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FAMILY MEMBERS OF INTENSIVE CARE UNIT PATIENTS' PERCEPTIONS OF PSYCHOSOCIAL SUPPORT RECEIVED IN A TERTIARY HOSPITAL IN JOHANNESBURG

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

Johannesburg, 2017

DECLARATION

I, Tlamelo Lebitsang Direng, declare this research report is myown 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 …….

……day of …… 2017

Protocol Number: M160552

DEDICATION

This study is dedicated to my family for the support and patience that you exercised throughout the time I was away from you.

ACKNOWLEDGEMENTS

"No one who achieves success does so without acknowledging the help of others. The wise and confident acknowledge this help with gratitude," Alfred North Whitehead.

Firstly glory is to the Almighty for the opportunity He granted me and for guiding me this far.

I would like to sincerely thank the following people for their enormous contribution towards the success of this study.

My supervisor Dr Shelley Schmollgruber for her continuous, support, guidance and encouragement and for inspiring me throughout the study. I wholeheartedly thank you.

To all the family members of ICU patients who participated in the study, from the bottom of my heart I thank you, this study would not have happened without your contribution.

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The statistician from the Postgraduate Research Office at the Faculty of Health Sciences for assisting with the statistical tests and data analysis.

My family, my dear husband Baaitse, and son Theo, for the support, encouragement and your continuous patience. Your sense of humour kept me going during tough times.

My colleagues, especially Tebogo, for their support; the sleepless nights we spent in discussion were not in vain.

ABSTRACT

Admission to an Intensive Care Unit can be intimidating to both the patient and family. The literature reviewed, suggested that the psychosocial care and support needs of family members are frequently overlooked, leaving them frustrated and vulnerable to emotional distress. Thus, the study intended to describe the family members' perception of psychosocial support received in Intensive Care Units.

The purpose of the study was to describe the perceptions of psychosocial support received in a tertiary academic hospital in Johannesburg of family members' of Intensive Care Unit patients.

This study utilised a non-experimental, descriptive quantitative survey and cross-sectional design. Non-probability purposive sampling was used, and the sample comprised of 100 (n=100) family members. Data was collected using a survey instrument developed by Hariharan *et al.* (2015), and analysed using descriptive and comparative statistics to describe the family members of Intensive Care Unit patients, perception of psychosocial support received in the Intensive Care Unit. Statistical tests included the Cronbach's reliability coefficient, Proportions and Chi-square tests; testing was done on the 0.05 ($p<0.05$) level of significance.

The results revealed a significant positive perception toward psychosocial support received in Intensive Care Units. Some inconsistencies were noted on the frequencies with which psychosocial support was provided. There was a significant disagreement in three priority items in the domain of transparency in decision-making and continuity of care; female family members or patients admitted for medical reasons were more likely to be in disagreement of items in this domain ($p<0.05$). Similarly, there was a significant disagreement to two priority items in the domain protection of human rights and dignity; family members' in the age category of 43 to 48 years, or a sibling relationship to the patient, were more likely to be in disagreement of items in this domain ($p<0.05$).

Recommendations are made for improvement in the provision of psychosocial support for family members in clinical practice and education of Intensive Care nurses.

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CHAPTER ONE

OVERVIEW OF THE STUDY

1.0. INTRODUCTION

Hospitalisation in an Intensive Care Unit causes discomfort and distress to both the patient and family. This arises from a variety of factors, such as fear of the unknown outcome of the illness, the possibility of death and a long period of separation from the sick family member, as well as disruption in the usual family routine. The intimidating environment of the Intensive Care Unit, with its complex and technological equipment, adds to the distress and discomfort of family members. Psychosocial support is fundamental concepts in nursing practice and an important goal to be achieved by all nurses. However, literature by researchers among others; Carlson, Spain, Muhtadie, McDade-Montez and Macia (2015) Gaeeni, Farahani, Seydfatemi and Mohammadi (2015) and McKinley and Elliot (2007) suggests family members of patients admitted to the Intensive Care Units are less than satisfied with the care and support provided by nurses.

This chapter provides an overview of the study, where the reader is introduced to the background of the study, problem statement, purpose, objectives and significance of the study and researcher assumptions. The research methodology, validity and reliability of the study are outlined and ethical considerations briefly discussed.

1.1 BACKGROUND OF THE STUDY

The Intensive Care Unit (ICU) is a dedicated area in a hospital that provides constant and close monitoring for patients with life-threatening illness and injuries and the complications thereof. Intensive Care Units have highly sophisticated equipment that can sustain life in previously fatal situations, such as infectious diseases and trauma (Matlakala, Bezuidenhout & Botha, 2014).The ongoing management and support in the Intensive Care Unit is dedicated to rescuing these patients.

The reason for admission to an Intensive Care Unit is usually an emergency, and also a life-threatening experience for the patient and family members. It has the potential to

disrupt the steady state of internal equilibrium usually maintained in the family unit (Morton & Fontaine, 2013) and can change the lives of the patient and those close to them in a minute, leaving little time for family adjustment. Paul and Rattray (2008) described the ICU experience as unique in the sense that the patient has little recall of the events, but relatives live through the whole event.

The unstable condition of the patient often takes precedence over addressing the psychological turmoil perceived by the family members (Bailey, Sabbagh, Carmen, Boileau & McVey, 2010). During this crucial time, the family members go through a mixture of emotions rendering them emotionally vulnerable and in need of emotional support (Sheaffer, 2010). Family members experience negative emotions such as fear, anxiety, frustrations, uncertainty and a sense of guilt, anger and irritation.

These emotions are attributable to the life-threatening situation, the possibility of a long-term hospitalisation, as well as uncertain outcome of the illness of their loved one. The focus of the medical team is to rescue the patient, while family members are focused on seeing their loved one get better. The majority of interactions between the nurses and family members are mostly task-oriented, and the nurses tend to direct and dominate such interactions. The ICU environment also contributes to the emotional roller coaster that family members maybe experiencing. Jerzierska, Borkowski and Gasynski (2014) highlighted in their study that the highly technical ICU environment is an unfamiliar territory that can be intimidating for the patient and their family.

As the medical team and family members maintain their focus on the critically ill patient, the needs and wishes of the family members goes unsupported during and after admission to the Intensive Care Unit. It can have both short- and long-term consequences for the family members. family members suffer greater levels of anxiety and depression than do the patients .In turn, the nurses' own discomfort and uncertainty about the patient's prognosis creates their own feelings of helplessness and the natural tendency to avoid contact with distressed people. This is supported by literature from studies by Carlson et al. (2015) and Fumis, Martins and Schettino (2015). Consequently, nurses avoid the contact with the family members, thus adding to the level of family distress

Family members' needs in ICU are known and have been studied extensively in the past four decades. Much of this work comes from the seminal work of Molter (1979), who developed the Critical Care Family Needs Inventory (CCFNI) a list of needs based on surveys with nursing students and extensive reviews. Molter and Leske developed 45 Likert-scale type questions, which comprise five domains, namely assurance, proximity, information, comfort and support. Researchers such as Carlson *et al.* (2015), Hinkle and Fitzpatrick (2011), Gentry, McArthur, Millegan, Morris-White, Scott and Williams (2013), Hashim and Hussin (2011) and Tilburgs *et al*. (2015) have used the CCFNI as a guiding tool for family needs in the ICU, with some using it in the original form or as a modified version. Overall, the results of these studies often disclose less than satisfaction with the care and support that family members receive in the ICU and out of the five domains, comfort and support has consistently ranked lowest. Therefore, the researcher was of the opinion that the CCFNI instrument might not be sensitive enough to capture the importance of these family needs.

An additional literature search revealed a recently developed instrument known as the Intensive Care Unit-Psychosocial Care (ICU-PC) scale. The instrument was developed to measure psychosocial care received in the ICU (Hariharan, Chivukula & Rana, 2015). This scale looked at three factors, namely protection of human rights and dignity, transparency in decision-making and care continuity and sustained patient family orientation. . Although many studies have looked at the importance of family needs in the Intensive Care setting, data is limited in South Africa, and internationally, on family member's perceptions and opinions of psychosocial support received in the Intensive Care setting.

1.2 PROBLEM STATEMENT

There are indications that the needs and expectations of family members of critically ill patients are often unmet in Intensive Care Units. The interactions between nurses and family members are usually task oriented with the nurse dominating the tasks. McKinley and Elliot (2007) and Carlson *et al* (2015). Concerns were raised that this may have a negative impact on the patients' recovery and the families' ability to cope with ensuing crises. However, current clinical practice indicates that although nurses provide support for

family members of critically ill patients, their primary focus is on the patients who need constant attention, thus neglecting the needs of family members.

Clinical guidelines for a family-centred approach to care have been developed for the Intensive Care Units to understand better and address the needs of families of critically ill patients (Davidson, Powers, Kamyar, Hedayat, *et al.*, 2007). There has been extensive research on the importance and satisfaction of family needs in South Africa, however limited studies to address unmet family needs have been conducted. South Africa is unique given the racial, cultural, ethnic and linguistic differences generated by its history and politics. It limits research from other countries and highlights the necessity for studies to be conducted within a South African context. A family-centred approach to care encourages implementation of interventions that will meet the patients' and family members' needs and ensure higher levels of satisfaction.

The study attempted to answer the following research question:

- What are family members' perceptions of psychosocial support received from Intensive Care nurses during admission of their relative to an Intensive Care Unit in a public hospital in Johannesburg, South Africa?

1.3 PURPOSE OF THE STUDY

The purpose of the study was to describe family members of critically ill patients' perceptions of psychosocial support received in the Intensive Care Unit of a public hospital. It was also the intention of the study to make recommendations for clinical practice and education of Intensive Care nurses.

1.4 RESEARCH OBJECTIVES

The objectives of the study were:

- To describe the family members', of critically ill patients, perceptions of psychosocial support received in the Intensive Care Unit.
- To compare the family members', of critically ill patients, demographic variables with their perceptions of psychosocial support received in Intensive Care Units.

1.5 SIGNIFICANCE OF THE STUDY

Inadequate literature is available in South Africa addressing the needs of family members in the Intensive Care Unit. By conducting this study, the results could contribute towards Intensive Care clinical practice and education in a drive towards family-centred care. It could improve or reinforce the quality of support that is offered by nurses, as well as highlight and help to define what family members perceive support needs in a South African context.

1.6 RESEARCHER'S ASSUMPTIONS

Burns and Grove (2011) state assumptions are statements that are often taken for granted or considered as truth, even though empirical research has not tested them. As such, assumptions are ideas formed without any evidence and not intended to be tested in a research study.

1.6.1 Meta-theoretical Assumptions

Meta-theoretical assumptions are defined as theories devised to analyse theoretical systems, or as formal systems that describe the structure of some other systems (Grove, Burns & Gray, 2013). The researcher accepts the family systems theory and assumes the nursing meta-theoretical assumptions of person, health, environment and nursing.

- Person

A person in this study is "a critically ill patient who is the recipient of nursing care and composed of the physiological, psychological, sociological and spiritual components" (Rogers & Keller, 2009). The patient is part of a family and a society and constantly interacts with his or her environment. When the patient receives treatment in an Intensive Care Unit, the family members encounter anxiety, stress, discomfort and frustration. Hence the nurse provides comfort and support for them.

- Environment

"All conditions, circumstances or influences surrounding and affecting the development and behaviour of a person and groups with particular considerations of mutuality of persons and earth resources" (Rogers & Keller, 2009).The environment consists of internal and external factors of influences surrounding the patient systems. The nursing personnel are concerned with the therapeutic environment in the Intensive Care Unit.

- Nursing

Nursing is described as assisting the individual sick (or well) in the performance of activities of daily living and helping them to gain independence as rapidly as possible. In this study, nursing refers to "caring for the critically ill patient in the Intensive Care Unit and providing comfort and support needs for their family members" (Morton & Fontaine, 2013), which is the role of the critical care or Intensive Care nurse.

- Health

Health is when the body, spirit and mind of an individual are in a state of ease, good balance and working well. Illness is when the body, mind and spirit are not at ease, and the internal state of equilibrium leads to an imbalance (Rogers & Keller, 2009). The imbalance may be due to factors from the internal or external environment. The critically ill patient depends on the Intensive Care nurse to provide them holistically with a therapeutic environment. The family members also need spiritual and psychological support during admission of their loved ones in ICU.

1.6.2 Theoretical Assumptions

A theory, as described in Burns and Grove (2011), is "a creative and rigorous structuring of ideas to describe, explain, predict or control a particular phenomenon or segment of empirical world." The Bowens Family Systems Theory views a family as a unit, which is connected emotionally hence, when one member is affected the whole follows (Bowens [1979] cited in Arnold & Boggs, 2011). Based on this theory, the following assumptions were made:

- A family is a unit and critical illness of one member affects the whole family.
- Nursing holistically means caring for the patient and family.
- Patients are persons who are constantly in touch with their environment, and the environment has an impact on their health.
- A family should be included in all levels of health care of one of their members.
- Family member's involvement or non-involvement in the care of their relative impacts on the outcome of illness.
- All nursing staff should fully practice family-centred care.

The main theoretical assumption of the study was that family members are affected by the hospitalisation of their loved ones, especially if the admission is in the Intensive Care Unit where patients are admitted with life-threatening conditions. The family undergoes a mixture of emotions and become vulnerable. The inclusion of family members of ICU patients in the care of their loved ones, caring for and supporting their needs, is an essential part of nursing care.

1.6.2.1 Operational definitions

- Intensive Care Unit (ICU)

Intensive Care Unit (ICU) is a specialised department of a hospital or healthcare facility where patients with actual or potentially life-threatening conditions are closely monitored (Morton & Fontaine 2013).The ICU environment is equipped with advanced technological equipment, which is used to monitor and treat the patient.

- Critically ill patient

In this study, critically ill patients means those who are admitted to the ICU to be supported with technology and treatment that require intense monitoring, with the aim to prevent, or be rescued from life-threatening complications (De Beer & Brysiewicz & Bhengu, 2011).

- Family member

A family member is "whoever a communicating patient defines as the family or anyone who shares the history and a future with the patient who is not communicating" (Schell & Puntillo, 2006). According to Bowen (1978), family members usually have an emotional connection, which leads them to be empathetic towards each other (in Arnold & Boggs, 2011).

- Psychosocial support

Psychosocial care is used as an umbrella term to include all the needs of patients and families; it is a method of delivering care that puts the patient and family at the centre of care (Zarubi, Reily & McCarter, 2008). Families and patients are empowered to question policies and practices and to offer their opinions/concerns so that the organisations reflect and evaluate better ways to meet their goal. In literature, the terms psychosocial care and psychosocial support are often used to mean the same thing. For the purpose of this study the term psychosocial support will be used throughout the report.

- Perception

Perception refers to the way in which something is regarded, understood or interpreted. In the Oxford Dictionary (2007) it is defined as the ability to identify, interpret and attach meaning to something. In this case, the perceptions of family members will be measured by using a questionnaire developed by Hariharan *et al.* (2015).

1.6.3 Methodological Assumptions

The term research refers to "a diligent systematic inquiry or investigation to validate and refine existing knowledge and generate new knowledge" (Grove *et al*., 2013). Tingen, Burnett, Murchison and Zhu (2009) stated research in "nursing has a tremendous influence on current and future professional nursing practice thus rendering it an essential component of the education process." In this study, the researcher recognises the importance of family-centred care and bases this on the family systems theory as an important aspect of nursing practice. Nursing research with emphasis on family-centred

care is essential to nursing as it increases nurse's awareness of the needs of family members. This quantitative, descriptive, non-experimental study was carried out to describe the perception of family members on the comfort and support needs offered by nurses, thus generating a body of knowledge for nursing practice in the critical care unit

1.7 OVERVIEW OF METHODOLOGY

1.7.1 Research Design

A research design is "a set of guidelines and instructions followed in addressing the research problem" (Burns & Grove, 2011). The research design used in this study was non-experimental, descriptive, a quantitative survey and cross-sectional directed towards understanding the psychosocial support family members received when their sick relatives were admitted to the ICU. The study was carried out in one general ICU at a tertiary hospital in Johannesburg. The Intensive Care Unit admits patients from all hospital services, including trauma, surgery and medical cases, and receives direct admissions from the emergency departments.

1.7.2 Research Methods

In this study, the population were family members of patients admitted to the general Intensive Care Unit at a tertiary hospital in Johannesburg. Purposive sampling was used to recruit participants for the study and after consultation with the statistician, a sample size of 100 participants (n=100) was agreed upon. This study was conducted over a period of three months. A questionnaire was used for data collection. The instrument developed by Hariharan *et al* . (2015) was used to collect data (**Appendix A**).

After obtaining permission from the hospital's management (**Appendix E**) the researcher approached the nurse manager for permission to collect data in the ICU. Participants who met the inclusion criteria were given an information letter (Appendix B) outlining the study, its purpose and procedures. The study was fully explained to the participants so that they would be able to give informed consent and upon agreeing to participate, they were asked to sign a consent form (**Appendix C**). They then completed the questionnaire (**Appendix A**) and once completed they were handed back to the researcher in a sealed

envelope. Data was analysed using descriptive and comparative statistics. Statistical tests included the Cronbach's reliability coefficient, Proportions and Chi-square tests. Testing was done at the 0.05 ($p<0.05$) level of significance.

1.8 ETHICAL CONSIDERATION

The following ethical issues were considered:

- Permission was obtained from the University of the Witwatersrand Postgraduate Committee.
- Protocols were submitted to the Department of Nursing Education to assess the feasibility of the study.
- Ethical clearance was obtained from the University of the Witwatersrand Human Research and Ethics Committee.
- Permission to conduct research was obtained from the hospital management and unit manager.
- Informed consent was obtained from the participants.
- Participation was voluntary, and participants were informed of their rights and that they could withdraw from the study at any time if they so wished.
- Confidentiality was maintained throughout the study and code numbers were used to protect participants.

1.9 VALIDITY AND RELIABILITY OF THE STUDY

Validity refers to "whether the instrument adequately covers what it is supposed to measure" while reliability refers to "the degree to which the instrument can be depended upon to yield consistent results, if repeatedly used over the same subjects or used by a different investigator" (Burns & Grove, 2011). To ensure validity and reliability in this study, consistency and accurate data recording was maintained. The researcher personally administered the questionnaires and ensured the participants understood the purpose and nature of the study. The researcher explained how data would be collected and assured the participants of anonymity. There was no manipulation of variables and this prevented threats of internal validity.

1.10 PLAN OF RESEARCH ACTION

The study will be presented as follows:

Chapter One:	Overview of the study
Chapter Two:	Literature review
Chapter Three:	Research design and methodology
Chapter Four:	Data analysis and results
Chapter Five:	Summary of study, main findings, recommendations and conclusion

1.11 SUMMARY

Chapter One outlined the background of the study, the problem statement, purpose, research questions and objectives were outlined and the significance of the study discussed. Researcher's assumptions were then briefly outlined, followed by an overview of the description of the research design and method. Measures to ensure validity and reliability were then discussed, followed by relevant ethical considerations of the study.

In the following chapter, 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 of family members of critically ill patients. This review will help the researcher “to build a logical framework for the study and set it in a tradition of inquiry and context of related studies” (Grove, Burns & Gray, 2013). It begins with the discussion on the impact of critical illness on family members. Studies from the needs of family members, patient-family centred care and nursing support in Intensive Care Units was presented. After that, the chapter concludes with a summary.

2.2 IMPACT OF CRITICAL ILLNESS ON FAMILY MEMBERS

A critical illness is described by Morton and Fontaine in Critical Care Nursing (2013) as "A sudden, unexpected and often life-threatening occurrence for both the patient and family that threatens the state of equilibrium in the family unit. A critical illness can be an acute illness, trauma or an episode of a previously unknown problem."

Patients admitted to an ICU are faced with a life-death situation. As admission to an Intensive Care Unit is mostly unplanned and usually an emergency, having a relative admitted to the unit can be stressful for family members.

"The Intensive Care admission is a frightening experience for family members, and the psychosocial impact that the admission have on family members can result in behaviour not conducive to patient care and or emotional health of the family." This is according to Benson and Kueakomoldey (2013) in their study entitled "Psychosocial impact of ICU admission for family members of critically ill patients." Response to critical illness by family members has been widely explored. Family members of a critically ill patient are affected by the admission of their loved one to an Intensive Care Unit.

The family is viewed "as the first social institution that bears culture, roles and unique structure signifying physical, mental social, spiritual and cultural health of its members. Any disorder in its parts will lead to the holistic disease" (Pourmemani, Khaleghdoost, Askandari & Avazeh, 2010). One of the challenges affecting a family system is when one of its members is hospitalised. When the admission is in an ICU, the impact becomes even more severe.

Studies by Hickman and Douglas (2010), Peter, Moss and Marc (2016), and Tilburgs *et al.* (2015) revealed that family members react differently during admission of a relative. While some choose avoidance and pretend the situation is not happening, others who are religious resort to scripture for comfort; few will face the situation and deal with it. The impact of an ICU admission on family members is discussed below.

2.2.1 Psychological Effects of an Admission of a Family Member to ICU

Family members of ICU patients usually experience a roller coaster of emotions during an admission of their loved one to an ICU. A study by Plaszewska-Zwyko and Gazda (2012) aimed at "determining the emotional reactions and needs of family members of ICU patients revealed that an admission of a member to the ICU leaves relatives and friends in a state of shock and disorganisation with little or no time to adjust. The high morbidity and mortality associated with ICU setting cause intense feelings of negative emotions such as fear, irritability, uncertainty, stress, guilt anger and frustration compounded by the fact that family members lack the experience to deal with catastrophic events. Such an admission disrupts the synergy of the entire family."

These emotions are attributable to the unknown outcome of the illness, the possibility of death and disability of their loved ones or just mere change in the family's daily living schedule (McKiernan & McCarthy, 2010). Due to these feelings, most family members are predisposed to post-traumatic stress disorder (PTSD). The study by McAdam, Fontaine, White, Dracup and Puntillo (2012), which aimed at "comparing PTSD, anxiety and depression, three months after ICU care experience in family members of patients at high risk of dying. Also, determining if patients final disposal influenced the difference," revealed that the symptoms did not differ according to the patient's final disposal. The study showed family members remained at high risk for anxiety, depression and PTSD.

Family members of ICU patients experience high levels of psychological stress and the symptoms of mental instability may continue after the patient is discharged from ICU. It was also echoed in a study entitled "Impact of chronic, critical illness on psychological outcomes of family members" by Hickman and Douglas (2010), who argued, "Critical illness has devastating physiological effects on the patient and psychological consequences on family members." They also stated that the severity of illness exposes family members to psychological distress, which for some, may linger long after the discharge or the death of the patient. Davidson *et al* (2011), in their study aimed at "assessing the family response to critical illness," agreed with this and stated that most family members of ICU patients were diagnosed with some conditions such as depression PTSD, acute stress disorder and distress. These symptoms may develop up to six months post admission of a relative.

This can be attributable to the concept of Erik Erickson's stages of development (cited in Arnold & Boggs, 2011).Erikson's model of the development stages of psychosocial growth described psychosocial development as a continuum, which begins at birth and extends to death. This continuum includes four major life cycle phases: childhood, adolescence, adulthood and old age. For each stage there are two conflicting tasks that one has to resolve in order to confidently progress to another stage and be a better adult, failure to resolve these tasks may lead to inadequacy. The tasks are –trust versus mistrust, autonomy versus shame, initiative versus guilt, industry versus inferiority, identity versus role confusion, intimacy versus isolation, generosity versus stagnation and integrity versus despair. An individual may progress from one development stage to the next level, or may digress to a lower developmental stage. A person who successfully resolved the tasks may handle sickness of a loved much better than the one who failed the tasks as these impact on psychosocial behaviours of individual and future relationships.

The person's self-concept, consisting of physiologic and psychological stressors, emotional health and developmental stage, are essential components of psychosocial assessment. Each family member experiences the stress of their loved one's critical illness differently depending on his/her stage of psychosocial development, for example, a teenager will differ from an adult member. These needs include, amongst others, communication, emotional needs (the ability to express grief, anger, denial, irritability, inability to trust), powerlessness, spirituality and education. Azoulay, Pochard, Chevret, Jourdain *et al.*

(2002) maintain that family members of patients may display Post Traumatic Stress Disorders after discharge or an unfavourable outcome.

The environment of the ICU can be entirely unfamiliar, scary and confusing to family members especially when they see their ill family member connected to all the intimidating equipment; the stress becomes even more pronounced if the nurses do not explain the purpose of the machines. Social isolation is also rife as patients are nursed in separate rooms or cubicles, which renders family members being worried about the isolation of their relative and whether the nurses will be near should the patient need immediate help (Buckley & Andrew, 2011).

Pang and Suen (2008) stated that fear of death is the top stressor in the ICU by both the patients and their relatives; other stressors include restricted visiting times and relatives not sure of the length of stay of their relative in the hospital as well as the pressure of having to give consent for treatment and procedures. It is, therefore, important for healthcare workers, especially nurses, to assist family members in adapting to the ICU environment while they have a relative admitted. The concept of family-centred care advocates for the family members' involvement in the care of their ill family member.

In their study, entitled Psychological Reactions in Family Members of Patients Hospitalised in Intensive Care Units, Jerzieska *et al.* (2014) stated that some family members might experience positive changes in their functioning called post-traumatic growth, such as appreciating interpersonal relationships, empathy or a complete revision of their lives.

2.2.2 Physiological Impact of Critical illness on Family Members

Studies by Salmond (2010), Hinkle and Fitzpatrick (2011) and Buckley & Andrew (2011), looked at the needs of American relatives of ICU patients. Perceptions of physicians, nurses and families agree that family worry and are overwhelmed by the unknown prognosis of their patient's illness, impending death, large medical bills and additional responsibilities. Some react to this by being angry, uncooperative, short tempered and hostile towards the patient and nursing staff, especially when they feel nurses are not doing enough for their patient; they may also not know what to say when they visit the patient.

The ICU environment is known to be a potentially hostile environment for the critically ill patient with its stressful environmental factors, such as noise, lights, restriction in mobility and social isolation (Wenham & Pittard, 2009); the array of technology, various infusion lines, the sounds of the equipment are unfamiliar to non-healthcare workers (Carlson *et al.*, 2015; Jerzieska *et al* 2014; McKiernan & McCarthy, 2010;). The ICU environment, added to the already challenging emotional state of having a relative admitted to an ICU, can be very overwhelming to family members (Nolen & Warren, 2014). As the nurses constantly have to watch patients the lights are always on and equipment that sounds alarms continuously monitor the ICU patients and for this reason, family members believe their loved ones do not to get rest or sleep. As a result, some family members transfer these perceptions to themselves thus ending up with a lack of sleep and anxiety (Fumis *et al.*, 2014). Family members also focus all their attention and strength towards the ICU, and this takes its toll rendering them stressed. Sleep disorder, exhaustion, psychosomatic disorders such as headaches, general body pains, eating disturbances have also been reported by family members of ICU patients (Hakio, Rantanen, Astedt-kurki & Suominen, 2014).

2.2.3 Functional Effects of Critical illness on Family Members

A critical illness or disability affects the entire family, because every family is a unit and each member has a unique role to play in the everyday functioning of the family unit. An illness of a family member forces the other members to modify their roles to accommodate those the ill person performed and in the process, lifestyles have to be adapted.

Critical illness can cause disequilibrium in the family structure. The sick member may have been a decision maker or breadwinner and sickness throws the family into turmoil, especially if the patient was an adult and head of the household and now dependent on the family members. Some additional constraints may be brought by the family having to settle heavy medical bills for their relative (Maxwell, Stuenkel & Saylor, 2007).

The ICU admission puts strain on the family members who are expected to be surrogate decision makers and advocate for the patient, while preparing for the possible loss of their relative. Family members can feel pressurised, as they are not sure whether they are making the right decisions for the patient. Feelings of guilt may be imminent if things do not go right.

The family is a buffer for patient anxiety, but may not be able to provide essential support for the patient. An unpublished article titled "Impact of illness on the family," from Euromed, states that illness can put a strain on the economic status of the family, interrupt career development for some family members as well as cause unequal distribution of resources among members, which can lead to conflict. Where adolescents are involved, they may drift away from other family members as they are still trying to find themselves or are dealing with their midlife transactions.

If the nurses do not recognise the changes happening within the family, family teachings may not be effective and nurses may fail to mobilise resources to help the family. The family may seem uninterested in the care of their loved one or become difficult to deal with, making provision of care and decision making for the sick relative very difficult (Hakio *et al.*, 2014). This may render the family members anxious and depressed, and post-traumatic stress disorder is highly likely to occur (Anderson, Arnold, Angus & Bryce, 2008; Jacelon & Henneman, 2014). It is therefore important for nurses to identify family needs in order to help family members of a critically ill patient to adapt (Hakio *et al.*, 2014).

Healthcare workers, especially nurses, need to assist family members to adapt to the ICU environment while one of their own is admitted. The concept of family-centred care advocates for the family members' involvement in the care of their sick relative.

2.3 NEEDS OF FAMILY MEMBERS IN ICU

Family member's needs in the ICU are known and have been extensively studied over the past four decades. Much of this work was in the seminal work of Molter (1979), and Molter and Leske (1983) who developed the Critical Care Family Needs Inventory (CCFNI), a list of needs based on surveys of nursing students and reviews. She developed 45 Likert-scale type questions distributed into five domains:

- Assurance (the necessity for hope in desired results).
- Proximity (the need for contact and remaining closer to the patient).
- Information (need for real information about the patient and regular updates on their progress).

- Comfort (the need to know that the hospital personnel care about the patient).
- Support (which includes available resources, support systems or structures).
-

Researchers have used Molter's CCFNI as a guiding tool for family needs in the ICU, with some using it as it is or as a modified version. These studies included Carlson *et al.* (2015), Gentry *et al* (2013), Hashim and Hussin (2011), Hinkle and Fitzpatrick (2011) and Tilburgs *et al*. (2015), and among many others.

Hinkle and Fitzpatrick (2011) studied the needs of American relatives of ICU patients. The purpose of the study was to investigate the difference between perceptions of relatives, physicians and nurses concerning relative's needs visiting the ICU. Twenty-eight physicians, 109 nurses and 101 family members took part in the study. The results showed that all three cadres placed the need for information at the top, while support and comfort were the least rated.

Hashim and Hussin (2011), in their study titled "Family needs of patients admitted to ICU in a public hospital". The study was conducted in Malaysia, where 100 family members participated showed similar results that family members placed the need for assurance at the top and, as with other studies; comfort and support were rated lower than proximity and information.

Gentry *et al* (2013) also looked at family members' needs in the ICU using the CCFNI.The results of this study which involved 40 participants showed that 100% of the participants ranked information as number one need followed by assurance and proximity. Support and comfort were rated lowest.

Another study by Carlson *et al.* (2015) described family members stress and satisfaction with communication and emotional support from healthcare personnel was carried out among 29 family members of trauma ICU patients in the USA. The findings of the study were that family members rated information as the most important need. Although they were satisfied with the care given, they were less than satisfied with the support they received from nurses.

Medina (2005) identified the following as needs of families of ICU patients: receiving assurance, remaining near the patient, receiving information, being comfortable and receiving support. The traditional healthcare professional-patient relationship should include a professional family relationship dimension as well (Coyle, 2000).

All these studies, for example Carlson *et al.* (2015), Gentry *et al.* (2013), Hashim and Hussin (2011), Hinkle and Fitzpatrick (2011)) and Tilburgs *et al*. (2015), concluded that family members rated comfort and support need lower than assurance, information and proximity. The reason for this, as explained by Sheaffer (2010), is that family members place the needs of the sick relative above their own, preferring to learn how the patient is doing than concentrate on their feelings

A cross-sectional study by Tilburgs *et al*. (2015), to determine the influence of instrumental, emotional support and informational support on quality of life of former ICU patients, revealed that the discrepancy between instrumental and emotional support had adverse psychological effects on patients after discharge from the ICU. Patients showed they received support from family members rather than professional healthcare workers.

From the above mentioned studies that looked at the importance of family needs between healthcare professionals (nurses, doctors, social workers) and family members, it is noted that there are inconsistencies between them. The inconsistencies come in the way the participants ranked the items. While in the studies by Carlson *et al* (2015), Gentry *et al* (2013) the participants ranked assurance as the top need while studies by Hinkle and Fitzpatrick (2011 and Hashim and Hussin (2011), ranked information at the top. Finally, other studies have highlighted additional needs such as decision-making, and patient and family orientation, which are not incorporated in the CCFNI.

One such study was done by Maxwell *et al.* (2007) with the purpose of exploring the needs of family members of critically ill patients, comparing the perceptions of nurses and family members. Thirty nurses and 20 family members participated in the study. The study revealed that nurses and family members rated the needs differently, but all agreed that nursing staff could do better to meet the needs of family members. Out of the top 10 items rated as important needs of family members by nurses, some statements were shared by family members as equally important, for example "to have questions answered honestly,"

"to know the expected outcome of the illness" and "to know exactly what is being done to the patient," as well as "to be assured that the patient is getting the best possible care.

One objective of this study by Maxwell *et al*. (2007) was to compare demographic variables with family members perceptions of support received in the ICU. Although limited literature is available on demographic variables and family needs in ICU, one study was done by Hoghaug, Fagermoen and Lerdal (2012), in Norway, with the title "The visitor's regard of their need for support, comfort, information, proximity and assurance in the ICU." The objective of the study was to describe the relationship between demographic variables and family needs among visitors in an ICU. The CCFNI was used, and 62 family members took part in the study. The findings of the study showed young visitors regarded their need for comfort, information and proximity as more important than did older visitors, women rather than men report a higher need for comfort and family members with lower education status felt support and comfort were more important, whereas the more educated opted for information and assurance as highly important.

Another quantitative study done in Tanzania by Kohi, Obogo and Mselle (2016) revealed there was poor communication between healthcare providers and family members, which often lead to anxiety and distress. Cultural beliefs were also shown to play a part in the breakdown of communication with family members not willing to hear about the poor condition of their sick relative. The study revealed family members were comfortable being told about the day-to-day progress of the patient but did not want to face up to the possibility of the death of their loved one.

A study by Gibart, Hori, Freistas and Mussi (2013), viewed comfort as multidimensional and a state of wellbeing experienced in physical, psycho-spiritual, social and environmental spheres. The study was conducted in several hospitals, with 250 family members taking part. In the study, family members felt their comfort needs were met when they were listened to, understood, their opinions were valued and they were treated with respect, as well as being accepted as they are. Family members considered comfort as being treated with kindness at the front desk, being greeted with a smile and spoken to by the staff.

Another study by Munyinginya and Brysiewicz (2014) looked at the needs of patients' family members in an ICU in Kigali. They revealed that family members viewed a comfortable waiting room with all things done to make waiting easier, such as communication from the nurses and promoting a family's ability to rest, as conveying a message of concern for their wellbeing and that of the patient.

Studies by Carlson *et al.* (2015), Gaeeni, Farahani, Seydfatemi and Mohammadi (2015) and Obringer, Hilgenberg & Booker (2012), looked at informational support to family members of ICU patients, perceptions of families and nurses. These studies have indicated that these needs are often overlooked, as the focus of healthcare professionals, as well as family members, is mainly for the patient who needs close monitoring and continuous care. The needs of family members are usually unnoticed and therefore unmet. Obringer, Hilgenberg and Booker (2012) looked at the needs of adult family members of ICU patients with the purpose of examining the perception of adult family member's needs of ICU patients in Midwest America. Forty-five family members participated, and the results showed they put assurance as the most important, while support was rated lowest.

Limited literature exists on the needs of family members of ICU patients in the South African context; however a few studies have been done on the needs of family members in Africa. The study by De Beer and Brysiewicz (2016) revealed there are no policies or strategies available in South Africa. The study showed that family members placed a great deal of emphasis on information sharing of treatment and procedures as well as the patients' progress; assurance was placed after information. Cultural and religious beliefs also emerged as a need along with emotional support or need for consolation.

2.3.1 Family Needs Not Met in the ICU

Studies reviewed revealed that comfort and support needs of family members of critically ill patients were inconsistently addressed or not met. Family members put assurance, information and proximity above comfort and support. Carlson *et al*. (2015), in their study, stated that support is usually rated low by family members due to their dissatisfaction; because their stress levels are high they place their demands too high and when not met, they mistake this for lack of support by healthcare staff. Family members may also be too overwhelmed as they are trying to cope with the complexity of the medical system, new

problems, decision-making for their sick relative, the possibility of losing the patient and large medical bills. Emotional avoidance may also contribute to them rejecting the support offered by healthcare workers.

Gaeeni *et al*. (2015) in their study that looked at informational support to family members of ICU patients, perceptions of families and nurses, also supported that notion that family members attribute the lack of information as lack of support from healthcare staff. The study revealed that family members want a consistent flow of honest information when they need it. Withholding information by healthcare workers was seen as a lack of support by family members.

The reviewed quantitative studies amongst them studies by Carlson *et al.* (2015), Gentry *et al.* (2013) Hashim and Hussin (2011), Hinkle and Fitzpatrick (2011), and Tilburgs *et al*. (2015) used the CCFNI and in these studies, comfort and support needs were consistently rated lower than other needs. This has led the researcher to believe that the instrument (CCFNI) may not be sufficiently sensitive to measure these constructs, hence the use of the Intensive Care Unit-Psychosocial Care (ICU-PC) scale. The ICU-PC scale was developed by Hariharan *et al*. (2015) and looked at three factors, protection of human rights and dignity, transparency in decision making and care continuity and sustained patient family orientation. The instrument was developed using 250 subjects to measure psychosocial care provided in the ICU.

Psychosocial support In the ICU refers to supportive interventions such as reassuring, giving hope, cheering up raising faith, strengthening patient's self-esteem, emotional support and empathetic touch as well as listening. As nursing moves from patient centred care which focused only on the patient, the above interventions are extended to the patient's family members as well. Hariharan *et al.* (2015) described the three categories of psychosocial support, which included protection of human dignity and rights, transparency for decision making and care continuity and sustained patient, family orientation.

2.3.1.1 Protection of human rights and dignity

Human dignity pertains to an individual's sense of self-respect and self-worth physically and psychological integrity and empowerment. Brink *et al.* (2012) stated that privacy is

one of the human rights. Privacy is the practice of maintaining the security and confidentiality around patient especially patients who are in ICU who are wholly dependent on health care workers. Family members need to know that their loved ones rights and dignity are maintained during the time they are separated from them.

2.3.1.2 Transparency for decision making and care continuity

Transparency refers to doing things in an open manner. Transparency in decision making gives family members the autonomy to decide on the care of their sick relative .Family plays a central role in decision medical decision making (Hakio *et al.,* 2014; Sedig, 2016). Providing family members with information make it easier for them to make the right decisions for their loved ones who are not in any position to make their own decisions. Reassurances help reduce their anxiety and participate in patient support (Hariharan *et al*. 2015).

2.3.1.3 Sustained patient family orientation

One of the psychosocial factors identified is family orientation. This focuses on orientating the family members on procedures done to patient and the patient is oriented in the changes of day, time and environment on daily basis (Hariharan *et al.* 2015)

2.4 FAMILY-FOCUSED CARE AND FAMILY-CENTRED CARE

Family-focused care implies that family support is included with support provided for the patient. Medina (2005) takes it to mean that nurses assess the needs of families and intervene to benefit the outcomes of the patients and the patients' families as a unit.

Ponte and Peterson (2008) noted that according to the Institute for Family-Centred Care in the USA (a group dedicated to advancing understanding and practice of patient-family-centred care), the four core concepts of patient-centred care are dignity and respect, information sharing, participation and collaboration. The role of the nurses in this instance is to implement these concepts for the patient and their families. The nurse as an educator educates the patient and family members on their needs and care of the patient. It is the role of nurses to link families with other professional support, for example, a social

worker, pastoral care and a rehabilitation therapist within the ICU at the loved one's side, to enhance family psychosocial support (Henneman & Cardin, 2002).

Shirey (2008) confirms that all of the above are contemporary care delivery models and are used interchangeably, while the expanded version is patient-family-centred care that incorporates a multidisciplinary approach.

Family support is used as an umbrella term to include all the needs of patients and families. According to Aruba, Reily and McCarter (2008), it is a method of delivering care, which places the patient and family at the centre. Families and patients are empowered to question policies and practices and offer their opinions/concerns so that the organisations reflect and evaluate better ways to meet their goal.

Nursing in the ICU entails information sharing, identifying family members' needs and resources that may be helpful if there is the need for a referral, such as social workers, counsellors and pastors. The nurse in the ICU ought to provide nursing care to the patient, education and support to the patient's family, act as liaison officer between patient, family and other healthcare teams whilst respecting the beliefs and values of the patient and family. Therefore, the more the support they get from nurses, the more confident family members are that their patient is getting the best care.

As nursing in present times moves from being patient-oriented to including families in the care, Intensive Care nurses should also accommodate the needs of family members. "As the first social institution, the family bears culture, roles and particular structure signifying physical, mental social, spiritual and cultural health of its members. Any disorder in its parts will lead to holistic disorder (Siahkali *et al.,* 2010). One of the challenges affecting a family system is when one of its members is hospitalised and when the admission is to an ICU, the impact becomes even more severe. It is during this time some needs such as care and support arise.

Mitchel and Chaboyer (2010) highlighted in their study, "family-centred care is a philosophy of care that sees a patient and his family as a unit rather than having the patient as the sole focus of care." They stated, "One's family is the single most important aspect of one's principle of psychological and physical health and has three elements of mutual

respect, collaboration and support. Family-centred care encourages true partnership through listening to the views and perspectives among the family members and the healthcare workers thus optimising the patient outcome."

The Institute for Family-Centred Care (2005), states that family-centred care incorporates holistic care, which includes planning, delivery and evaluation of healthcare, while a study by Johnson, Abrahams and Shelton (2009), viewed family-centred care as an approach that offers a framework within which to begin examining policies, programmes and practices for hospitals to begin a journey to transform organisational healthcare culture. These studies put forward one concept that a family is a natural extension of the patient hence they cannot be excluded from the care of their sick relative. Family-centred care emphasises the importance of family participation and collaboration with the nurses and other healthcare workers.

Studies by Jacelon and Henneman (2014), Wong Liamputtong, Koch and Rawson (2015) and Tilburgs *et al.* (2015) revealed that family members provide social support through the provision of a close and familiar relationship. Family members provide clarification about the patient's preferences and make decision-making about care and treatment easier for the healthcare personnel. In turn, family members experience easier communication with nurses, which makes them feel confident that nurses care for their relative.

The behaviour of nurses, such as treating the family as people and showing empathy, sharing information and encouraging them with assurance and support, demonstrates the commitment to the patient. According to Rippin (2016) an ICU that invites family presence and participation fulfils social, emotional and informational needs of the patient's family. The study went on to say, that family members who are allowed to be present during lifesaving procedures become less anxious and are confident that healthcare professionals cared for their loved one.

Family members, when included in the care of their relatives, feel useful and contributing to the wellbeing of the patient. The studies revealed that family members who were included in the care of the patient had lower stress levels and were better placed to cope with adverse outcomes such as death. The support they got from the nursing staff made them feel useful and at ease knowing they were doing something for the patient.

2.4.1 Family members perceptions in participation of support

A study by Mitchel and Chaboyer (2010) aimed to describe family perceptions of providing physical support to their relatives with bedside nurses support. Ten family members participated in the study and the findings showed they felt helpful when they took part in the care of the patient, they felt connected to the patient and contributing to his wellbeing. The authors highlighted that relatives who were included in the care of the patient felt more comfortable and were able to open up more about their feelings, were in a better position to accept the patients 'condition and communicate easily with the nursing personnel.

2.4.2 Nursing support in the ICU

The nurses' role is to care for the patient and their family. It is the nurses' obligation to promote the well-being and autonomy of the patient and their relatives (Othman, Subramanian, Ali Hassan and Haque (2016). The nurse assesses the needs of family members, and how the admission has affected them, and acts as a liaison officer when referral to other teams, such as social workers or psychologists, is needed. The nurse assesses the family's coping strategies and attends to their comfort, cognitive and psychological needs. The need for interactions, such as explaining equipment, procedures and treatment in the ICU, are the roles of the nurse.

Although the family's needs in the ICU are not always met, literature has revealed that nurses do attempt to respond to these needs. Nurses take roles to meet support and comfort needs of family members. Coyer, Wheeler, Wetzig and Couchman (2007) outlined that "the provision and promotion of comfort through focused nursing interventions are essential in the ICU." They argued that daily nursing routine of bathing, feeding and positioning of the patient provides comfort to the patient. Managing stressors in the ICU, reduction of isolation and loneliness as well as providing a comfortable environment is essential, as well as adjusting schedules to accommodate visiting times to allow family members more time with their sick relative. Communication with the patient and family members often reduces stress, hence enhancing comfort.

"Nurse –family relationships in the ICU are extremely important. Nurses act as a resource for the family of the critically ill individual by providing interventions such as information sharing, family meetings, bedside family-patient interactions to meet family needs of support and comfort. Inconsistency in meeting these needs may negatively affect the family perception and adaptation to the crisis thus affecting the patient outcome. Nurses act as mediators and interpret information that helps family members to understand what doctors are saying and enable them to make appropriate decisions for their sick relative" (Maxwell *et al.,* 2007).

Family members who were given the opportunity to take part in the care of their sick relative felt they were doing something for them. According to Mitchel and Chaboyer (2010) and Rippin (2016) assisting helped the families to cope better with the sickness of their relative and offer support to the patient. Participation of family members makes decision-making in the ICU easier and in turn, makes them comfortable and less anxious. This was seconded by Loghmani, Borhani and Abbaszadeh (2014), who stated nurses in the Intensive Care Unit provide emotional support by being empathetic or putting themselves in the place of family members. It helps in understanding how family members feel about their sick relative, helps provide comfort by listening to family member's fears and wishes, as well as providing counselling sessions. Mutual understanding is viewed in the study as one of the factors that nurses use in the provision of support to the family members.

Nurses can also provide comfort by displaying friendly behaviour and respecting the family. Facilitating a trusting relationship between the nurses and family members makes family members comfortable and able to cope with the patients' admission to the ICU. Communication between family members and nurses facilitates a healthy environment, which promotes comfort.

Patients in the ICU are critically ill hence premonitions of the disease are not usually satisfactory. Spiritual issues are important during the period of critical illness as family members often turn to God, by praying, fasting and worshipping, to help the sick family. The nurses encourage family members to seek spirituality by allowing them time to pray for their loved one.

2.5 SUMMARY

An admission to an ICU is stressful to the family members of the sick individual. Previous studies have revealed that family members go through a mixture of emotions and the intimidating environment of the ICU, with lots of sophisticated equipment, adds to the distress that already exists due to the illness of a family member. It is therefore during this time that family members need comfort and emotional support from the nurses. However, studies reveal that these needs are usually unmet as the focus of both family members and nurses is on the sick person.

Most authors who studied the needs of family members of ICU patients used the CCFNI, which was developed by Molter in 1979 either as the original or modified version (Carlson *et al.,* 2015; Gentry *et al.,* 2013; Hashim & Hussin, 2011; Hinkle & Fitzpatrick, 2011; Tilburgs *et al.,* 2015). The questionnaire developed by Hariharan et al. (2015) which was used in this study also looked at psychosocial support in the ICU. These studies have revealed that comfort and psychosocial support needs are usually ranked lower than the needs of assurance, proximity and information. This is because family members consider the health of their sick relative more important than their comfort. According to the literature reviewed, family members of ICU patients were satisfied and felt supported if they received information about their loved ones. Where information was provided, family members felt happy and comfortable with the care provided to their relative.

Family members included in the care of their loved ones felt fulfilled and viewed themselves as doing something useful for their loved one, which illustrates that nurses should include family members in the care of their relatives. However, with the evolving of nursing, the nurses now see the need for family-centred care in which the focus of psychosocial support does not revolve only around the patient, but includes their family and loved ones. With the inception of family-centred care, family members take part in the caring of their sick relative and find it easy to open up to nurses about their fears, thus enabling nurses to meet their needs.

The next chapter will discuss the methodology used in the study.

CHAPTER THREE

RESEARCH DESIGN AND METHODS

3.1 INTRODUCTION

Research methodology refers to the steps, procedures and strategies for gathering and analysing research data (Polit & Beck, 2012). In this chapter, the research design and methods were discussed, which included the setting, study population, sample and sampling, data collection, the instrument used including its validity and reliability, ethical considerations as well as the validity and reliability of the study as a whole.

3.2 OBJECTIVES

For consistency, the objectives of the study are repeated.

The objectives of the study were:

- To describe the family members of critically ill patient's perceptions of psychosocial support received in the Intensive Care Unit.
- To compare the family members of critically ill patient's demographic variables with their perceptions of psychosocial support received in Intensive Care Units.

3.3 RESEARCH DESIGN

A research design is "a set of guidelines and instructions followed in addressing the research problem" (Burns & Grove, 2011), which includes how data is to be collected, what instrument will be used and how the instrument will be used as well as an intended means for analysis of the data collected (Polit & Beck, 2012). These techniques include the inclusion-exclusion criteria that are used to select the target population, the sampling techniques, data collection, the instrument and reliability and validity of the tool.

In this study, the research design was quantitative, non-experimental and descriptive directed towards understanding the nature of psychosocial support family members received when they had relatives admitted to an Intensive Care Unit.

3.3.1 Quantitative

The "Quantitative research design is a systematic process used to gather and statistically analyse information as measured by an instrument" (Burns & Grove, 2009). Quantitative research studies concepts that can be measured and turned into numbers. Quantitative research is "deductive or it tests theories as compared to qualitative which generates theories" (Burns & Grove, 2011). Quantitative research produces results that can be generalised as it uses large sample sizes and, it is easy to analyse as it uses data that are structured in the form of numbers (Brink,Van Der Walt & Van Rensberg, 2012).

3.3.2 Non-experimental

This is a research design in which manipulation of the independent variable is impossible, inappropriate or impractical (Brink *et al.*, 2012). The study was considered as non-experimental because it took place in the natural setting where there was no manipulation of the subjects.

3.3.3 Descriptive

Descriptive, as a research design, refers to the situation in which phenomenon is described or the relationship between variables examined; no attempt is made to determine cause-effect relationships ((Brink *et al.*, 2012). These designs may be used when more information is required in a particular field to provide a picture of a phenomenon. It encompasses a variety of designs, which use both qualitative and quantitative methods.

The design was chosen because the researcher sought to describe the perceptions of family members', of critically ill patients, psychosocial support received in the Intensive Care Unit.

3.3.4 Setting

The "research setting is defined as a site for conducting research" (Burns & Grove, 2011). The study was conducted in one general Intensive Care Unit in an academic tertiary hospital in Johannesburg. The ICU admits patients from all hospital services including

trauma, surgery and medical disciplines, as well as direct admissions from the emergency departments. The bed capacity of the unit is 12 beds and about 55 patients are admitted per month, with a bed occupancy rate of 95%.

The unit comprised both Intensive Care and non-Intensive Care nurses. The unit visitor's waiting room was used for data collection. Family members who met the inclusion criteria were approached and the study was explained to them. Those who voluntarily agreed to take part were then given the questionnaire to complete after signing a consent form.

3.4 RESEARCH METHODS

3.4.1 Population

Population in research refers to "a set of individuals or objects with the same characteristics" (Polit & Beck, 2012). The target population for this study was family members of patients admitted to a general ICU in a tertiary hospital in Johannesburg.

3.4.2 Sample and Sampling

Purposive sampling was used to recruit participants for the study. Purposive sampling is "a non-probability sampling method in which the researcher selects specific individuals from the population with the purpose of study or research" (Burns & Grove, 2011).

Following discussion with a biomedical statistician, an adjusted sample size of 100 (n=100) was achieved, with a confidence level of 95% (1.96), the margin of error of 5% and prevalence of 80%. This sample size was a representative sample as the results can be generalised to the population.

The sample size was calculated using a statistical formula:

$$n^* = \frac{z^2 \times p(1-p)}{d^2}$$

Where n*=estimated sample size, z=confidence interval at 95% (1.96), p=estimated prevalence of patient's bed occupancy in selected ICUs 80% (0.8), d=margin of error at 5% (0.5)

Inclusion criteria

Family members of a patient who had been admitted to the Intensive Care Unit for more than 48 hours were included in the study. These were family members who had visited the patient on several occasions and had time to interact with the nursing staff. Two (2) family members for each patient were included in the study. The family members were able to give consent.

Exclusion criteria

Family members whose relatives had died in the Intensive Care Unit were excluded, as this may have been too sensitive for them. First-time visitors were also excluded as they have not had much interaction time with the nurses.

3.4.3 Data Collection

Data collection is defined by Burns and Grove (2011) "as a system of gathering and measuring information on targeted variables in an established systematic fashion which enables one to answer relevant questions and evaluate outcomes". Before they could participate in the study the respondents had to provide written consent.

Informed consent refers to an ethical requirement for assuring that respondents understand what it means to participate in a particular study so that they can decide in a conscious, deliberate way whether to participate or not" (Polit & Beck, 2012). Informed consent is an important factor for ensuring respect for the person while doing research. For respondents to give informed consent, they have to be given important information about the study. This information includes research, its objectives, purpose and the research methods

Appointments were arranged with those who met the inclusion criteria, and they were given respondent information letters to read beforehand. Data was collected during visiting hours, which was from three o'clock to five o'clock (3 to 5 pm) as this is the time when family members were available. The unit visitor's waiting room was used for data collection and the researcher was available to answer any questions the respondents had or

to clarify anything they did not understand. The respondents were then given the data collection questionnaire to complete.

3.4.3.1 Instrument

The questionnaire in the study was developed by Hariharan, Chivukula & Rana (2015), as identified in the literature, and used to collect data.

The self-administered questionnaire contained two sections. The first section (Section A) was the demographic data of the respondents who were family members. This included research code, age, gender, relationship to the patient, the reason for their relative's admission and duration of stay in ICU. Section B composed of instructions and 18 questions, followed by a Likert scale table to rate the responses as 1 = never, 2 = rarely, 3= sometimes, 4 = most often and 5 = always against 18 items. The questionnaire scale measures psychosocial support offered to patients and family members in the ICU. Three categories or domains were identified from 18 items of the ICU-PC scale:

- protection of human dignity and rights (items 10, 11, 12, 13, 14, 16 and 17),
- transparency for decision-making and care continuity (items 1, 2, 3, 4, 5, 6, 7 and 8)
- Sustained patient, family orientation (items 9, 15 and 18).

There was reverse scoring with three remaining items of 5, 9 and 17, where 5 = never, 4 = rarely, 3 = sometimes, 2 = most often and 1 = always. Permission to use the instrument was granted (Appendix G).

3.4.3.2 Validity and Reliability of the Instrument

The authors (Hariharan *et al.*, 2015) developed the original questionnaire based on pertinent reviews related to psychosocial care meant for patients admitted in a cardiac ICU. The tool went through three phases being the development, content evaluation and the pre-test and reliability analysis phases. During the development phase 50 items were developed from in-depth interviews with patients admitted in the cardiac ICU.A review of the items were done by 4 nurses with 8 to 10 years' experience as ICU nurses. After the review 35 items were adopted. In the content evaluation phase a panel of experts in the field of psychology (5 psychologist) and medicine(5 surgeons/intensivists) were asked to evaluate

the items. CVR for each item was .62 ;11 items were deleted and 24 items retained as items in the preliminary form of the ICU-PC scale for its trial (pre-test)and reliability analysis.

A five-point Likert scale ranging from 1=never to 5=always was assigned the 24 remaining items. The scale was pilot tested with a sample of 50 cardiac patients to observe correlations among the 24 items and estimates based on the response of the clinical sample. After data analysis on the 24 items, 6 items were removed due to their comparatively low item-total correlation. The remaining 18 items revealed a high internal consistency with an alpha coefficient of .75 and an average item correlation of r.34. The obtained alpha value exceeded the recommended value of .70 indicating adequate internal consistency of the questionnaire.

3.4.4 Data Analysis

The data analysis is a process for reducing, organising and giving data a meaning (Burns & Grove, 2011), while Polit and Beck (2012) defined it "as the systematic organisation and synthesis of research data and in quantitative studies, the testing of hypothesis using those data." In this study, data were analysed using inferential and descriptive statistics. Inferential statistics "is the use of statistics to make inferences or predictions about people based on data collected from a small sample drawn from the population." Descriptive and inferential statistics were used for data analysis. Descriptive statistics is the use of statistics to organise and present data in a study in an important way that describes the basic facts of the data and enables analysis (Grove *et al.* 2013).

Descriptive statistics that is frequencies, median, mean, percentages and standard deviations were used to summarise the demographic data and the respondents' response on the Likert scale. Mean and standard deviation were used to describe demographic data. Frequency tables, percentages were used to summarise the respondents' responses. Tables, bar and pie charts were also used for easy presentation and interpretation of the results. Inferential statistics were also used. The Cronbachs' Alpha was calculated to check the reliability of the questionnaire in respect to the three psychosocial factors being-Protection of human rights and dignity; Transparency for decision making and continuity of care and

Sustained patient-family orientation. Statistical assistance was sort from a statistician during data analysis.

3.4.5. Pre- testing the instrument

A pre-testing procedure "is a smaller version of proposed study conducted to develop or refine the methodology such as the treatment, instrument or data collector process" The purpose of conducting a pre-test procedure is to help identify if the respondents understand the questionnaire, to see if any of the questions may be misinterpreted and to clarify if the methods, sample and instruments are adequate and appropriate (Grove *et al*., 2013).

In this study the pre-test was conducted with five (N=5) respondents. These were five family members of patients admitted in the general ICU. The results of the pretesting procedure showed that the respondents had no difficulty in completing the questionnaire.

3.5 ETHICAL CONSIDERATIONS

3.5.1 Informed Consent

The respondents were informed about the study objectives, significance and research methods, what was expected of them as respondents, which was to complete the questionnaire as honestly as they could and the likely time it would take to complete the questionnaire. Respondents were made aware that participation in the study was by choice and that they could pull out from the study at any point, without the risk of penalties.

Respondents were informed that there were no gains or benefits for participating in the study and that it was solely for education purposes. Confidentiality and privacy issues were discussed with respondents, with assurance that their identity and that of their sick relative would not be revealed or linked to the data collected.

Respondents were assured that personal information would not be shared with anyone and that what they said would remain between themselves and the researcher. To ensure privacy and confidentiality, the researcher allocated respondents research codes to avoid

the use of their real names. The information was given in the form of a letter (**Appendix B**) and reinforced verbally to ensure the respondents understood.

Respondents who agreed to take part in the study gave consent by signing a consent form (**Appendix C**).

The researcher made available her contact numbers for respondents to contact her should they need clarification concerning the study, or if they had any questions.

3.5.2 Permission to Conduct the Study

The protocol was submitted to the Department of Nursing Education for peer review and was then submitted to Postgraduate Committee for approval of the study (**Appendix F**). The protocol was submitted to the University of the Witwatersrand Human Rights and Research Committee for approval (**Appendix D**). Permission was obtained to use tool from the developers (**Appendix G**).Permission was also obtained from the CEO of the participating hospital to use the hospital as setting for the study (**Appendix E**).

An information letter was given to the respondents to read before they decided to participate in the study (**Appendix B**).Respondents who agreed to take part in the study signed a consent form to affirm their participation in the study (**Appendix C**).

3.5.3 Anonymity

"Anonymity is the protection of respondents' confidentiality such that even the researcher cannot link individuals with information provided" (Polit & Beck, 2012). It is the process of keeping a person's identity a secret.

The researcher ensured that the identities of the respondents were kept unknown by using research codes in place of real names. In doing so, the respondents identification and data were not linked to them in any way, and they were assured of confidentiality throughout the duration of the study

3.5.4 Confidentiality

Ensuring confidentiality in research is very important. Confidentiality refers to the fact that information given by respondents will not be discussed or divulged to the public, or made available to any unauthorised people (Brink *et al.,* 2012).

The researcher ensured confidentiality by being the only person who handled the completed questionnaires. Using research codes also helped in maintaining confidentiality as the information was not linked to any person directly. The researcher ensured privacy and dignity of the respondents throughout the study.

3.6 VALIDITY AND RELIABILITY OF THE STUDY

"Validity refers to whether the instrument adequately covers what it is supposed to measure while reliability refers to the degree to which the instrument can be depended upon to yield consistent results if repeatedly used over the same subjects or used by a different investigator" (Burns & Grove, 2011). To ensure validity and reliability in this study, consistency and accurate data recording was maintained. The researcher personally administered the questionnaires and ensured that the respondents understood the purpose and nature of the study. The researcher explained how data would be collected and assured the respondents of anonymity. There was no manipulation of variables and prevented threats to internal validity.

3.7 SUMMARY

In this chapter, methodological issues were discussed, including research design, the study population, the research setting, and the data collection procedure, as well as the instrument used, including its validity and reliability, and ethical issues were considered.

The next chapter will describe the results after analysing the data.

CHAPTER FOUR

RESULTS AND DISCUSSION OF FINDINGS

4.1 INTRODUCTION

Data files were set within the computer statistical software package STATA version 13.1; data was entered once then verified during the second direct entry. Descriptive and comparative statistics were used to achieve the study objectives. The comparative statistics were employed to describe and synthesise questionnaire scores to compare the socio-demographic data of family members with obtained level of measurements to test for statistical significance. Statistical tests included the Cronbach's reliability coefficient alpha, Proportion and Chi-square tests. Testing was done at the 0.05 level of significance (p=0.05). Findings will be discussed on construct, scale and item levels.

This chapter describes the analysis of data using descriptive and comparative statistical tests and interpretation of findings.

4.2 APPROACH TO DATA ANALYSIS

Descriptive statistics were used to present interpretation of the socio-demographic data of family members: age, gender and relationship to patient and patient clinical data, inclusive of the reason for admission and length of ICU stay. Frequency distributions, cross tables, histograms and pie graphs were used to provide an overall coherent presentation and description of the data. Percentages of these results were taken to the nearest whole number.

Cronbach's reliability coefficient alpha was applied to assess the reliability of the summative rating scale (Likert scale) composed of total questionnaire scores for transparency in decision-making and care continuity, protection of human rights and dignity and sustained patient/family orientation (construct variables). When comparing item scores, the Proportions test and Chi-square tests were used to test for significance of differences in the frequencies of responses for transparency in decision-making and care continuity, protection of human rights and dignity and sustained patient/family

orientations. Testing was done at the item level to further explore the data. When comparing categorical variables the response was similar to the latter - the Proportions test and Chi-square test were used to test for significance of differences in the frequencies of participants responses for transparency in decision-making and care continuity, protection of human rights and dignity and sustained patient/family orientation and selected socio-demographic (relationship to patient, gender, age and reason for admission) variables. Frequency distributions and cross tables were used to provide an overall summary of the data. Collapsing the categories on the Likert scale was done to facilitate the presentation of the data however, it was noted that a larger percentage of respondents answered strongly and moderately agree or disagree on the itemised analysis. Measurement of descriptive statistics was used to summarise the data.

The level of statistical significance was set at $p<0.05$. A biomedical statistician from the Faculty of Health Sciences, University of the Witwatersrand, assisted in the analysis of the data using the statistical package 'STATA' version 13.

4.3 RESULTS AND FINDINGS

4.3.1 Questionnaire Section A: Socio-demographic Data

This section related to respondent demographic data, which comprised five items. Items included age, gender, relationship to the patient, the reason for admission and duration of stay in ICU. This information was obtained using a self-administered questionnaire within the admission period, between 2 and 27 days after consent was obtained.

One hundred (n=100) family members or significant others made up the sample size. **Table 4.1** provides an overview of results. Items were grouped together to allow ease of discussion.

Table 4.1 Demographic data of respondents for the total sample (n=100)

Item	Category	Frequency	Percentage
A1	Age		
	18 to 30 years	45	45.0%
	31 to 42 years	31	31.0%
	43 to 48 years	23	23.0%
	>49 years	1	1.0%
A2	Gender		
	Male	28	28.0%
	Female	72	72.0%
A3	Relationship to patient		
	Parent	15	15.0%
	Child	26	26.0%
	Sibling	23	23.0%
	Spouse	21	21.0%
	Other	15	15.0%
A4	Reason for admission		
	Medical	19	19.0%
	Surgical (elective)	50	50.0%
	Emergency	31	31.0%
A5	Length of stay in ICU		
	2 to 7 days	79	79.0%
	8 to 14 days	14	14.0%
	14 to 21 days	3	3.0%
	>21 days	4	4.0%

Females accounted for 72.0% (n = 72) and males 28.0% (n = 28) of the total sample (n = 100). The highest (45.0%: n = 45) responses were between the ages of 18 to 30 years, followed by 31.0% (n = 31) and 23.0% (n = 23) in the 31 to 42 and 43 to 48 age categories, respectively. It can be extrapolated from the results that the majority (72.0%) of the respondents were females, between the ages of 18 and 42 years (76.0%). In terms of the age distribution of family members, the study of Kosco and Warren (2000) indicated the mean age of the family members was 47.5 years (SD = 13.2: range: 25 to 78 years), whereas Hinkle and Fitzpatrick (2011) reported a mean age of 58 years in their sample (n=101). **Figure 4.1** presents the results of age distribution of respondents.

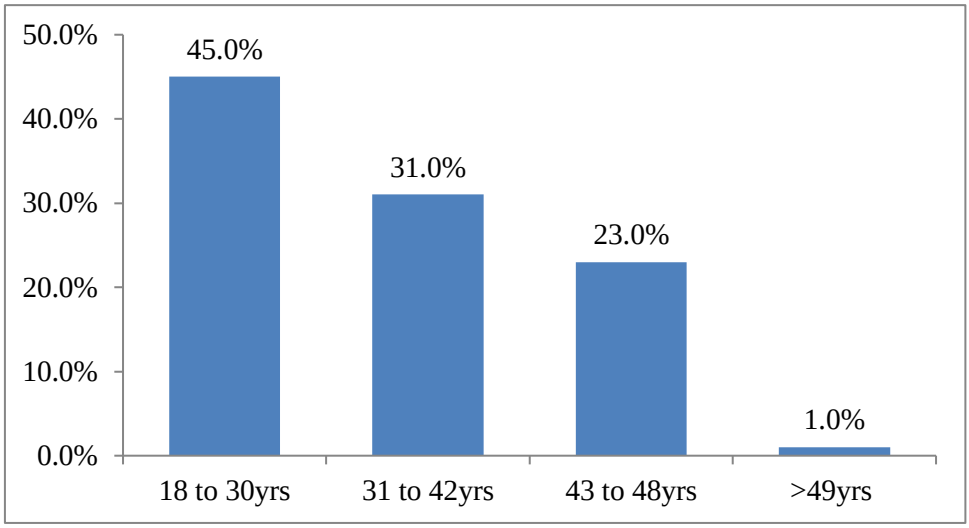

Figure 4.1 Age distributions of respondents

The respondent's relationship to the patient was slightly higher (26.0%: n = 26) as adult children, followed by siblings (23.0%: n = 23), spouse (21.0%: n=21), significant other or parent (15.0%: n = 15). In terms of the relationship to patients, the study by Hoghaug *et al.* (2012) indicated the most (38.7%) to be sons or daughters and the minority (11.3%) as brothers or sisters, whereas Hinkle and Fitzpatrick (2011) reported 44% of relatives interviewed were the spouses of the patient, and 27% were adult children. **Figure 4.2** presents the results of respondent's' relationship to patients.

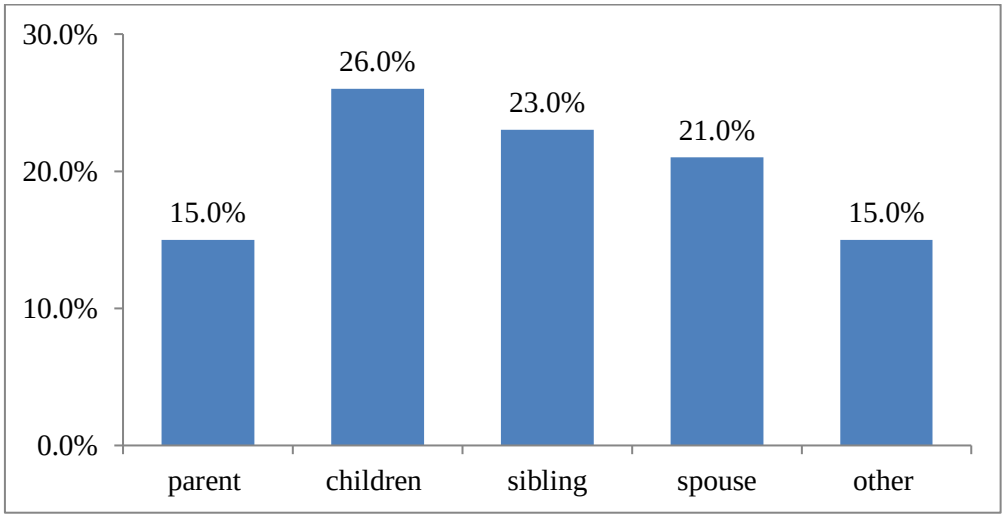

Figure 4.2 Respondents relationship to patients

In this study, an analysis between patients' reason for admission to ICU revealed the majority (50.0%: n = 50) were elective surgical cases, followed by 31.0% and 19.0% of

emergency and medical cases, respectively. In terms of reason for the patient's admission to ICU, Hoghaug *et al.* (2012) indicated the majority (82.3%) as acute (emergency) cases and 14.5% as elective surgery, whereas Hariharan *et al.* (2015) reported a total sample of 250 (100%) patients who had undergone elective cardiothoracic surgery. **Figure 4.3** presents the results of the reason for admission to ICU.

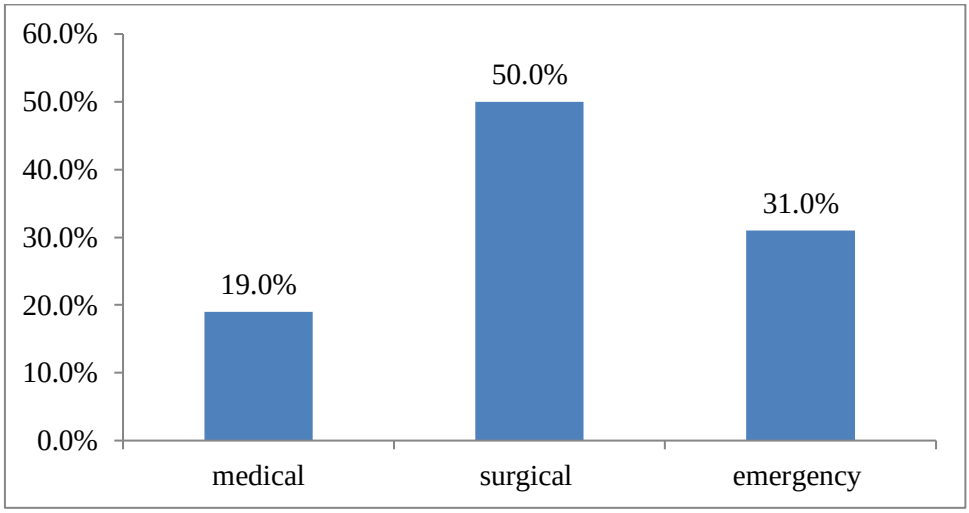

Figure 4.3 Reason for patients ICU admission

In terms of duration of patients' stay in ICU, the majority (79.0%: n = 79) were between 2 to 7 days, followed by 14.0% (n = 14) and 3.0% (n = 3) in the 8 to 14 and 15 to 21 days categories, respectively. In this study, the length of patient stay distribution trend is consistent with similar studies conducted overseas (Europe), as Hoghaug *et al.* (2012) indicated 56.3% between 3 to 7 days, 29.0% and 9.7% between 8 to 14 and 15 to 21 days respectively and, Hinkle and Fitzpatrick (2011) reported the average length of stay was 11 days with a range of 2 to 112 days. **Figure 4.4** presents the results of frequency distributions obtained for patients' length of stay in ICU.

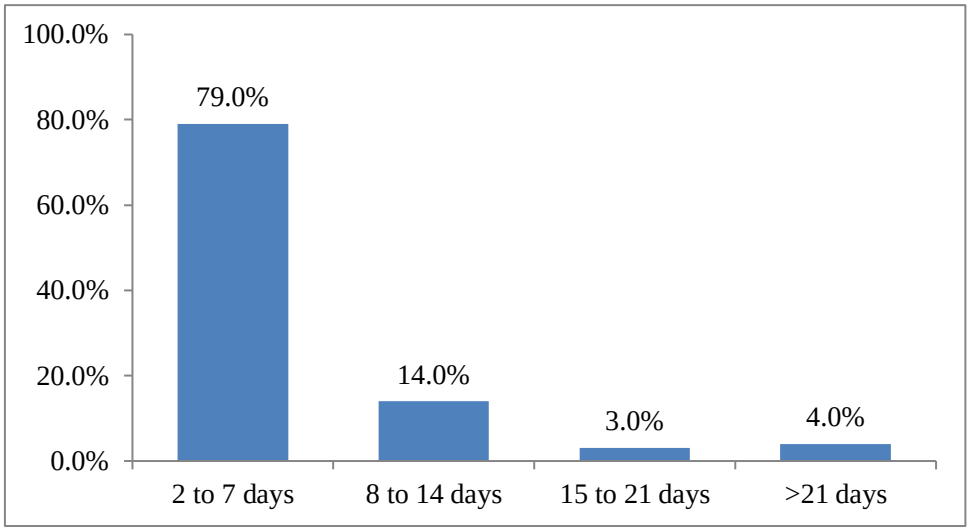

Figure 4.4 Frequency distributions obtained for patients length of stay in ICU

4.3.2 Questionnaire Section B: Family members' Perceptions of Psychosocial Support

This section comprised 18 items, responses to which were obtained from the respondents by the researcher through a structured interview process, specifically within an admission period of the patient in the Intensive Care Unit, to determine the family members' perceptions of psychosocial support provided by Intensive Care nurses. Descriptive and comparative statistics were used to analyse the data on the scale, construct and item levels.

The total sample comprised 100 respondents who were family or significant others of adult patients admitted to one multidisciplinary Intensive Care Unit. The instrument used in the study is the ICU-PC scale. This questionnaire measures family members', of critically ill patients, experience of psychosocial support provided by Intensive Care nurses inclusive of three subscales, namely (i) transparency for decision-making and care continuity, (ii) protection of human rights and dignity, and (iii) sustained patient and family orientation, on a five-point Likert-type scale, with the rating option of 1, 2, 3, 4 or 5 reflected as never, rarely, sometimes, most often and always, respectively.

Data were analysed to determine family members', of critically ill patients, perceptions of psychosocial support received from Intensive Care nurses after collapsing one of the categories of the Likert scale, where 1 and 2 were used as never and rarely, respectively to

form the *never and rarely* category. Collapsing of the categories on the Likert scale was done to ease discussion of the data, however it was noted that a larger presentation of respondents answered moderate disagreement in the itemised analysis. The decision for collapsing the categories was informed by the statistician in consultation with the researcher's supervisor.

4.3.2.1 Transparency for decision-making and care continuity

The first section related to the family members' responses for transparency in decision-making and care continuity. Eight items (items B1 to B8) were included in this section. **Table 4.2** displays these results.

Table 4.2 Frequencies obtained for respondents' responses for transparency in decision-making and care continuity

Item	Statement	Respondents responses					
		Never and rarely		Sometimes		Most often and always	
		n	%	n	%	N	%
B1	The family is informed in advance about the expenditure of the patient.	26	26.0%	15	15.0%	59	59.0%
B2	Specific time is allocated to the family by one of the healthcare team to answer questions.	14	14.0%	16	16.0%	70	70.0%
B3	The diagnosis is informed to the family.	6	6.0%	5	5.0%	83	**83.0%**
B4	The doctor's experience and expertise in handling particular kinds of cases is notified.	15	15.0%	16	16.0%	69	69.0%
B5	The family members are unsure to where they can lodge a complaint or present their grievances.	41	41.0%	16	16.0%	43	43.0%
B6	The patient/family is clearly informed about the benefits of the treatment programme.	11	11.0%	24	24.0%	64	64.0%

Table 4.2: continued

Item	Statement	Respondents responses					
		Never and rarely		Sometimes		Most often and always	
		n	%	n	%	N	%
B7	The patient's feelings, agitation and anxiety are handled effectively by the ICU team.	25	**25.0%**	28	28.0%	47	47.0%
B8	The patient is assured that his/her family is just outside the ICU and available on call."	42	**42.0%**	21	21.0%	37	37.0%

Items B1 to B8 on the data collection instrument enquired about how the respondents experienced transparency in decision-making and care continuity. The majority (83%; n = 83) of family members most often or always experienced that "*the diagnosis is informed to the family*" (item B3), with 70 (n = 70: 70.0%) agreeing that "*specific time is allocated to the family by one of the healthcare team to answer questions*" (item B2). Most family members agreed, "*The family is clearly instructed about the benefits of the treatment programme*" (item B6), and only 59 (n = 59: 59.0%) family members were most often or always "*informed in advance about the expenditure of the patient*" (item B1).

However, opinion was split, with 43 (n = 43: 43%) family members were most often or always "*unsure of where they can lodge a complaint or present their grievances*" (item B5), and 41.0% (n = 41) as never or rarely experienced this care practice, 42.0% (n = 42) of family members never or rarely experienced that "*the patient is assured that the family is just outside the ICU and available on call*" (item B8), and 25 (n = 25: 25.0%) family members never or rarely experienced that "*the patients feeling, agitation and anxiety are handled effectively by the ICU team*" (item B7).

4.3.2.2 Protection of human rights and dignity

The next section related to family members' responses for the protection of human rights and dignity. Seven items (Items B10 to B16) were included in this section. **Table 4.3** displays these results.

Table 4.3 Frequencies obtained from respondents for protection of human rights and dignity

Item	Statement	Respondents responses					
		Never and rarely		Sometimes		Most often and always	
		n	%	n	%	n	%
B10	A curtain is drawn around the patient during examination, procedure and treatment.	3	3.0%	-	-	97	97.0%
B11	There is a provision in the hospital to take care of the spiritual needs of the patient/family.	9	9.0%	7	7.0%	84	84.0%
B12	The family is kept informed about the progress or decline of the patients' health status.	7	7.0%	5	5.0%	88	88.0%
B13	There is an exit meeting before the patient is discharged, where the patient or family is explained about post-discharge care such as diet, exercise, alarm signals, etc.	67	67.0%	6	6.0%	27	27.0%
B14	A curtain is around the patient while taking care of his/her toilet and bowel needs.	3	3.0%	-	-	97	97.0%
B16	A curtain is drawn around the patient while he/she is sponged.	3	3.0%	5	5.0%	92	92.0%
B17	The family is uncertain as to where the patient is taken for specific tests.	44	44.0%	21	21.0%	35	35.0%

Items 10, 11, 12, 13, 14, 16 and 17 on the data collection instrument enquired about how the family experienced protection of human rights and dignity of their family member. An overwhelming majority (97.0%: n=97) of family members most often or always experienced the care practices that "*a curtain is drawn around the patient during examination, procedure and treatment*" (item B10), "*a curtain is drawn when taking care of toilet and bowel needs*" (item B14) and "*a curtain is drawn when the patient is sponged*" (item B16) (97.0%: n = 97; 92.0%, n = 92, respectively). More than three-quarters (>75%) of family members were most often or always in agreement that "*there is provision in the*

hospital to take care of the spiritual needs of the patient/family" (item B11) and "*the family is kept informed about the progress or decline of the patient's health status*" (item B12).

However, two-thirds (67.0%: n = 67) of the family members disagreed that they had never or rarely experienced "*an exit meeting before the patient was discharged, where the patient or family is informed about post-discharge care such as diet, exercise, alarm signals etc*" (item B13), and 35 (n = 35: 35.0%) of the family members most often or always experienced that "*the family is uncertain where the patient is taken for specific tests*" (item B17).

4.3.2.3 Sustained patient-family orientation

The final section related to family members' responses for the sustained patient and family orientation. Two items (items 15 and 18) were included in this section.

Table 4.4 Frequencies obtained for respondents experience of sustained patient family orientation

Item	Statement	Respondents responses					
		Never and rarely		Sometimes		Most often and always	
		n	%	n	%	n	%
B9	Patient's family are informed about tests and procedures only after they are done	30	30%	9	9%	61	61%
B15	The patient is kept informed about the change in day, date and time (day and night).	26	26.0%	19	19.0%	55	55.0%
B18	The doctor or the nurse briefs the family about the condition of the patient on a day-to-day basis.	7	7.0%	11	11.0%	82	82.0%

Items 15 and 18 on the data collection instrument enquired how the family experienced sustained patient and family orientation. The majority (82.0%: n = 82) of family members most often or always experienced that "*the doctor or the nurse briefs the family about the*

condition of the patient on a day-to-day basis" (item B18), and 55 (n = 55: 55.0%) family members most often or always experienced the care practice that "*the patient is kept informed about the change in day, date and time (day and night*)", whilst one-quarter (26.0%: n = 26) never or rarely experienced this care practice (item B15).

4.3.3 Comparative Statistics

Construct scores and total item scores were of interest for further analysis to compare results with the categorical variables. Cronbach's alpha summative rating scale was used and the sum of individual item scores was used. Results of the process are summarised in **Table 4.5**.

Table 4.5 Summary Cronbach's reliability coefficient for individual item scores (B1 to B18)

Item	n	Item-test correlation	Item-rest correlation	Average inter-item covariance	Alpha
B1	100	0.55	0.42	0.22	0.69
B2	100	0.69	0.61	0.20	0.68
B3	100	0.60	0.53	0.22	0.69
B4	100	0.51	0.39	0.22	0.69
B5	100	0.20	0.39	0.26	0.74
B6	100	0.59	0.49	0.21	0.69
B7	100	0.38	0.25	0.23	0.71
B8	100	0.49	0.37	0.22	0.70
B9	100	0.21	0.49	0.26	0.74
B10	100	0.28	0.23	0.25	0.72
B11	100	0.37	0.26	0.24	0.71
B12	100	0.47	0.38	0.23	0.70
B13	100	0.40	0.25	0.23	0.72
B14	100	0.28	0.22	0.25	0.71
B15	100	0.64	0.54	0.20	0.68
B16	100	0.32	0.25	0.25	0.71
B17	100	0.23	0.59	0.25	0.74
B18	100	0.54	0.45	0.23	0.69
Test scale				**0.21**	**0.71**

Results were based solely on the reliability coefficient and no items were omitted to maximise reliability of the coefficient alphas. Results yielded Cronbach's alphas of 0.68 to 0.74 on individual items and 0.72 on the total questionnaire scores. These findings meet

the standard 0.70 to 0.80 for reliability (Nunnally, 1978), suggesting a positive relationship exists between variables of the total item scores. **Table 4.5** displays these results.

Based on an observed difference in the construct variables of total item scores, the item scores were then tested to determine whether they were significant or not. Collapsing of the categories was done to facilitate the presentation of the data, where 1 and 2 = *disagree* and 3, 4 and 5 = *agree*. The proportion test was employed to proportionate the data by construct variables (transparency for decision-making and care continuity, protection of human rights and dignity and sustained patient and family orientation).

The proportion test was employed to measure the proportions of members with the characteristic in two samples (agree and disagree) from the population to gauge whether the proportions that existed were significant. The test employed the two proportions Z-test to determine whether the hypothesised difference between population proportions differs from the observed difference. The mean, standard error and 95% CI was calculated from the pooled data and the Chi-square test was used to assess the probability associated with the z-score. Testing was done on the 0.05 (p=0.05) level of significance. An overview of this process is provided in **Tables 4.6 to 4.8**,

Table 4.6 Summary statistical tests for transparency of decision-making and care continuity items by socio-demographic characteristics

Category	Sub-category	Agree			Disagree			p-value
		M	SE	95% CI	M	SE	95% CI	
Age of family member	18 to 30 years	0.66	0.05	0.57-0.75	0.34	0.05	0.25-0.43	0.000*
	31 to 42 years	0.18	0.04	0.11-0.10	0.18	0.04	0.10-0.26	1.000
	43 to 48 years	0.22	0.04	0.14-0.30	0.12	0.03	0.06-0.18	0.598
	>49 years	0.01	0.01	0.01-0.03	-	-	-	0.316
Gender	Male	0.64	0.05	0.54-0.73	0.36	0.05	0.26-0.45	0.001*
	Female	0.36	0.05	0.26-0.45	0.57	0.05	0.47-0.66	0.047*
Relationship to patient	Parent	0.53	0.05	0.43-0.62	0.47	0.05	0.37-0.56	0.396
	Child	0.62	0.05	0.52-0.71	0.38	0.05	0.28-0.47	0.000*
	Sibling	0.57	0.05	0.47-0.67	0.43	0.05	0.33-0.52	0.047*
	Spouse	0.61	0.05	0.51-0.70	0.39	0.05	0.29-0.48	0.001*
	Other	0.60	0.05	0.50-0.69	0.40	0.05	0.30-0.49	0.005*
Reason for admission	Medical	0.36	0.05	0.26-0.45	0.64	0.05	0.54-0.73	0.001*
	Surgical	0.58	0.05	0.48-0.67	0.42	0.05	0.48-0.67	0.024*
	Emergency	0.52	0.05	0.42-0.61	0.04	0.09	0.00-0.07	0.000*

Key: *=statistical significance

Of the socio-demographic parameters tested in this study by two (agree and disagree) categories in the construct of **transparency in decision-making and care continuity** (items 1 to 8), **10 parameters were statistically ($p<0.05$) significant**. **Four** related to **family members relationship to the patient, three** related to the **reason for ICU admission, two** related to **gender and one** related to the **age of the family member.**

Of the four statistically ($p<0.05$) significant parameters related to **family members relationship to patient,** these were a **child, sibling, spouse and other, implying that they were more likely to be in agreement with the items in this domain. Similarly,** of the three statistically ($p<0.05$) significant parameters related to the **patient's reason for ICU admission** these were **medical, surgical and emergency,** implying that the family members were more likely to be **in agreement with the items in this domain**. The two statistically ($p<0.05$) significant parameters related to **gender** were **males and females,** implying that they were more likely to be in **agreement with the items in this domain.** The one statistically ($p<0.05$) significant parameter related to the **age of family member** was between **18 to 30 years,** implying they were more likely to be in **agreement with the items in this domain**. **Table 4.6** displays these results.

Table 4.7 Summary statistical tests for protection of human rights and dignity by socio-demographic characteristics

Category	Sub-category	Agree			Disagree			p-value
		M	SE	95% CI	M	SE	95% CI	
Age of family member	18 to 30 years	0.52	0.05	0.42-0.62	0.48	0.05	0.38-0.58	0.572
	31 to 42 years	0.58	0.05	0.32-0.52	0.42	0.05	0.32-0.52	0.024*
	43 to 48 years	0.45	0.05	0.35-0.55	0.54	0.05	0.44-0.64	0.203
	>49 years	0.78	0.04	0.69-0.86	0.22	0.05	0.14-0.30	0.000*
Gender	Male	0.57	0.05	0.47-0.66	0.43	0.05	0.33-0.53	0.048*
	Female	0.61	0.48	0.51-0.70	0.39	0.05	0.29-0.48	0.002*
Relationship to patient	Parent	0.67	0.05	0.57-0.76	0.33	0.05	0.24-0.42	0.000*
	Child	0.50	0.05	0.40-0.59	0.50	0.05	0.40-0.59	1.000
	Sibling	0.62	0.04	0.52-0.71	0.38	0.05	0.28-0.47	0.000*
	Spouse	0.70	0.04	0.61-0.78	0.30	0.05	0.21-0.38	0.000*
	Other	0.53	0.05	0.43-0.63	0.47	0.05	0.37-0.56	0.361
Reason for admission	Medical	0.58	0.05	0.48-0.67	0.42	0.05	0.32-051	0.024*
	Surgical	0.68	0.05	0.59-0.77	0.32	0.05	0.23-0.41	0.000*
	Emergency	0.60	0.05	0.50-0.69	0.40	0.05	0.30-0.49	0.005*

Key: *=statistical significance

Of the 15 socio-demographic parameters that were tested in this study by two (agree and disagree) categories in the construct of **protection of human rights and dignity** (items 10, 11, 12, 13, 14, 16 and 17), 10 parameters were statistically ($p<0.05$) significant. **Three** related to the **family members relationship to the patient**, **three** related to the **reason for ICU admission**, **two** related to **gender** and **two** related to the **age of the family member**.

Of the three statistically ($p<0.05$) significant parameters related to **family members relationship to patient** these were a **parent, sibling and spouse, implying they were more likely to be in agreement with the items in this domain. Similarly,** of the three statistically ($p<0.05$) significant parameters related to the **patient's reason for ICU admission,** these were **medical, surgical and emergency,** implying that the family members were more likely to be **in agreement with the items in this domain**. The two statistically ($p<0.05$) significant parameters related to **gender** were **males and females,** implying they were more likely to be in **agreement with the items in this domain.** The two statistically ($p<0.05$) significant parameters related to the **age of family member** were between **31 to 42** and **more than 49 years** respectively**,** implying they were more likely to be in **agreement with the items in this domain**. Table 4.7 displays these results.

Table 4.8 Summary statistical tests for sustained patient and family orientation by socio-demographic characteristics

Category	Subcategory	Agree			Disagree			p-value
		M	SE	95% CI	M	SE	95% CI	
Age of family member	18 to 30 years	0.57	0.05	0.47-0.67	0.43	0.05	0.33-0.53	0.047
	31 to 42 years	0.39	0.05	0.51-0.71	0.61	0.05	0.51-0.71	0.019
	43 to 48 years	0.36	0.05	0.54-0.73	0.64	0.05	0.54-0.73	0.001*
	>49 years	0.65	0.05	0.56-0.74	0.35	0.05	0.26-0.44	0.000*
Gender	Male	0.46	0.05	0.36-0.55	0.54	0.05	0.44-0.64	0.257
	Female	0.50	0.05	0.40-0.59	0.49	0.05	0.39-0.58	0.887
Relationship to patient	Parent	0.53	0.05	0.43-0.63	0.47	0.05	0.37-0.57	0.396
	Child	0.60	0.05	0.50-0.69	0.40	0.05	0.30-0.49	0.005*
	Sibling	0.33	0.05	0.24-0.42	0.67	0.05	0.58-0.76	0.000*
	Spouse	0.52	0.05	0.42-0.61	0.48	0.05	0.38-0.58	0.572
	Other	0.47	0.05	0.37-0.57	0.53	0.05	0.43-0.63	0.396
Reason for admission	Medical	0.52	0.05	0.42-0.62	0.48	0.05	0.38-0.57	0.517
	Surgical	0.47	0.05	0.38-0.56	0.52	0.05	0.42-0.62	0.479
	Emergency	0.47	0.05	0.37-0.56	0.53	0.05	0.43-0.63	0.396

Key: *=statistical significance

Of the 15 socio-demographic parameters that were tested in this study by two (agree and disagree) categories in the construct of the sustained patient and family orientation (items 15 and 18), **four parameters were statistically ($p<0.05$) significant**. **Two** related to the **age of family member** and **two** related to **family member relationship to the patient.** Of the two statistically ($p<0.05$) significant parameters related to the **age of family member** these were between the ages of **31 to 43** and **more than 49 years** respectively, implying that these family members were more likely to be in **agreement with the items in this**

domain. Similarly, of the two statistically ($p<0.05$) significant parameters related to **family member relationship with patient,** these were **child and sibling** respectively, implying that these family members were more likely to be in **agreement with the items in this domain**. **Table 4.8** displays these results.

4.4 DISCUSSION OF MAIN FINDINGS

The purpose of this study was to describe family members', of critically ill patients, perceptions of psychosocial support received in one adult ICU in a public hospital. The intention of the study was to make recommendations for clinical practice and education of Intensive Care nurses.

The *first objective* of the study was to describe the family members of critically ill patients perception of psychosocial support received in Intensive Care Units. Included were protection of human rights and dignity, transparency for decision making and care continuity and sustained patient family orientation.

The distribution of the sample revealed females accounted for 72% (n=72) and males 28% (n=28). A close majority (45%) of the family members were between ages of 18 to 30 years, 31 (n=31: 31%) and 24 (n = 24: 24%) were in the 31 to 42 and 43 to 49 age categories. Regarding relationships to the patient, a majority (>85%) of the family members were related to the patient as an adult child, sibling, spouse and significant other or parent. The main reason for admission was related to elective surgical procedures for most of the patients, followed by 31 (n = 31: 31%) and 19 (n = 19: 19%) patient cases as an emergency or medical condition. On average, more than three quarters (79%: n = 79) of the patients were admitted to the ICU for between 2 to 7 days. The distribution of the sample is similar to previously published studies by Hariharan *et al.* (2015), Hinkle and Fitzpatrick (2011) and Hoghaug *et al.* (2012).

In this study, the next part of the questionnaire related to family members of patients, perceptions of psychosocial support received. Also, this section was divided into three parts, namely transparency in decision-making and continuity of care, protection of human rights and dignity, and sustained patient-family orientation.

Transparency for decision making and care continuity

Regarding **transparency in decision making and continuity of care**, the findings in this study revealed the majority 83% (M = 4.57, SD = 0.98) of family members of patients were most often/always in agreement with Item B3 that states, "*The diagnosis is informed to the family,"* which is higher than the mean of 3.89 and 3.59 reported in the studies of Hinkle and Fitzpatrick (2011) and Maxwell *et al.* (2007). Seventy percent (M = 4.04, SD = 1.28) of family members in this current study were in most often/always in agreement with item B2 that states, "*Specific time is allocated to the family by one of the healthcare team to answer questions,*" which is higher than the means of 3.80 and 3.81 reported in the studies of Maxwell *et al.* (2007) and Hinkle and Fitzpatrick (2011). Sixty-four percent (M = 3. 97, SD = 1.31) were most often/always in agreement with item B6 that states, "*The patient/family is clearly informed about the benefits of the treatment programme,"* which is similar to the mean of 3.90 reported in the Maxwell *et al.* (2007) study, but slightly higher than the mean of 3.81 reported in the study of Hinkle and Fitzpatrick (2011).

Conversely, results in this study revealed 41% (M = 3.09, SD = 1.58) of family members of patients were never/rarely in agreement with item B5, which states "*The family were unsure to where they could lodge a complaint or present their grievances."* These results are comparable with similar studies conducted in the USA, where one study (Maxwell et al., 2007) indicated a mean score of 3.16 among their family members, and another (Hinkle & Fitzpatrick, 2011) reported a mean score of 2.56.

In this current study, 42% (M = 3.04, SD = 1.51) were never/rarely in agreement with item B8, which states, "*The patient is assured that his/her family is just outside the ICU and available on call."* These results are lower than the mean score of 3.17 indicated in the study of Maxwell *et al.* (2007). Twenty-five percent (M = 3.51, SD = 1.35) of family members in this current study were never/rarely in agreement with item B7, which states, "*The patient's feeling, agitation and anxiety are not handled effectively by the ICU team*." These findings are comparable with one South African study, in which Rodrigues (2010) reported that 22% of family members of patients were less than satisfied with this aspect of care; other studies conducted overseas have reported similar results (Heyland & Tranmer, 2001; Stricker, Niemann, Bugnon, Wurz *et al.* (2007).

Protection of human rights and dignity

With respect to **protection of human rights and dignity**, findings in this study revealed a majority of 97% (M = 4.87, SD = 0.53) of family members of critically ill patients were most often/always in agreement with item B10, which states, "*A curtain is drawn around the patient during examination, procedure and treatment.*" Ninety-seven percent (M = 4.84, SD = 0.71) were most often/always in agreement with item B14, which states, "*A curtain is drawn around the patient while taking care of his/her toilet and bowel needs.*" Ninety-two percent (M = 4.76, SD = 0.73) were most often/always in agreement with item B16, which states, *"A curtain is drawn around the patient while he/she is sponged.*" These findings are consistent with similar studies conducted overseas by Gaeeni *et al.* (2015), and Jacelon and Henneman (2014).

In this study, 88% percent (M = 4.53, SD = 1.04) were most often/always in agreement with item B12, which states, "*The family is kept informed about the progress or decline of the patients' health status*." These findings are higher than the mean score of 3.85 reported in the studies of Maxwell *et al.* (2007), and Hinkle and Fitzpatrick (2011) respectively, and mean score of 2.83 indicated in the study of Bailey *et al.* (2010). Eighty-four percent (M = 4.46, SD = 1.14) of family members in this study, were most often/always in agreement with item B11, which states, "*There is a provision in the hospital to take care of the spiritual needs of the patient/family.*" These findings are higher than the mean score of 2.72 and 1.83 reported in the study of Hinkle and Fitzpatrick (2011) and Bailey *et al.* (2010) respectively.

Conversely, findings in this study revealed a majority of 67% (M = 2.34, SD = 1.64) of family members of critically ill patients were never/rarely in agreement with item B13, which states, "*There is an exit meeting before the patient is discharged, where the patient and family is informed about post-discharge care such as diet, exercise, alarm signals.*" These findings are lower than the mean of 3.60 reported in the study of Maxwell *et al.* (2007), but similar to the mean score of 2.32 indicated in Bailey *et al.* (2010).

In this current study, 44% (M = 2.86, SD = 1.64) of family members were never/rarely in agreement with item B17, which states, "*The family is uncertain as to where the patient is*

taken for specific tests." These results are slightly lower than the mean scores of 3.93 and 3.17 reported in the studies of Maxwell *et al.* (2007) and Bailey *et al*. (2010) respectively.

Sustained patient family orientation

Related to **sustained patient-family orientation**, findings in this study revealed the majority (82%) (M = 4.48, SD = 1.12) of family members of critically ill patients were most often/always in agreement with item B18, which states, "*The doctor or the nurse briefs the family about the condition of the patient on a day-to-day basis."* These findings are higher than the mean scores of 3.93 and 3.02 reported in the American studies of Hinkle and Fitzpatrick (2011) and Bailey *et al.* (2010) respectively. Fifty-five percent (M = 3.65, SD = 1.49) of the family members in this current study were mostly often/always in agreement with item B15, which states, "*The patient is kept informed about the day, date and time (day and night)."*

The *second objective* of the study was to compare the family members', of critically ill patients, demographic variables with their perceptions of psychosocial support received in Intensive Care Units.

In this study, transparency of decision-making and continuity of care were examined by agreement and disagreement scores to find out if family members', of patients, socio-demographic variables had any significant impact. Results showed significant differences in **age** categories **between 18 to 30 years, gender, relationship to patients** in the categories of **child, sibling, spouse, significant other and parent**, and **reason for admission**, implying there was likely to be **agreement with items** in this domain. Results showed significant differences in **females** and **medical reason for admission,** implying that they were more likely to be in **disagreement with items** in this domain.

Similarly, protection of human rights and dignity were examined by agreement and disagreement scores to find out if family members', of critically ill patients, socio-demographic variables had any significant impact. Results showed significant differences in **age of family member, gender, relationship to patient and reason for admission**, implying they were more likely to be in **agreement with items** in this domain.

In this study, sustained patient-family orientation was examined by agreement and disagreement scores to find out if family members', of critically ill patients, socio-demographic variables had any significant impact. Results showed significant differences in the **age category of >49 years** and **adult child relationship to patient**, implying they were more likely to be in **agreement with items** in this domain. Results showed significant differences in the age categories between **43 to 48 years** and **sibling relationship to patient** implying they were more likely to be **disagreement with items** in this domain.

4.5 SUMMARY

This chapter described the descriptive and comparative statistics that were used to illustrate and analyse the data collected, and the data and interpretation of the findings were presented. The following chapter will discuss the limitations of the study, summary of research findings, conclusions and recommendations for further research.

CHAPTER FIVE

SUMMARY OF STUDY, MAIN RESULTS, RECOMMENDATIONS AND CONCLUSIONS

5.1 INTRODUCTION

The final chapter of the research report presents a summary of the study, main findings and conclusions from the main findings. This will be followed by a discussion of the limitations of the study and recommendations for clinical research, nursing education and for further research in this area.

5.2 SUMMARY OF THE STUDY

5.2.1 Purpose of the Study

The purpose of the study was to describe family members', of critically ill patients, perceptions of psychosocial support received in the Intensive Care Unit of a public hospital. It was also the intention of the study to make recommendations for clinical practice and education of Intensive Care nurses.

5.2.2 Objectives

The objectives of the study were to:

- Describe the family members', of critically ill patients, perceptions of psychosocial support received in the Intensive Care Unit.
- Compare the family members', of critically ill patients, demographic variables with their perceptions of psychosocial support received in Intensive Care Units.

5.2.3 Methodology

The research design used in the study was a non-experimental, descriptive and quantitative survey designed towards understanding the family members', of critically ill patients, perceptions of psychosocial support received in the Intensive Care Unit. Two family

members of a patient who had been admitted to the ICU for more than 48 hours were included in the study. Family members whose relatives had died were excluded, as it could be too sensitive to them. First-time visitors were also excluded, as they may not have interacted with the nurses. A sample of 100 (n=100) participants participated in the study. Data was collected over a period of two months from September to November 2016.

A questionnaire was used for data collection. The questionnaire developed by Hariharan *et al* (2015) as identified in the literature, was used to collect data. The self-administered questionnaire contained two sections. The first section (Section A) was the demographic data of the family member and patient. Second section (Section B) included a set of instructions and 18 questions followed by a Likert scale table to rate the responses, where 1 = never, 2 = rarely = 3 = sometimes, 4 = most often and 5 = always, against 18 items. Permission to use the instrument was granted (**Appendix G)** and the instrument was validated.

Data was analysed using descriptive and comparative statistics. Statistical assistance was sort from a statistician when analysing the data for statistical analysis. A pre-testing procedure was conducted with five respondents. The results of the pilot test were not included in the major study. No major changes were made to the instrument used for data collection after the pre-testing procedure.

5.3 SUMMARY OF THE MAIN RESEARCH FINDINGS

The demographic data showed the majority of the family respondents were female (72%) with 28% being male; 55% were between the ages of 31 to 48 years, compared to 45% in the 18 to 30 year age categories; 26% were related to the patient as an adult child, followed by slightly lower 23%, 21% and 15% in the categories of a sibling, spouse or significant other and parent, respectively; 50% of patients were admitted for elective surgery and 70% were admitted to the ICU for between 2 to 7 days, followed by 14% and 3% in the categories of 8 to 14 and 15 to 21 days, respectively.

Section B of the questionnaire related to family members of critically ill patients perceptions of psychosocial care received in the ICU. This section was also divided into

three parts namely transparency in decision making and care continuity, protection of human rights and dignity and sustained patient family orientation.

Regarding **transparency in decision-making and continuity of care**, the findings of this study showed that family members', of critically ill patients, perception indicated a significant positive perception towards psychosocial support received in Intensive Care Units. This was evident by their >60% frequency score, significantly agreeing to the three priority items as follows: item B3 states that, "The diagnosis is always informed to the family," item B2 states that, "Specific time is allocated to the family by one of the healthcare team to answer questions," item B6 asserts that, "The family is clearly informed about the benefits of the treatment programme." This is in agreement with study by Gentry, McArthur, Millegan, Morris-White, Scott and Williams (2013) showed that family members placed need for information above other needs.

Conversely, there was a significant family member's disagreement or rejection to items B5, B8 and B7. Item B5 states that, "Family were unsure where they can lodge a complaint or present their grievances," item B8 states that, "The patient is assured that the family is just outside the ICU and available on call," item B7 asserts that, "The patient's feelings, agitation and anxiety are handled effectively by the ICU team."

Regarding **protection of human rights and dignity**, the findings of the study showed that family members', of critically ill patients, perception indicated a significantly positive perception of psychosocial support received in Intensive Care Units. This was evident by their >90% frequency score, significantly agreeing to three priority items: item B10 states that, "A curtain is drawn around the patient during examination, procedure and treatment," item B14 states that, "A curtain is drawn when taking care of toilet and bowel needs," item B16 states that, "A curtain is drawn when the patient is being sponged. >75% frequency score, significantly agreeing to two priority items: item B11 states that, "There is provision in the hospital to take care of the spiritual needs of the patient/family," item B12 asserts that, "The family is kept informed about the progress or decline of the patient's health status."

There was a significant family member's disagreement or rejection to items B13 and B17. Item B13 states that, "An exit meeting before the patient was discharged, where the patient

or family is informed about post-discharge care such as diet, exercise and alarm signals," item B17 states that, "The family is uncertain where the patient is taken for specific tests."

Regarding **sustained patient-family orientation,** the findings in this study showed that family members of critically ill patients indicated a positive perception towards psychosocial care received in the ICUs. This was evident by their >80% frequency score, significantly agreeing to one priority item: item B18 states that, "The doctor or the nurse briefs the family about the condition of the patient on a day-to-day basis." This was also in agreement with a study by Gentry, McArthur, Millegan, Morris-White, Scott and Williams (2013) which states family members placed need for information about the welfare of their relative as important. There was disagreement with item B9 and B15; item B9 states "patients' family is informed about tests and procedures only after they were done" and B15 states "the patient is kept informed about the changes in day and time (time and say)

In this study, transparency for decision-making and continuity of care were examined by agreement and disagreement scores to find out if family members', of critically ill patients, socio-demographic variables had any significant impact on results indicated in significant differences in **females** and **medical reason for admission,** implying they were more likely to be in **disagreement with items** in this domain. Similarly, sustained patient-family orientation were examined by agreement and disagreement scores to find out if family members', of critically ill patients, socio-demographic variables had any significant impact on results illustrated in significant differences in the age categories between **43 to 48 years** and **sibling relationship to patient,** implying they were more likely to be **disagreement with items** in this domain.

5.4 LIMITATIONS OF THE STUDY

Limitations are shortcomings or conditions that cannot be controlled by the researcher that place restrictions on methodology or conclusions. They are weaknesses identified in the study (Brink et al., 2012; Polit & Beck 2012).

Limitations identified in this study included:

- Use of quantitative instead of a qualitative research methodology. Qualitative data would have allowed the participants to answer in a free form and non-structured

manner and also allow the researcher to observe non-communicative behaviours of the participants. However the use of quantitative was time saving as most respondents took less than 10 minutes to complete the questionnaire

- Use of a smaller sample size-This was limiting in the sense that the research was done on only 100 (n=100) participants hence the results cannot be generalised to the whole population. The facts that the study was on only one setting make it impossible for the results to be transferable to other settings.

- The study was done using one Intensive Care in one institution ,this was limiting because the results cannot be generalised to other institutions .It will be important to repeat the study in other settings in order to challenge or support the findings

5.5 RECOMMENDATIONS

The focus on family-centred care and evidence-based practice on family needs have been highlighted in this study. The ICU nurses' focus should be more on the inclusion of family member's needs, rather than just on the patient alone, to achieve an optimal outcome. The following recommendations have been made for nursing education, nursing research and nursing practice.

5.5.1 Recommendations for Clinical Nursing Practice

The results of the study showed that the family members of ICU patients agreed with practices in the Intensive Care Unit. There was a high degree of agreement with the items that formed protection of human rights and dignity and a significant disagreement with the items which from transparency for decision making and continuity of care as well as sustained patient and family orientation. Nurses should therefore thrive to strengthen the informational relationship between themselves and family members of ICU patients. Involve family members more in decision making for their sick relative as well as familiarise themselves with the needs of family members and the implications of meeting or not meeting such needs. Psychosocial support should be provided to the family members to help them cope with the discomfort and distress associated with the admission of a sick family member to the ICU.

Nurses in the ICU are urged to conduct a family needs assessment. Needs assessment should include all aspects of psychosocial support being; protection of human rights and dignity; transparency in decision making and continuity of care and sustained patient-family orientation. Needs assessment should be done during planning and be continuous as the needs may change along the way. The nurse should include the family members in all aspects of care. Nurses should embark on continuous in-service training and updates on the current issues about family-centred care as this will help them to be informed on new development hence improve patient and family support.

5.5.2 Recommendations for Nursing Education

Family-centred care should be incorporated into the nursing curriculum for critical care nurses, to facilitate and reinforce the importance of including families in the care of the patient as well as understanding their needs. Intensive Care nurses are urged to embark on research to keep updated on new information about family-centred care, which can be achieved by using information and technology facilities. Current and relevant reading materials should be available for a nurse to read about family needs in the Intensive Care.

5.5.3 Recommendations for Nursing Research

The results of the study showed that nursing practice should be driven by the need to meet the needs of patients and their families. A further exploratory study is recommended to explore concepts related to evidence-based practices on the needs of family members. There is need to continue nursing research in this field especially in the African context. Research in a different hospital should be done in order to compare the findings.

5.6 CONCLUSION

The researcher conducted the study with the aim of describing the family members', of critically ill patients, perception of psychosocial support received in the Intensive Care Unit at a tertiary hospital in Johannesburg, South Africa. The results revealed a significant positive perception toward psychosocial care received in Intensive Care Units, with some inconsistencies noted on the frequencies with which psychosocial care was provided. There was a significant disagreement to three priority items in the domain of transparency in

decision-making and continuity of care (items B5, B8 and B7). Female family members or patients admitted for medical reasons were more likely to be in disagreement of items in this domain ($p<0.05$). Similarly, there was a significant disagreement to two priority items in the protection of human rights and dignity domain (items B11 and B12).

Family members in the age category between 43 and 48 years or a sibling relationship to the patient were more likely to be in disagreement of items in this domain ($p<0.05$). The results of this study indicated similarities to previous studies, which indicated that family members received psychosocial care and support in Intensive Care Units, however, most studies were conducted in well-developed countries. There is little evidence in the African context therefore, it is important for such studies to be carried out in African countries including South Africa and the researchers' home country of Botswana, as the difference in culture may yield different results.

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APPENDIX A

DATA COLLECTION INSTRUMENT

SECTION A

Demographic data

(Information provided here in any form will be kept confidential and used purely for the purpose of research)

1. Research Code_____

3. Relationship to patient (Please the appropriate box)

Mother	
Father	
Son	
Daughter	
Husband	
Wife	
Sister	
Brother	
Other (specify)	

4 Age of family member

18-24years	
25-30years	
30-36years	
37-42years	
43-48years	
49years+	

5. Gender of family member (Please tick the appropriate box)

Male	
Female	

6. Reason for admission to ICU (Please tick the appropriate box)

Surgical	
Medical	
emergency	

7. Duration of patient's stay in ICU_____

SECTION B

INSTRUCTIONS

There is an attempt to observe and identify the practices in ICU.The rating scale relates to the specific practices adopted in the ICU of the hospital your relative or loved one is admitted. Listed below are few statements. The statements refer to you as patient and/or patients' family. Kindly read them carefully and respond appropriately by giving information regarding the ICU practices. You need to read each statement and select by encircling/ticking a response from five options mentioned in columns.

1=Never 2= Rarely, 3=Sometimes,
4=Most often 5=Always

1. The family is informed in advance about the expenditure of the procedures.	1	2	3	4	5
2. Specific time is allocated to the family by one of the healthcare team to answer questions and concerns.	1	2	3	4	5
3. The diagnosis is informed to the family.	1	2	3	4	5
4. The doctor's experience and expertise in handling particular kind of cases is notified.	1	2	3	4	5
5. The family members are unsure as to where they can lodge a complaint or represent their grievances.	1	2	3	4	5
6. The patient/family is clearly informed about the benefits of the treatment programme.	1	2	3	4	5
7. The patients' feelings, agitation and anxiety are handled effectively by the ICU team.	1	2	3	4	5
8. The patient is assured that his/her family is just outside the ICU and available on call.	1	2	3	4	5
9. Patients/family are informed about tests and procedure only	1	2	3	4	5

after they are done.					
10. A curtain is drawn around the patient during examinations, procedures and treatment.	1	2	3	4	5
11. There is provision in the hospital to take care of spiritual needs of the patient/family.	1	2	3	4	5
12. The family is kept informed about the progress or decline of the patients' health status.	1	2	3	4	5
13. There is an exit meeting before the patient is discharged, where the patient or family is informed about post-discharge care such as diet, exercise, alarm signals, etc.	1	2	3	4	5
14. A curtain is drawn around the patient while taking care of his/her toilet and bowel needs.	1	2	3	4	5
15. The patient is kept informed about changes in the day, date and time (day and night).	1	2	3	4	5
16. Privacy is provided for the patient while he/she is sponged.	1	2	3	4	5
17. The family is uncertain as to where the patient is taken for specific tests.	1	2	3	4	5
18. The doctor or the nurse briefs the family about the condition of the patient on a day-to-day basis.	1	2	3	4	5

Adapted, with permission, from the ICU-PC Scale (Hariharan et al. 2015)

THANK YOU FOR YOUR COOPERATION

APPENDIX B

RESPONDENTS 'INFORMATION LETTER

Dear Sir/Madam

My name is Tlamelo Direng and I am a student at the University of the Witwatersrand, pursuing a Master's degree in Intensive Care nursing. I am conducting a research project as a requirement to complete my degree. The title of my research project is:

FAMILY MEMBERS' OF INTENSIVE CARE UNIT PATIENTS PERCEPTIONS OF PSYCHOSOCIAL SUPPORT RECEIVED IN A TERTIARY HOSPITAL IN JOHANNESBURG.

The objective of my study is to describe the family members', of Intensive Care patients, perceptions of psychosocial support received during admission of their relatives in ICU

I hereby invite you to participate in a study that seeks to describe the psychosocial support needs of family members of ICU patients offered by nurses. I would like you to complete a checklist. It is required that you rate all the items independently using a five-point Likert scale. The items are part of psychosocial support practices in the ICU.

Your participation in the study is voluntary, and you are assured your identity will not be compromised in any way. You can withdraw from the study at any time, if you so wish, and no penalties will be implemented. I assure you that all the information and your opinions are highly confidential. If you agree to participate, you will be required to complete a consent form and return it to me in the addressed envelope provided. The questionnaire will take ten to fifteen minutes to complete.

I would also like to inform you that there are no benefits from participating in the study. However, I hope the results will help in describing psychosocial support needs offered in ICU and therefore improve or reinforce the support that is provided to patients and their relatives.

Should you require any information or clarification on the study, or your rights as a participant, feel free to contact me on telephone number 0785678677 or email me at the following address: tdireng@yahoo.com

Thank you in advance

Yours sincerely

Tlamelo Direng
MSc Nursing Student

APPENDIX C

FAMILY MEMBERS' OF INTENSIVE CARE UNIT PATIENTS PERCEPTIONS OF PSYCHOSOCIAL SUPPORT RECEIVED IN A TERTIARY HOSPITAL IN JOHANNESBURG.

RESPONDENT CONSENT FORM

I_____, do hereby give consent to participate in the research study.

I have read and understood the contents of the information sheet, and I voluntarily give consent to be part of the study.

Signed_____ Date_____

Witness_____

APPENDIX D

R14/49 Ms Tlamelo Direng

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M160552

NAME: (Principal Investigator)	Ms Tlamelo Direng
DEPARTMENT:	Nursing Education Charlotte Maxeke Johannesburg Academic Hospital
PROJECT TITLE:	Family Members of Intensive Care Unit Patients' Perception of Comfort and Support Needs Offered by Nurses in a Tertiary Hospital in Johannesburg
DATE CONSIDERED:	27/05/2016
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr Shelley Schmollgruber
APPROVED BY:	Professor P. Cleaton-Jones, Chairperson, HREC (Medical)
DATE OF APPROVAL:	29/06/2016

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 in Room 10004, 10th floor, Senate House/2nd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/We fully understand the 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**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially review in May and will therefore be due in the month of May each year.

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX E

Hospital Permission Letter

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

CHARLOTTE MAXEKE JOHANNESBURG ACADEMIC HOSPITAL

Enquiries:
Ms. G. Ngwenya
Office of the Nursing Director
Tell: (011): 488-4558
Fax: (011): 488-3786
05 September 2016

Ms. Tlamelo Direng
Department of Nursing Education
Faculty of Health Sciences
University of Witwatersrand

Dear. Tlamelo Direng

RE: **"Family Members of Intensive Care Unit Patients' Perception of Comfort and Support Needs Offered by Nurses in a Tertiary Hospital in Johannesburg"**

Permission is granted for you to conduct the above recruitment activities as described in your request provided:

1. Charlotte Maxeke Johannesburg Academic hospital will not in anyway incur or inherit costs as a result of the said study.
2. Your study shall not disrupt services at the study sites.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study.
5.

Please liaise with the Head of Department and Unit Manager or Sister in Charge to agree on the dates and time that would suit all parties.

Kindly forward this office with the results of your study on completion of the research.

Supported / ~~not supported~~

Ms. M.M Pule
Nursing Director
Date: 2016/09/05

Approved / not approved

Ms. G. Bogoshi
Chief Executive Officer
09.09.2016

APPENDIX F

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

12 June 2017
Person No: 1250634
TAA

Mrs TL Direng
P.o Box 835
Mogoditshane
Botswana
Botswana

Dear Mrs Direng

Master of Science in Nursing: Change of title of research

I am pleased to inform you that the following change in the title of your Research Report for the degree of **Master of Science in Nursing** has been approved:

From:	**Family members of ICU patients' perceptions of comfort and support care offered by nurses in a Tertiary Hospital in Johannesburg**
To:	**Family members of Intensive Care Unit patients' perceptions of psychosocial support received in a Tertiary Hospital in Johannesburg**

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX G

Permission to use Instrument

Dr Suvashisa Rana <suvemail@gmail.com>
To
Tlamelo Direng
Mar 20 at 11:13 AM
Dear Direng,

The authors appreciate your interest in the Intensive Care Unit-Psychosocial Care (**ICU-PC**) Scale, and I am pleased to grant you permission to use the **ICU-PC Scale** in your research. This permission to use the **ICU-PC Scale** does not extend beyond you and your immediate research team. That is, others who desire to use the scale must request permission for themselves. Nevertheless, you are directed to cite the details about the scale in your report under Reference Section.

The authors would appreciate if you would send any published article of yours using **ICU-PC Scale.**
With best wishes,
Rana

Dr Suvashisa Rana, Assistant Professor
Centre for Health Psychology
University of Hyderabad
Central University Campus PO
Gachibowli, Hyderabad - 500 046, India

N.B. The information in this e-mail is strictly confidential and is exclusively for the recipient. Access to this e-mail by anyone else is unauthorised. Copying, further forwarding, or distribution beyond the original recipient without written permission shall be treated as unlawful.

On Fri, Mar 18, 2016 at 2:16 AM, Tlamelo Direng <tdireng@yahoo.com> wrote:

From -Tlamelo Direng
Subject: permission to use tool
To Dr S.Rana
Centre for Psychology, University of Hyderabad, India

Dear Dr Rana
I would like your permission to use your tool, Intensive Care Unit-Psychosocial Care (ICU-PC) scale as i conduct my research which is titled "FAMILY MEMBERS OF ICU PATIENTS PERCEPTION OF EMOTIONAL SUPPORT FROM NURSES DURING ADMISSION OF THEIR LOVED ONES IN ICU"The purpose of my study is to describe the support that family members receive from nurses during admission of their relatives in a tertiary hospital in Johannesburg, South Africa. I would also like to know if am allowed to make some adjustments on the tool to fit my study
I am a registered nurse currently pursuing my Master's degree in nursing specialising in intensive care nursing at the University of the Witwatersrand in Johannesburg South Africa.

Thank you
Sincerely
Tlamelo Direng
tdireng@yahoo.com

APPENDIX H

Gill Smithies

Proofreading & Language Editing Services

59, Lewis Drive, Amanzimtoti, 4126, Kwazulu Natal

Cell: 071 352 5410 Email: moramist@vodamail.co.za

Work Certificate

To	Dr Shelley Schmollgruber
Address	Wits Dept of Nursing Education
Date	4/08/2017
Subject	Thesis: FAMILY MEMBERS', OF INTENSIVE CARE UNIT PATIENTS, PERCEPTION OF PSYCHOSOCIAL SUPPORT RECEIVED IN A TERTIARY HOSPITAL IN JOHANNESBURG by Tlamelo Lebitsang Direng
Ref	SS/GS/19

I, Gill Smithies, certify that I have proofed the following thesis, Forward, Chapters 1 to 5, Appendices and References: *Family Members' of Intensive Care Patients Perceptions of Psychosocial Support received in a Tertiary Hospital in Johannesburg*, by Tlamelo Lebitsang Direng, to the standard as required by Wits Dept. of Nursing Education.

Gill Smithies
04/08/2107