave the response "sometimes," "usually" and "always" to questions regarding the existence of collaboration in family-centred care; 52% of these responded "always." In addition, the study findings revealed that approximately 60% of participants gave the response "sometimes," "usually" and “always” to questions regarding the existence of support in family-centred care. Overall, findings suggested a level of respect helped some family members to build a collaborative relationship with members of the multidisciplinary team (nurses and doctors) and, in turn, they felt supported in the unit.

In the semi-structured interview component of the study, five themes emerged from the data and thematic analysis. These included Communication, Partnership, Caring environment, Proximity need, Religion and cultural practices.

In this current study, communication emerged as a main theme due to lack of updates, incomplete handover and attitude from healthcare providers. Mostly the poor communication aspect was from the medical doctor’s side, as relatives were satisfied with communication from nurses. Davidson *et al.* (2009) described communication as vital in meeting family needs. Good interaction between family members and healthcare providers not only reduces stress and anxiety, but also enhances patient satisfaction and outcomes (Schmollgruber, 2019).

Healthcare provider’s attitudes also affect communication as family members are concerned about asking lots of question, but the responses should be polite and professional. Information should be consistent to family, and they in turn should be given the opportunity to ask questions for their own understanding. Family members should be provided with unbiased information at their level of understanding (Baas, 2012), as they are also involved in the care of their loved one.

Participants in this study expressed perceptions of being satisfied with involvement in the care of their loved ones. Some participants did not want to be involved in the care as they felt that it would be interfering with healthcare providers work. The involvement of healthcare providers in the care of patients promotes sharing of information, thus enhancing patient satisfaction and learning opportunities. Families are part of the healthcare team, not only significant in the patient’s lives (Jones and Khan, 2017). Other participants stated that healthcare providers should supervise them in some activities of caring for their loved ones in the ICU; however, families should not be forced to participate in caring for their loved ones in ICU (Mitchell *et al*., 2009).

Participants perceived the caring environment as they entered the ICU; they were greeted by a nurse and accompanied to the bedside. Healthcare providers also offered family members emotional support and referral for counselling for those who in need. Family-centred care approach today states that ICUs have taken over the role of caring for family members, not only the patient lying on the bed (Latour and Coombs, 2017). Families asked about religion and cultural practices in the unit at that time, as they felt welcome in the ICU.

Participants perceived cultural and religious practices were still under improvement in the unit. Participants were scared to practice their rituals, as they did not receive information that they could be performed in the unit. Families felt these cultural practices should be accommodated and families be informed that it can be done at any time. Cultural and religious practices offer support and hope, and allow coping in family members (Brysiewicz and Bhengu, 2010). Through cultural and religious practices, the proximity need for the family is met as they communicate with their ancestors.

Family members perceived the proximity need as met in the adult ICU, however a few participants who were not satisfied about the unit meeting this need. Family members wanted to spend more time next to their loved ones in ICU. These findings were similar to those of Al-Mutair et al. (2013), who discovered that during critical illness family members want to be close to their loved ones and see them recovering in front of them. The presence of restrictive visiting times had a negative impact on the proximity need in ICU.

6.4 APPLICATION OF THEORY TO THE FINDINGS

When applying the Family Centred Care theory to the findings, respect, collaboration and support was identified as key principles for the application of Family centred care in the ICU. Despite the recognition of different views regarding respect, collaboration and support it was evident that participants recognised the need for open and clear communication with health care providers throughout their critical illness experience. Communication enables the development of a respectful therapeutic relationship and partnership between health care providers and family members in ICU. Also, it provides an opportunity to reduce anxiety and empower family to advocate on behalf of their loved ones in their best interests. Collaborative partnerships between health care professionals and family members are an underlying tenet for achievement of family centred care. Participants also recognised their needs to not only be in close proximity of their loved one, but also to be involved in care activities for their loved ones such as, bathing, brushing hair, or massaging their loved ones. Support enables family needs to be met and thereby prevents in the immediate and long-term physical and psychological problems on family well-being. Family plays an important role in the full recovery of their loved one. Recognition of the need for improvement in provision of family centred care in the ICU, religious and cultural needs should be considered and incorporated into the individualised plan of care.

6.5 LIMITATIONS OF THE STUDY

The following limitations are recognised by the researcher in this study.

This study was conducted at a single South African private hospital and therefore the results cannot be generalised to other private and public hospitals, only to the specific adult Intensive Care Unit in which the study was conducted.

Although a validated questionnaire was used in the survey component of the study, the Cronbach alpha, used to measure internal consistency for the respect subscale, was 0.65, which is lower than the accepted threshold of 0.70 for internal consistency. This could be related to the small sample size, therefore findings in this subscale should be viewed with caution, and the study should be repeated with a larger study sample.

As noted in the data analysis section of this study, the sample became too small to create subgroups for further analysis in order to compare the association between demographics and participant responses.

The findings of this study may not be an accurate observation of actual practice in the ICU, as only the perceptions of family members of patients in the ICU regarding family-centred care were captured; no healthcare professionals participated.

6.6 RECOMMENDATIONS ARISING FROM THE STUDY

The findings of this study provide an insight into the perceptions of family members of patients admitted to the adult ICU of a South African private hospital with regard to family-centred care. These findings have implications for clinical practice, education and further research.

6.6.1 Recommendations for Clinical Practice

The results of this study showed that the family members of patients in ICU on average (60%) agreed with respect, collaboration and support related to family centred care. Despite this, healthcare professionals should thrive to strengthen the relationship between themselves and family members of ICU patients.

Healthcare professionals should be aware of the needs of family members and the implications of not meeting such needs. Respect, collaboration and support should be provided to the family members to help them cope with discomfort and distress associated with the admission of a sick family member.

Healthcare professionals are urged to conduct a family needs assessment when planning the care of the patient as this will assist them in the implementation and evaluation of family centred care.

Healthcare professionals should embark on continuous professional development and updates on the current issues about family centred care as this will help them to keep informed on new developments about family centred care.

6.6.2 Recommendations for Education

Healthcare providers' understanding and awareness of family-centred care is still under improvement and more needs to be done to improve it, especially in the South African context. Interdisciplinary teams also need to be trained about benefits and strategies of implementing family-centred care.

Family centred care should be incorporated into the curricular for healthcare professionals. This will reinforce the importance of including the families in the care of the patients as well as understanding their needs. This will assist healthcare professions to help family members to cope with the admission of their loved one to ICU.

Healthcare professionals are also urged to embark on research to keep abreast on new information about family-centred care, which can be achieved by using information and technology facilities.

6.6.3 Recommendations for Further Research

This study was conducted in one South African private ICU with a smaller sample size. A bigger sample size is required to generalise the results.

Research in a different hospital should be done to compare the findings.

Further research is still required on strategies to involve different cultural practices in the ICU and different religious practices as this has shown family satisfaction with care. Families still feel that rituals need to be performed for their sick relative's even while in hospital. A further exploratory study is recommended to explore concepts related to culture and religious practices on the needs of South African family members.

6.7 CONCLUSION

Family-centred care is an emerging concept in healthcare and lies at the forefront of healthcare delivery as it influences quality of care. This dissertation explored the perceptions of family members of patients admitted in the adult ICU of a South African private hospital with regard to family-centred care. This study demonstrated that family members who participated in this study were, on average, in agreement with adequate respect, collaboration and support regarding family-centred care. Open communication and interdisciplinary team members (nurses and doctors) partnerships with family members are necessary to provide professional support to address informational needs, anxiety and satisfaction with care of family members of patients in ICU, and an interventional study is recommended for further research.

REFERENCE LIST

Al-mutair, A. S., Plummer, V., O`Brien, A. and Clerehen, R. (2013) ‘Family needs and involvement in the intensive care unit : a literature review’, *Journal of Clinical Nursing* pp. 1805–1817. doi: 10.1111/jocn.12065.

Almaze, J. P. B. and De Beer, J. (2017) ‘Patient- and family-centred care practices of emergency nurses in emergency departments in the Durban area, KwaZulu-Natal, South Africa’, *South African Journal of Critical Care*, 33(2), p. 59. doi: 10.7196/317.

Baas, L.S. (2012). Patient - and family -centred care. Heart Lung, *The Journal of Cradiopulmonary and Acute Care*, 41(6):534-535.

Backman, C., Chartrand, J., Dingwall, O. and Shea, B. (2017) ‘Effectiveness of person- and family- centered care transition interventions : a systematic review protocol’.*Systematic Reviews*, 6(1) , pp. 1–5. doi: 10.1186/s13643-017-0554-z.

Badenhorst, C. (2012). *Research Writing: Breaking The Barriers*. Pretoria: Van Schaik Publishers.

Bailey, J. J., Sabbgh, M., Loiselle, C. G., Boileau, J. and McVey, L. (2010) ‘Supporting families in the ICU: A descriptive correlational study of informational support, anxiety, and satisfaction with care’, *Intensive and Critical Care Nursing*, 26(2), pp. 114–122. doi: 10.1016/j.iccn.2009.12.006.

Bamm, E. L. and Rosenbaum, P. (2008) ‘Family-centered theory: Origins, development, barriers, and supports to implementation in rehabilitation medicine’, *Archives of Physical Medicine and Rehabilitation*, 89(8), pp. 1618–1624. doi: 10.1016/j.apmr.2007.12.034.

Botma,Y., Greef, M., Mulaudzi, F.M. and Wright, S.C.D. (2010). *Research In Health Sciences.* Cape Town: Pearson education.

Brysiewicz, P. and Bhengu, B. R. (2010) ‘The experiences of nurses in providing psychosocial support to families of critically ill trauma patients in intensive care units A study in the Durban metropolitan area’, *South African Journal of Critical Care*, 26, (2): pp 2.

Brysiewicz, P. and Chipps, J. (2006) ‘The effectiveness of in-hospital psychosocial intervention programmes for families of critically ill patients – a systematic review’, *South African Jouranl of Critical Care* , 22 (2), pp. 68-76.

Chapman, D. K., Collingridge, D.S., Mitchell, L.A., Wright, E.S., Hopkins, R.O., Butler, J.M. and Brown, S.M. (2016) ‘Satisfaction With Elimination of all Visitation Restrictions in a Mixed -Profile Intensive Care Unit’, *American Journal of Critical Care*, 25(1), pp. 46–50. doi.org/10.4037/ajcc2016789.

Ciufo, D., Hader, R. and Holly, C. (2011) ‘A comprehensive systematic review of visitation models in adult critical care units within the context of patient- and family-centred care’, *International Journal of Evidence-Based Healthcare*, 9(4), pp. 362–387. doi: 10.1111/j.1744-1609.2011.00229.x.

Clark, A.P. and Guzzetta, C.E. (2017). Ask the Experts, A paradigm shift for patient /family -centered care in intensive care units: Bring in the Family, *American Assocaition of Critical Care Nurses*, 37(2), p.96-98.

Clarke, V. and Braun, V. (2013) ‘*Teaching thematic analysis : Overcoming challenges and developing strategies for effective learning*`. Associate Professor in Sexuality Studies Department of Psychology Faculty of Health and Life Sciences University of the West of England Coldharbour Lane Br’, 26, pp. 120–123.

Clay, A. M. and Parsh, B. (2016). `Patient and family centered care : Its not just for pediatrics anymore`, *American Medical Association Journal of Ethics*, 18(1), pp. 40–44.

Collins, K.M.T., Onwuegbuzie, A.J. and Sutton, I.L. (2006). A Model Incorporating the Rationale and Purpose for Conducting Mixed -Methods Research in Special Education and Beyond, *A Contemporary Journal*. 4(1), p. 67-100.

Coyne, I., O`Neill, C., Murphy, M., Costello, T. and O`Shea, R. (2011) ‘What does family-centred care mean to nurses and how do they think it could be enhanced in practice’, *Journal of advanced nursing* pp. 2561–2573. doi: 10.1111/j.1365-2648.2011.05768.x.

Coyne, I. (2013) ‘Families and health-care professionals ’ perspectives and expectations of family-centred care : hidden expectations and unclear roles’, *Health Expectations* 18, pp. 796–808. doi: 10.1111/hex.12104.

Creswell, J.W. (2014). *Research Design* : *Qualitative, Quantitative & Mixed Methods Approaches*. 4th edition. London : Sage Publishers.

Creswell, J.W. and Plano Clark, V.L. (2011). *Designing and conducting mixed methods research*. 2nd edition.London: Sage Publishers.

Creswell, J.W. and Creswell, J.D. (2018). *Research Design : Qualitative, Quantitative and Mixed Methods Approaches*.5th edition. London: Sage Publishers.

Davidson, J. E. (2009) ‘Family-Centered Care’:, American Association of *Critical Care Nurses*. 29(3),pp 28-33. doi: 10.4037/ccn2009611.

De Beer, J. and Brysiewicz, P. (2016a) ‘The needs of family members of intensive care unit patients: A grounded theory study’, *South African Journal of Critical Care*, 32(2), p. 44. doi: 10.7196/SAJCC.2016.v32i2.298.

De Beer , J. and Brysiewicz, P. (2016b): The conceptualization of family care during critical illness in KwaZulu-Natal , South Africa’, *Health SA Gesondheid*., 22, pp. 20–27. doi: 10.1016/j.hsag.2016.01.006.

De Beer, J. and Brysiewicz, P. (2019) ‘Developing a theory of family care during critical illness’, *South African Journal of Critical Care* 35(1), pp. 19–24.

Denham, S. A. (2015) ‘F.A. Davis: Denham, Eggenberger, Young, & Krumwiede, Family-Focused Nursing Care Instructor Manual-Chapter 2, Moving to Family Focused Care Denham, S.A. (Editor)’. https://www.fadavis.com/product/nursing-family-focused-nursing-care-denham-krumweide-eg Date Accessed: 26 January 2020.

Frivold, G., Bjørg, D., Heyland, D.K. and Slettebø, A. (2018) ‘Family members ’ satisfaction with care and decision making in intensive care units and post stay follow up needs — a sectional survey study’, *Nursing Open John Wiley and Sons Ltd* (August 2016), pp. 6–14. doi: 10.1002/nop2.97.

Garrouste-orgeas, M., Willems, V., Timsit, J., Diaw, F., Brochon, S., Vesin, A., Philippart, F., Tabah, A., Coquet, I., Bruel, C., Moulard, M., Carlet, J. and Misset, B. (2010) ‘Opinions of families , staff , and patients about family participation in care in intensive care units’, *Journal of Critical Care*., 25(4), pp. 634–640. doi: 10.1016/j.jcrc.2010.03.001.

Gerritsen, R. T., Hartog, C. S. and Curtis, J. R. (2017) ‘New developments in the provision of family - centered care in the intensive care unit’, *Intensive Care Medicine*., 43(4), pp. 550–553. doi: 10.1007/s00134-017-4684-5.

Hickman , R. and Douglas, S. (2011) ‘NIH Public Access: Impact of Chronic Critical Illness on the Psychological Outcomes of Family Members’, *American Association of Colleges of Nursing, Advanced critical Care*, 21(1), pp. 80–91.

Institute of Patient and Family Centered Care . (2010) ‘Advancing The Practice of Patient and Family-Centered Care in Hospitals, How to Get Started…? available on https://www.ipfcc.org/resources/getting_started.pdf Date Accessed: 16 February 2020.

Jones, H. and Khan, N. (2017) ‘Outcomes of Patient- and Family-Centered Care Interventions in the ICU: A Systematic Review and Meta-Analysis’, *American College ofCritical Care medicine*, pp. 1751–1761. doi: 10.1097/CCM.0000000000002624.

Jordan, P. (2018). Family-centred care in intensive care units. *South African Journal of Critical Care*, 34(2), pp 34-35.

Karlsson, C., Andershed , B., Engstrom, A. and Tisell, A. (2011) ‘Family members ’ satisfaction with critical care : a pilot study’, *British Association of Critical Care Nurses* 16(1), pp.11-18.

Kean, S. and Mitchell, M. (2014) ‘How do intensive care nurses perceive families in intensive care? Insights from the United Kingdom and Australia’, *Journal of Clinical Nursing*, 23(5–6), pp. 663–672. doi: 10.1111/jocn.12195.

Koukouli, S., Lambraki, M., Alevizaki, A. and Stavropoulou, A. (2018) ‘The experience of Greek families of critically ill patients : Exploring their needs and coping strategies’, *Intensive & Critical Care Nursing*. 45, pp. 44–51. doi: 10.1016/j.iccn.2017.12.001.

Latour, J. M. and Coombs, M. (2017) ‘Family-centred care in Intensive Care: Moving the evidence forward—A call for papers’, *Intensive and Critical Care Nursing*. 42, pp. 1–2. doi: 10.1016/j.iccn.2017.07.003.

Marshall, J. C., Bosco, L., Adhikari, N.K., Connolly, B., Diaz, J. V., Dorman, T., Fowler, L.A., Meyfroidt, G., Nakagawa, S., Pelosi, P., Vincent , J.L., Vollman, K. and Zimmerman, J. (2017) ‘What is an intensive care unit? A report of the task force of the World Federation of Societies of Intensive and Critical Care Medicine’, *Journal of Critical Care*. 37, pp. 270–276. doi: 10.1016/j.jcrc.2016.07.015.

Mitchell, M., Chaboyer, W., Burmuister, E. and Foster, M. (2009) ‘Positive Effects of a Nursing Intervention on Family-centered Care in Adult Critical Care’, *American Journal of Critical Care*, 18(6), pp. 543–552. doi: 10.4037/ajcc2009226.

Mitchell, M. and Chaboyer, W. (2010) 'Family-Centred Care- a way to connect patients, families and nurses in critical care', *Intensive and Critical Care Nursing*. 26, pp. 154-160.doi : 10.1016/j.iccn.2010.03.003.

Morgaine, C. (2001) 'Family Systems Theory', *winter 2001*. Available online http: //web.pdx.edu/~cbcm/CFS410U/FamilySystemsTheory.pdf [Date of Access: 10 October 2019].

Mph, M. O., McMillan, S.E.,Reeves, S., Schmitt, M.H., Puntillo, K. and Kitto, S. (2015) 'Patient and family involvement in adult critical and intensive care settings : a scoping review', *Health Expectations* (ii), pp. 1183–1202. doi: 10.1111/hex.12402.

Nelson, J.E., Walker, A.S., Luhrs, C.A., Cortez, T.B. and Pronovost, P.J.(2009) ` Family meetings made simpler: A toolkit for the ICU`, *Journal of Critical Care*, (24) 4 , p. 1-11. doi: 10.1016/j.jcrc.2009.02.007.

Obringer, K., Hilgenberg, C. and Booker, K. (2012) 'Needs of adult family members of intensive care unit patients', *Journal of clinical nursing* (217), pp. 1651–1658. doi: 10.1111/j.1365-2702.2011.03989.x.

Oxford English Dictionary (2015). *Oxford Advanced Learner's Dictionary*, *International Student's Edition*. 7th edition. Oxford: Oxford University Pess.

Plano Clark, V.L. (2010). The Adoption and Practice of Mixed Methods: U.S. Trends in Federally Funded Health-Related Research, *Sagepub.com/journals Permission.nav,* p.428-440.

Polit, D. F. and Beck, C. T. (2012) *Nursing Research: Generating and Assesing Evidence for Nursing Practice*, 9th edition. Wolters Kluwer Health/Lippincott Williams & Wilkins.

Republic of South Africa. (2004) 'National Health Act [No. 61 of 2003]', in *Review of National Health Act no 61 of 2003, Pretoria. Government Press.*

Rückholdt, M., Tofler, G.H., Randall, S. and Buckley, T. (2019) ‘Coping by family members of critically ill hospitalised patients : An integrative review’, internationa Journal of Nursing Studies 97, pp. 40–54. doi: 10.1016/j.ijnurstu.2019.04.016.

Schmollgruber, S. (2015) *Development Of Competency Standards To Inform Intensive Care Nursing Practice*. Johannesburg: Faculty of Health Sciences, University of Witwatersrand. (Thesis-PhD).

Schmollgruber, S. (2019) ‘Family care in intensive care units’, *South African Journal of Critical Care*, 35(1), p. 12040.

Scribante, J., Schmollgruber, S. and Nel, E. (2004). Perspectives on critical care nursing : South Africa. *Connect The World of Critical Care Nursing*, 4(3): p. 111-115.

Sharma, K., Mogensen, K. M. and Robinson, M. K. (2019) ‘Pathophysiology of Critical Illness and Role of Nutrition Pathophysiology of Critical Illness’, *American Society for Parental and Enteral Nutrition* 34(1), pp. 12–22. doi: 10.1002/ncp.10232.

Shields, L. (2010) ‘Questioning family-centred care’, *Journal of clinical nursing*, pp. 2629–2638. doi: 10.1111/j.1365-2702.2010.03214.x.

Shields, L. (2015) ‘What is “ family-centered care ”?’,*European Journal of Person Centered Healthcare* 3(2), pp. 139–144.

Soury-lavergne, A., Hauchard, I., Dray, S., Baillot, M., Bertholet, E., Clabault, K., Jeune, S., Lendroit, C.,Lelias, I., Lombardo, V., Maetens, Y., Meziani, F., Reignier, J., Souweine, B., Tabah, A., Barrau, K. and Roch, A. (2011) ‘Survey of caregiver opinions on the practicalities of family-centred care in intensive care units’, *Journal of clinical nursing* pp. 1060–1067. doi: 10.1111/j.1365-2702.2011.03866.x.

South African Nursing Council. (2005) *Nursing Act no. (33 OF 2005)*. Pretoria, pp. 1–45. doi:2005.https://www.sanc.co.za/pdf/Nursing%20Act%202005. [Date of Access: 12 October 2019].

Streubert, H. and Carpenter, R (2011) '*Qualitative Research in Nursing: Advancing the Humanistic Imperative*. 5th edn. Philadelphia: Wolters Kluwer Lippincot Williams & Wilkins.

Van Horn, E. and Tesh, A. (2000) 'Impact of Critical Care Hospitalisation on Family Members: Stress and Responses.', *Dimensions of Critical Care Nursing*, 19, pp. 40–49.

van Mol, M. M. C*.,* Boeter, T.G.W., Verharen, L., Kompanje, E.J.O, Bakker, J. and Nijkamp, M.D.(2017) 'Patient- and family-centred care in the intensive care unit: a challenge in the daily practice of healthcare professionals', *Journal of Clinical Nursing*, 26(19–20), pp. 3212–3223. doi: 10.1111/jocn.13669.

Wang, W.L., Feng, J.Y., Wang, C.J. and Chen, J.H. (2016). The Chinese family-centered care survey for adult intensive care unit: A psychometric study. *Applied Nursing Research*, 29: 125-130.

Wetzig, K. and Mitchell, M. (2017). The needs of families of ICU trauma patients: An intergrative review, *the official journal of the British Association of Critical Crae Nurses,* 41. doi : 10.1016/j.iccn.2017.02.006.

Welford, C., Murphy, K. and Casey, D. (2011) 'Demystifying nursing research terminology. Part 1', Nurse Researcher, 18(4), pp. 38–43. doi: 10.7748/nr2011.07.18.4.38.c8635.

Welford, C., Murphy, K. and Casey, D. (2012) 'Demystifying nursing research terminology: Part 2', Nurse Researcher, 19(2), pp. 29–35.

Wong, P., Liamputtong, P., Koch, S. and Rawson, H. (2017). Barriers to regaining control within a constructivist grounded theory of family resilience in ICU: Living with uncertainty , *Journal of Clinical Nursing*, p. 4390-4402.

Wong, P., Liamputtong, P., Koch, S. and Rawson, H. (2018) 'Barriers to families ' regaining control in ICU :Disconnectedness', Nursing in Critical Care, pp. 1–7.

APPENDIX A

PERCEPTIONS OF RELATIVES REGARDING FAMILY CENTERED CARE AT ASOUTH AFRICAN PRIVATE HOSPITAL ADULT INTENSIVE CARE UNIT

Family-Centered Care Survey.

These questions are for the family member of the patient, no names are needed.

Section A

Please circle the letter that is the correct answer and fill in the blanks.

1. Your age:

	(Circle one number)
18 – 25 years	1
26 – 35 years	2
36 – 55 years	3
56 – 70 years	4
71 – 80 years	5
over 80 years	6

2. Your gender:

	(Circle one number)
Male	1
Female	2

3. Your relationship to the patient is:

	(Circle one number)
Partner	1
Daughter/Son	2
Sister/Brother	3
Other, *please state*	4

4. How long does it take you to travel to the hospital from home?

____

5. The main reason your relative was admitted to Intensive Care Unit was

____

Section B

Please read each statement and circle the number that best describes your answer, in this section we are looking at how often the following statements occur.

		Never	Sometimes	Usually	Always
6.	When I come to the Intensive Care Unit I feel I am welcome to be there.	1	2	3	4
7.	Other members of my family are welcome to attend with me in the unit.	1	2	3	4
8.	I am able to be with my relative through some procedures.	1	2	3	4
9.	I have a right to question medical and allied health recommendations about my relative as much as I want.	1	2	3	4
10.	I fee like a visitor rather than a relative when I attend the unit.	1	2	3	4
11.	Did you feel your relative's procedures were carried out with privacy and confidentiality?	1	2	3	4
12.	I feel prepared for discharge to the ward.	1	2	3	4
13.	The staff give me honest information about the care that my relative may need.	1	2	3	4
14.	I know whom to call after I get home if I need help or reassurance.	1	2	3	4
15.	When decisions are being made about care the staff include me.	1	2	3	4
16.	I am being taught what I need to know about the care my relative may need.	1	2	3	4
17.	I know the name of the doctor with primary responsibility for my relative's care.	1	2	3	4
18.	I can easily understand the written material that has been given to me.	1	2	3	4
19.	The staff include family members in the care of my relative.	1	2	3	4

		Never	Sometimes	Usually	Always
20.	I feel overwhelmed by the information given to me about my relative.	1	2	3	4
21.	All team members are familiar with my relative's special needs.	1	2	3	4
22.	All team members listen to my concerns.	1	2	3	4
23.	Whenever possible I get to see the same team member for each area of care.	1	2	3	4
24.	The staff know who my important support people are.	1	2	3	4
25.	The staff understand what my family and I are going through.	1	2	3	4

End of survey – thank you for your assistance. Please return this to the researcher.

Additional information to be collected by researchers from hospital records

(1) Patient's TISS score ______________

(2) Patient's Length of Stay in hospital _______________

(3) Readmission ________________

APPENDIX B

PERCEPTIONS OF RELATIVES REGARDING FAMILY CENTERED CARE AT A SOUTH AFRICAN PRIVATE HOSPITAL ADULT INTENSIVE CARE UNIT

INFORMATION LETTER

Dear ……………….. (name of family member)

My name is Siyabonga Buthelezi, I am an intensive care nurse. I am currently registered for a MSc (Nursing) degree at the University of the Witwatersrand in the Department of Nursing Education. I intend to describe perceptions of relatives regarding family-centered care at a South African private hospital. May I ask you to consider participating in this study? As a family member of a loved one admitted to the intensive care unit, I would be interested in your viewpoints about the care you received as a family member.

Should you agree to participate, I will ask you to allow me to ask you some questions using a questionnaire or to allow me to interview you individually at a venue of your choice. I will schedule an appointment at a date or time convenient to you. The individual interview should take approximately 30 to 40 minutes of your time. With your permission I will audiotape the interviews for transcription and analysis.

Participation in the study is voluntary. You may choose to participate or withdraw from the study at any time. Anonymity and confidentiality is ensured. I will personally transcribe the tape recordings they will be kept separately from the transcripts and they will be destroyed once the study is completed. No names or any other identifying information regarding the hospital or the intensive care unit will be noted on the transcribed data. All transcripts will be kept under lock and key and only my supervisors will have access to the data. I will be happy to supply you with a copy of the transcription of the interview should you so wish. Information in the report will be written in general terms and no personal information will be given. Kindly note the data will be destroyed after 2 years if the report is published, otherwise after 6 years if there is no publication.

I appreciate that you will derive no direct benefit from participating. However, I hope that the completed study will assist nurses in the intensive care unit to understand the family members perspectives of family centered care. I have applied to the Faculty of Health Sciences, School of Therapeutics Postgraduate Research Committee and the Ethics Committee of the University of the Witwatersrand to conduct the study. I have also applied to the management of the Life Rose Park Hospital for permission to conduct the study. Should you require additional information about this study and its procedures Professor Clem Penny, the chairperson can be contacted at 011 717 2301 email: clem.penny@wits.ac.za or the secretary of the committee, Mrs Zanele Ndlovu can be contacted at 011 717 1234 email: zanele.ndlovu@wits.ac.za .

Thank you for taking the time to read this information letter. If you wish to participate in the study please sign the attached consent form. However, should you require any more information, you are welcome to contact me in the Department of Nursing Education or on the cell phone number 0797129265 or email address: sbuthelezi89@gmail.com.

Yours sincerely
Siyabonga Buthelezi

Supervisors: Professor Shelley Schmollgruber, email: shelley.schmollgruber@wits.ac.za
Dr Fikile Klaas, email: fikile.klaas@wits.ac.za

APPENDIX C

PERCEPTIONS OF RELATIVES REGARDING FAMILY CENTERED CARE AT A SOUTH AFRICAN PRIVATE HOSPITAL ADULT INTENSIVE CARE UNIT

CONSENT FORM

I, ………………………… (name of participant) as the family member of patient (name of patient) ……………………… give permission to be included in this research study.

I have read and understood the contents of the information sheet and I have been given the opportunity to ask questions I might have regarding the procedure and my consent to being included in the study.

I hereby declare my voluntary participation in the study.

Date: ………………………………..   Signature …………………………..

APPENDIX D

PERCEPTIONS OF RELATIVES REGARDING FAMILY CENTERED CARE AT A SOUTH AFRICAN PRIVATE HOSPITAL ADULT INTENSIVE CARE UNIT

CONSENT FOR AUDIO TAPE RECORDING DURING THE STUDY INTERVIEW

I ………………………………….. (name of participant) having been informed on the purpose of audio-taping this interview, hereby give consent to have the interview audio-taped for the study entitled “ Perceptions of relatives regarding family centered care at a South African Hospital Adult Intensive Care Unit”.

Date: ……………………………….. Signature …………………………..

APPENDIX E

PERCEPTIONS OF RELATIVES REGARDING FAMILY CENTERED CARE AT A SOUTH AFRICAN PRIVATE HOSPITAL ADULT INTENSIVE CARE UNIT

SEMI-STRUCTURED INTERVIEW GUIDE

OPENING QUESTIONS:

Based on your experience of your loved one’s admission to the intensive care unit, what are your feelings and perceptions about family centered care?

Family care is the care and attention **you** received from the health care professionals **asfamily of a sick patient in ICU**.

FOLLOW UP QUESTIONS

- As a family member how do healthcare professionals communicate with your loved one (probes for communication with family, culturally relevant and understanding)?
- As a family member tell me a story of your most satisfying experiences regarding family centered care you experienced as a family member of a patient in the intensive care unit (probe for positive experiences or worst experiences, if this arises)
- What are your real expectations regarding family support and involvement in healthcare decisions of your loved one in the intensive care unit? (probe for level of support, decision making and involvement).
- What strategies can you suggest we implement to enhance family centered care in the intensive care unit? (probe for visiting hours, information seeking appointments with health care practitioners, involvement in care procedures for loved one)

The proceeds of this discussion will be brought to you for validation after transcriptions of this interview.

Thank you for your time.

APPENDIX F

Example of an Interview Transcript

Participant number 3

***Inter viewer*:** based on admission of your family member in ICU what are your feelings and perceptions about family centered care?

***Interviewee*:** while my husband was in ICU from 4th of September 2019 until the ninth I must complement the nursing staff of multi ICUbecause **the nursing staff kept me informed about what is happening. The first day was more difficult because there was a young male nurse working there I can see he looked a bit frustrated for me and so I asked him what is going on. He said it is his first time in ICU he is trying to understand all of these machines and everything. I was anxious on the first day as a family member because I did not expect to hear all that since my husband just came out theatre**. The other reason I was more scared he was only supposed to be in theatre for two hours according to what the Doctor said but then he got out after four hours. So I just prayed to God please let him know what is doing but after that the shift was finish and other nurses that came on duty trying to do their work and at times I felt like he is left alone. **Some other nurses were very helpful trying to comfort me and talking to me about what is happening now.** You must remember I have a friend who is a Doctor also he explained to me some of the things after the operation.

My husband was delirious seeing things and talking things that do not make sense but my psychology background also helped me a lot to understand the situation. **In terms of attending to us as a family no one really paid attention to us as a family to see if we coping with all this and how are the other family members seeing the situation. The children were writing exams and my husband usually helps them a lot with studying at home so there was chaos and routine changes as well.**

Interviewer: How did you perceive the communication between the health care providers, family and the loved one in ICU?

***Interviewee*:** **I found that there was good communication between the patient and health care staff and towards the family members as well because the other day I came with the grandfather and he kept on asking one and the same questions and it was irritating but they kept his mind and answered him politely.** The grandfather was also aware of what is going on after that information. The engagement with me will be like good morning and how are you , then I will do the rest of the questioning as well so I am not sure if I did not ask I was going to be given information or not by the nursing staff. **The nursing staff was lot more informative to us than the Doctors did. The surgeon Doctor that operated my husband did not have time for me and no time to even answer my questions. You will see she will be saying I am going out I am on my way out now as if other patients are more important to her than my husband.**

The communication between the doctors and us as family was very rushed. Only one day where she explained why there was lot of cutting they did in theatre with the colon of my husband. The other day I told the Surgeon Doctor that he is not okay because infection levels went up a lot and he was confused and I was asking the nurses which physician you would suggest we ask to see him because I think he needs more help now. The reason for this I don't know but I believe in holistic care a lot. **Since the operation took longer than expected the surgeon should have thought that we need to bring a physician on board as well to prevent further complications.**

The surgeon has been treating my husband alone by herself and on day six when my husband complicates then she start to think about bringing the physician along. **The**

way the surgeon responded to me as a family member that was concerned that time was not good because she was like I have to be in theatre now there is a Doctor who will come to see him I am rushing to theater now. **At five o'clock in the evening I called her rooms to say I want to tell the surgeon that the physician she said will come to see my husband never came until now as she said in the morning what is wrong now.**

Interviewer: mhh, what were your expectations regarding family involvement in decision making and support in ICU?

Interviewee: My expectations are that **there should be a proper communication with the family members even in future**. **I would like to see the Doctors showing a little bit of interest in patients because you might be seeing 50 patients as a Doctor but remember this is my loved one too.** The other thing is this is private sector I am paying the Doctor she is not doing this for free, yes you might be seeing other patients but my husband is also sick now. **I don't need half an hour of your time just few minutes to explain to us as family what is going on**. She called a physician to come see my loved one but she never follow up if that physician did come or not. Then now while I was talking to the physician, he said my husband was complicating that he needs ICU attention otherwise the condition could be fatal if we have to wait for another 6 hours more. **Doctors should follow up on their referral system. Immediately the physician said to nurse stop all this treatment written on these charts and wrote all the new things and now as a family member you wonder what the surgeon was giving my loved one.** The surgeon said nothing is wrong with the wound something is wrong on the lungs but then the physician changed the whole prescription then what is happening. So for me there should be proper follow up and someone should be following up if the plan of care is what has been stated.

Interviewer: what were your most satisfying experiences and what were the worst experiences if you had any in the unit?

Interviewee**: I had a very good relationship with the nurses and good communication with the nursing staff as I received most information from them about my husband**. **I started to feel relieved as I see my husband starting to recover and I got reassurance from the nurses.** The worst experiences **were that there was not a good handover because at times the food will be changed by the dietician but nurses will not change it and that happened twice with my husband and I had to request to change the surgeon to another surgeon because I was not satisfied with one nurse I started with because of the attitude and poor communication with us.The other day the other nurse realized that the medication has been stopped two days ago but it was not supposed to be stopped but that happened because of poor handover**.
You must remember this is critical care meaning if you work in ICU you should not take things light, every bit of medication and instruction is vital. **At some point you can see that there is no proper flow of information amongst the health care providers.** The other good thing that was done to me**, I was tired from work a male nurse brought me a cup of coffee and that was good and the other sister provided health talk to my husband about smoking cessation that showed more caring.The nurses, some of them you can see that they are highly knowledgeable as they explain to us and teach us about infection and they quote research and studies that have been done.**
This other day all the nurses saw that everything was going wrong with my husband I could see it on their eyes. **The other sister with long pony tail came to me and asked how are you doing this morning? I told her I am not fine because of the situation. She said we can see and we feel it for you as well. I immediately broke into tears and she gave me a hug. To me that showed emotional support and empathy from the staff.**

The other thing is that other nurses will be walking around to all the patients in the whole unit, to me that brought comfort to see that **now and then there is a sister walking around checking all patients and staff working on patients if everything is still fine. That brings a sense of caring environment.I ended developing relationship of trust with four staff members that I knew that if there is a problem I should come to talk to. That for me made the burden bearable because I know they got my back even if I go home.**

Interviewer**:** What are your real expectations regarding family support and involvement in the unit?

Interviewee**:** As a family member I liked it **to be given a chance to help him with water and being involved with Doctors during rounds because after the incident of changing the surgeon the doctors wanted me to be there always when they do their rounds to give me information and keep me informed of the progress.**
As a family we were allowed to bring in the picture of our religious teacher that we believe unto. And we used ashes on his face that brings the sense of protection.We used it but we were not sure if we are allowed to put it but the nurses never said anything to us about it. In my opinion our cultural involvement was good because the **nurses allowed us to pray for him and to do our religious practices as well on him. The other night I prayed using Mantra which is very good in healing people, it is a Hindu culture although there are different religions in the family.** The Rosary plays a very big psychological role. It’s like the ashes meaning that I have done the prayer therefore this is Gods protection and Rosary also declares that God is nearer to you and protecting you. We wanted to do the prayers more often and to be closer to him. That is why **we want to be more close to our families when they are sick.**
At times I feel like the visiting times are utilized by physiotherapists because they do their work just before visiting hours and now the patients are tired wants to sleep. **The family members must sit there while they are not communicating with their loved one because they are sleepy there should be a right way of synchronizing care with hospital routines, medications and activities with visiting times.The family should also be considered in that case because they want to visit**. As a wife I want to be involved and I want to know why this is needed to be done like tracheostomy. **I want to be part of care like when they clean the wound I want to be there and see** , **it is important to get family involved and you get chance to ask questions and learn about other ICU things. I was alone at home with children and my husband usually was the one who takes them to school and other activities now I had to change the whole routine of mine and I had to travel to head office at times with my work. It was chaotic but the support from the nurses and my extended family members helped me to cope.**

Interviewer: what strategies you suggest we can implement to enhance family centered care in the adult ICU?

Interviewee: The main important thing **is to have a look at visiting hours if the hours cannot be synchronized to care rendered to patient during the whole day**. The **Doctors should be more informative to us as family from day one of admission**. There should be **more ways of getting the family involved in the care of patient**. We **should be informed as family of what is expected from us and what is allowed in ICU and be given a bit of orientation. We should be enquired if we do have specific spiritual or religious things we want to bring along like bringing in the beads to be placed under the pillow. We must be taught on how the ICU operates.** There should be more engagement on family based care like what we can do to make him more comfortable and feel like he is at home. **We should have a small booklet or a guide even if nurses are busy you can just be given that booklet with do`s and don’ts, it should also be according to cultural aspects of people. We also have traditional values that are very**

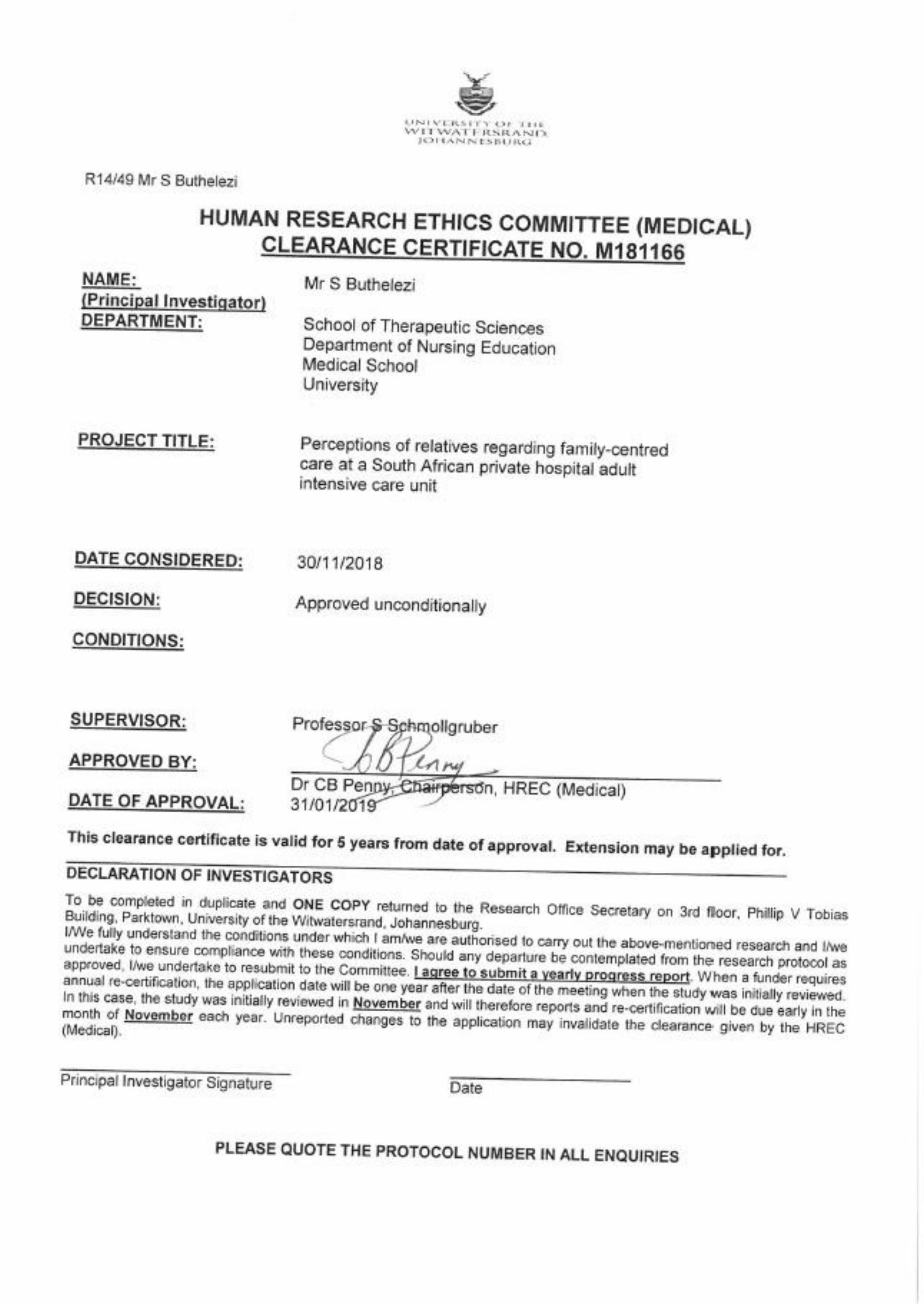
important. At some point we wanted to burn ashes but we did not know if we can do that because we thought ICU is a very clean environment.

Interviewer: Thank you so much for your time this concludes our interview.

Interviewee: Thank you.

APPENDIX G

Ethical Clearance Certificate



UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Mr S Buthelezi

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M181166

NAME: (Principal Investigator) Mr S Buthelezi

DEPARTMENT: School of Therapeutic Sciences
Department of Nursing Education
Medical School
University

PROJECT TITLE: Perceptions of relatives regarding family-centred care at a South African private hospital adult intensive care unit

DATE CONSIDERED: 30/11/2018

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR: Professor S Schmollgruber

APPROVED BY: Dr CB Penny, Chairperson, HREC (Medical)

DATE OF APPROVAL: 31/01/2019

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on 3rd floor, Phillip V Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.
I/We fully understand the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date of the meeting when the study was initially reviewed. In this case, the study was initially reviewed in **November** and will therefore reports and re-certification will be due early in the month of **November** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

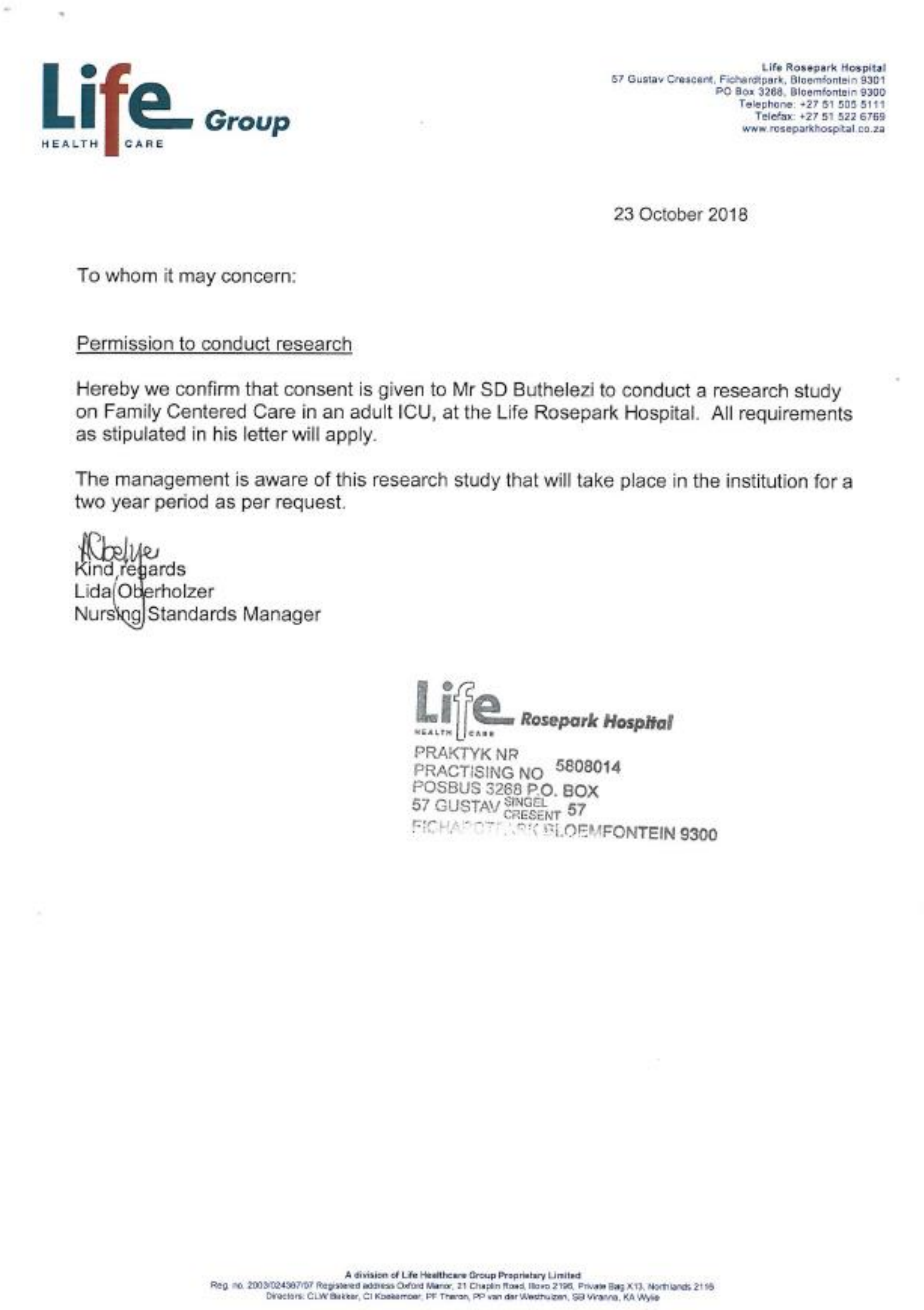
Principal Investigator Signature

Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX H

Permission to Conduct Research



Life Healthcare Group

Life Rosepark Hospital
57 Gustav Crescent, Fichardtpark, Bloemfontein 9301
PO Box 3268, Bloemfontein 9300
Telephone: +27 51 505 5111
Telefax: +27 51 522 6769
www.roseparkhospital.co.za

23 October 2018

To whom it may concern:

Permission to conduct research

Hereby we confirm that consent is given to Mr SD Buthelezi to conduct a research study on Family Centered Care in an adult ICU, at the Life Rosepark Hospital. All requirements as stipulated in his letter will apply.

The management is aware of this research study that will take place in the institution for a two year period as per request.

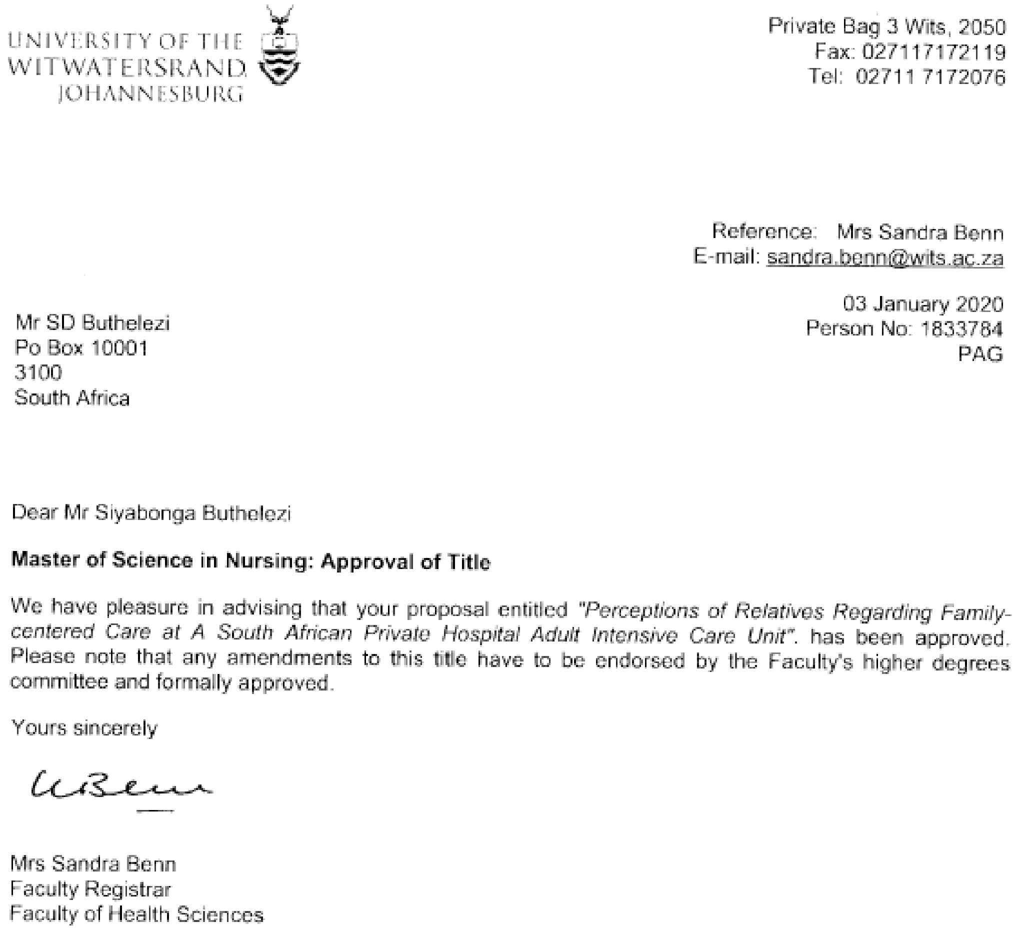
Kind regards
Lida Oberholzer
Nursing Standards Manager

Life Healthcare Rosepark Hospital
PRAKTYK NR
PRACTISING NO 5808014
POSBUS 3268 P.O. BOX
57 GUSTAV SINGEL CRESENT 57
FICHARDTPARK BLOEMFONTEIN 9300

A division of Life Healthcare Group Proprietary Limited
Reg. no. 2003/024367/07 Registered address Oxford Manor, 21 Chaplin Road, Illovo 2196, Private Bag X13, Northlands 2116
Directors: CLW Bakker, CI Koekemoer, PF Theron, PP van der Westhuizen, SB Viranna, KA Wylie

APPENDIX I

Postgraduate Approval of Study



UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

03 January 2020
Person No: 1833784
PAG

Mr SD Buthelezi
Po Box 10001
3100
South Africa

Dear Mr Siyabonga Buthelezi

Master of Science in Nursing: Approval of Title

We have pleasure in advising that your proposal entitled *"Perceptions of Relatives Regarding Family-centered Care at A South African Private Hospital Adult Intensive Care Unit"*. has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX J

PERMISSION TO USE INSTRUMENT

Dear Shelley
It was so good to see you in Melbourne - I'd have liked a longer chat with you but time got away.

In reference to the use of my instrument:

Please find attached the survey I used for my adult ICU study. I have also included a paper where we analysed the psychometrics of the tool. See page 794 - table 1 , right hand column where you will see the items that belong to the 3 concepts - respect; collaboration and support.

I give permission for this survey to be used with suitable referencing of my work. I hope your student has great success with his project. I would be very interested in hearing about it in due course.
Kind Regards

Marion

Professor Marion Mitchell I Professor Critical Care (RN, PhD, FACCCN, Centaur Fellow, Honorary Fellow
School of Health in Social Science – The University of Edinburgh)
Higher Degree Research Convenor
School of Nursing and Midwifery I Menzies Health Institute Queensland I **Griffith University**
Address N48 2.14, Nathan Campus, 170 Kessels Road, Nathan, QLD, 4111.

Nurse Practice Development Unit I **Princess Alexandra Hospital**
Ipswich Road, Woolloongabba, QLD, 4102.
Ph: +61 (0)7 3176 7772 (PAH) I +61 (0)7 3735 5115 (Griffith University)
Email: marion.mitchell@griffith.edu.au I http://www.griffith.edu.au

---

From: Shelley Schmollgruber <Shelley.Schmollgruber@wits.ac.za>
Sent: Monday, August 6, 2018 1:59:26 PM
To: Marion Mitchell
Subject: request for permission to use an instrument

Dear Prof Mitchell,
I am currently supervising a student who is wanting to conduct a mixed method study on family centered care in an adult ICU. We would like to know if you would be willing to give us permission to use the instrument that you used in your study entitled: Positive effects of a nursing intervention on family-centered care in adult critical care (Mitchell et al. 2009) Published in the American Journal of Critical Care.

If you are in agreement can I please ask you to send us a copy of the instrument with a short note stating that you give us permission to use the instrument. An email approval will also suffice. Our university does require the student to include a copy of permission for instruments used from the authors for ethical clearance and a copy in his thesis. The student is doing his MSc study by dissertation and we anticipate that he will complete the study next year. As part of the degree requirement he is required to prepare a manuscript for publication.

Looking forward to you response,
Kind regards

Prof Shelley Schmollgruber (PhD)
Associate Professor.
Specialisation: Intensive and Critical Care Nursing, Trauma and Emergency Nursing.

e-mail: shelley.schmollgruber@wits.ac.za
Tel: +27 (0) 11 488 4270
address: 7 York Road, Parktown, Johannesburg, South Africa, 2193.

Department of
Nursing Education

Language Proofing and Editing

Gill Smithies

Proofreading & Language Editing Services

59, Lewis Drive, Amanzimtoti, 4126, Kwazulu Natal

Cell: 071 352 5410 E-mail: moramist@vodamail.co.za

Work Certificate

To	Dr. Shelley Schmollgruber
Address	Wits Dept. of Nursing Education
Date	15/04/2020
Subject	Thesis: PERCEPTIONS OF RELATIVES REGARDING FAMILY-CENTRED CARE AT A SOUTH AFRICAN PRIVATE HOSPITAL'S ADULT INTENSIVE CARE UNIT,by S. Buthelezi
Ref	SS/GS/32

I, Gill Smithies, certify that I have proofed the following for language, grammar and style:

Thesis: Perceptions of relatives regarding family-centred care at a South African private hospital's adult Intensive Care Unit, by S. Buthelezi,

to the standard as required by Wits Dept. of Nursing Education.

Gill Smithies