

CHAPTER ONE

OVERVIEW OF THE STUDY

1.1 INTRODUCTION

As social beings humans cherish relationships with family and friends. The quality of relationships influences the quality of lives. From the moment a family member or friend's wellbeing is threatened the possibility of loss makes the future suddenly become uncertain. The role of professional healthcare workers is to care for these patients holistically which includes caring for their families.

Most studies done in this regard have assessed whether families' needs have been met in the ICU. The measurement of family satisfaction with the care received is however still required, as meeting needs does not always give the assurance that families are indeed satisfied with the care process. Insight into the opinions of family members regarding the care received is a priority in improving family-centred care for the benefit of family members and patient outcomes.

1.2 BACKGROUND TO THE STUDY

The concept of family needs was first identified by Molter (1979). This gave rise to the development of the Critical Care Family Needs Inventory (CCFNI) (Leske [1986] cited in Maxwell, Stuenkel & Saylor, 2007). The CCFNI comprises a list of 45 needs statements

that are categorized according to five dimensions; support, comfort, proximity, information, and assurance.

Numerous studies conducted worldwide have used the CCFNI to identify and rank in order of importance the needs of families (Kosco & Warren, 2000; Azoulay, Pochard, Chevret, Lemaire, Mokhtari, Le Gall, Dhainaut & Schlemmer, 2001; Azoulay, Pochard, Chevret, Arich, Brivet, Brun, Charles, Desmetree, Dubois, Galliot, Garrouste-Oregas, Goldgran-Toledano, Herbecq, Joly, Jourdain, Kaidomar, Lepape, Letellier, Marie, Page, Parrot, Rodie-Talbere, Sermet, Tenallion, Thuong, Tulasne, Le Gall & Schlemmer, 2003; Takman & Severinsson, 2005; Verhaeghe, DeFloor, Van Zuuren, Duijnste & Grypdonck, 2005). Only one study (Burr, 1998) confirmed the degree of confirmation of the CCFNI using semi-structured interviews on a sample of 105 families. Although many similarities were found, this study also revealed some differences that were not reflected in the CCFNI, namely the need of family members to give reassurance and support to the patient, as well as their need to protect the patient and others (Burr, 1998).

Despite the widespread use of the CCFNI, a more recent study (Verhaeghe, et al., 2005) using a systematic review, found that caregivers not only underrate family member needs, but also do not sufficiently undertake to meet these needs. Studies have shown that the priority needs most frequently not met appear to be assurance (Molter, 1979; Leske, 1986; Warren, 1993; Kosco & Warren, 2000; Maxwell, Stuenkel & Saylor, 2007) and information (Auerbach, Kiesler, Wartella, Rausch, Ward & Ivatury, 2005; Verhaeghe, et al., 2005; Soderstrom, Saveman & Benzein 2006). If families do not understand the information received further interaction with nurses may be compromised (Soderstrom, et al., 2006).

More recent, studies have focused on exploring family needs using a qualitative approach (Hupcey, 1999; Holden, Harrison & Johnson, 2002; Williams, 2005; Soderstrom, et al., 2006; Stayt, 2007). Collectively, these studies have introduced new findings, such as the importance of family in providing support to patients, the role of family in contributing to patient care and the nurse's role in supporting families, which are not incorporated in the CCFNI or the Needs Met Inventory. Moreover, these studies have highlighted discrepancies in the rank order of importance of the five main categories in comparison with those initially proposed by Molter (1979) and subsequent studies.

Van Horn & Kautz (2007) quote Chesla, Fisher, Skaff, et al. (2003) and Condon & McCarthy (2006) in stating that the inadequate functioning of the family during the illness experience can lead to poor outcomes which can negatively affect the patient. According to Azoulay et al. (2001) it is the responsibility of healthcare professionals to meet family needs. Kosco & Warren (2000) have also reported that nurses are in close proximity to patients and therefore more accessible and likely to address families' needs as they arise.

As stated by Heyland (2001) cited in Heyland & Tranmer (2001) "needs assessments are not synonymous with satisfaction because unmet needs do not always translate into dissatisfaction and meeting needs does not guarantee satisfaction". Therefore it is important to measure family satisfaction to improve the quality of care in ICU (Wall, Engelberg, Downey, Heyland & Randall Curtis, 2007).

In the ICU environment patients are often unable to speak for themselves and cannot make decisions as they may be mechanically ventilated, sedated or confused. Decision- making

therefore becomes a difficult task for the family who act as “surrogate decision makers” (Wall, et al., 2007) placing an additional burden and stress on the family.

A study using the Family Satisfaction with care in the Intensive Care Unit (FS-ICU) 24 questionnaire revealed that there was an increased level of satisfaction with care and information/decision-making as compared with satisfaction with emotional support, co-ordination of care and communication. Overall satisfaction with care was reportedly moderately higher than satisfaction with information and decision-making (Stricker, Kimberger, Schmidlin, Zwahlen, Mohr & Rothen, 2009). Several researchers have also found that it is necessary to enhance end-of-life care specifically with regards to communication and decision- making (Kryworuchko & Heyland, 2009).

An earlier Canadian study conducted using the Family Needs instrument to measure the ability to meet family needs in the ICU concluded that consistent communication by the same healthcare worker was significant when assessing the ICUs capability of meeting families’ needs (Johnson, Wilson, Cavanaugh, Bryden, Gudmundson & Moodley, 1998) and may have been a valuable assessment instrument which led to the development of the Family Satisfaction questionnaire by Heyland.

A Canadian multicentre study stated that families recognize that patients who experience withdrawal of life support die in a more comfortable manner (Rocker, Heyland, Cook, Dodek & Kustogiannis, 2004). Withholding or withdrawing therapies that sustain life may affect family satisfaction. This is a complicated and involved process that is dependent on the many diverse features of patients and families. Studies have shown that there is an increased level of family satisfaction if treatment is stuttered or slowly withdrawn.

Furthermore if the patient is intubated, extubating the patient prior to death is promoted if the situation allows.

It has been found that decreased family satisfaction occurs if a patient stays in ICU for an extended period and eventually dies. A Family could perceive this as prolonging life needlessly by artificial means (Gerstel, Engelberg, Koepsell & Randall Curtis, 2008).

Many studies have been conducted centred around dying in ICU and the end- of- life care. Interestingly a recent family satisfaction study conducted in the USA revealed that when a patient died in ICU the families' satisfaction with the care received was superior to that of families of patients who lived (Wall, et al., 2007). This emphasizes the need to direct attention to all families equally, regardless of the severity of the condition of the patient.

One of the latest Canadian studies suggests that in order to improve the quality of care as perceived by the family, the satisfaction of families with the approach that was used to provide care needs to be assessed (Kryworuchko, et al., 2009).

The Institute of Medicine of the USA describes that a high standard of care is characterized by an emphasis on safety, efficiency and the fair treatment of the patient who is given top priority. Thus patient-centred care includes the family in care (Wall, et al., 2007).

The majority of these studies have been conducted under first world conditions. There is a paucity of studies in the South African context. Provision of family support remains a vital process in helping families cope and come to terms with this experience. It has been suggested that nurses are ideally positioned to provide family support more than any other

healthcare professionals. However, the ability of nurses to meet families' needs may be inconsistent and families' needs are therefore often unmet and this may lead to feelings of dissatisfaction.

1.3 PROBLEM STATEMENT

The needs and expectations of families are often unmet in the intensive care units. If these needs remain unmet this may have a negative impact on the patients' recovery and the families' ongoing ability to cope with the ensuing crises (Holden, et al., 2002; Fox-Wasylyshyn, El Masri & Williamson, 2005; Stricker, Niemann, Bugnon, Wurz, Rohrer & Rothen, 2007)).

To better understand this impact, family satisfaction studies have been conducted in countries such as Canada, USA and Europe (Heyland & Tranmer, 2001; Wall, et al., 2007; Stricker, et al., 2007). There has been extensive research on family needs, in South Africa however, limited family satisfaction studies have been conducted. South Africa is unique given the racial, cultural, ethnic and linguistic differences generated by its history and politics. This renders research from other countries less appropriate and highlights the necessity for family satisfaction studies to be conducted within a South African context. Family satisfaction studies will pave the way for identification of the specific problems faced by the families of ICU patients in South Africa. Furthermore it will create a platform for the implementation of strategies aimed at enhancing family centred nursing care which in turn could improve the clinical outcomes of patients.

1.4 PURPOSE OF THE STUDY

The purpose of this study is to describe family members' opinions regarding the quality of care and decision- making within a tertiary public sector academic hospital in Johannesburg, South Africa. The continued assessment and measurement of the opinions, perceptions and experiences of care and decision- making of families may contribute to the achievement of improved quality and absolute care for patients and their families in South Africa.

1.5 RESEARCH OBJECTIVES

- To describe families' satisfaction with care provided in the intensive care units.
- To describe families satisfaction with decision making in the intensive care units.

1.6 SIGNIFICANCE OF THE STUDY

As far as has been established no family satisfaction studies have been conducted in South Africa. The literature reviewed has highlighted that families' needs are not adequately being met and families' satisfaction with care received is superior to their satisfaction with decision-making (Stricker, et al., 2009). This identifies a gap that exists with regard to meeting the families' need for information and communication. This study will contribute to a more extensive study as it includes families of patients who have died in ICU. Results of this study can be used to identify problems experienced and those perceived by family

members. The results can further be used to implement strategies and programmes to educate and train healthcare teams on family nursing in guiding clinical practice. The data collected in this study can be used to improve the process of quality care delivery and informed decision-making in the ICU. Improving the quality of care delivered may improve patient safety, recovery rates and ultimately achieve the enhancement of family satisfaction.

1.7 PARADIGMATIC PERSPECTIVES

A paradigm is how one views naturally occurring events and its assumptions related to the events (Polit & Beck, 2008).

1.7.1 Meta-theoretical assumptions

According to Polit & Beck (2008), Meta theory is the analysis of theory that is used as the point of departure of a study, while an assumption is a principle that is recognized as being true and logical but has not been proven. This study draws from the general systems theory which is based on the holistic health model. The general systems theory was first introduced in 1928 by biologist Ludwig von Bertalanffy (Schmollgruber & Bruce, 2002)

Man- Within this general systems approach the patient and the family form an integrated whole, an open system (each part of the system interacts with each other) which is dependent on each other to maintain a balance. The patient and the family have psychological, social, emotional and physical needs. To ensure that a balance is maintained

needs are firstly identified and ideally met. Meeting needs enhances patient recovery and outcomes which in turn ensures the overall wellbeing of the family. Unmet needs negatively affect the patient and the family causing further disequilibrium.

Health- is the physical, psychological and psychosocial state of wellbeing. On admission to ICU the initial emphasis is on the physical wellbeing of the patient due to their life threatening critical illness.

Nursing- Within this general systems approach the patient and the family in synchrony is the focus of goal-directed nursing care. The nurse is required to continuously assess the patient and carry out appropriate interventions, to provide humane, holistic and quality services to promote and restore health.

Environment- includes the internal environment (mind, body and spirit) and the external environment (ICU, healthcare workers and waiting room) Free-flowing input in this open system is received from both the internal and external environment continuously. Any changes to either the internal or external environment positively or negatively affect the entire family system.

1.7.2 Theoretical assumptions

A theory is an explanation of a phenomenon and its relationship between variables that are related to the phenomenon (de Vos, Strydom, Fouche & Delpont, 2005).

This study is based on the family systems theory (McClowry, 1992) and the crisis theory (Haber, 1982)

The theoretical assumptions that follow are applicable to this study:

- The admission of a critically ill patient to an intensive care unit is a crisis for the patient and family disrupting the family's normal day-day functioning thereby creating disequilibrium.
- Each family system is diverse with unique psychological, psychosocial, emotional and physical needs which arise from this crisis.
- Holistic nursing care for the patient includes care of the family. The assessment and timely identification of needs of both the patient and family is significant in helping the family cope and come to terms with the illness.
- Meeting family needs is associated with increased family satisfaction
- Involving the family in patient care, the provision of honest daily information and communication about the patient's condition may improve patient recovery and outcomes
- A nurse-family relationship should be built on mutual respect, honesty and integrity

The core theoretical statement of this study is that the patient cannot be nursed monastically, the family forms an integral part of holistic nursing care. Needs arise from the crisis and if met family satisfaction increases thereby involving the family in care and decision- making which in turn enhances patient recovery and outcomes.

1.7.2.1 Operational definitions

Intensive care unit (ICU):

This is a specifically designated area in the hospital, with specialised equipment and skilled personnel, for the care of critically ill patients requiring immediate and continuous attention (Urden, Stacy & Lough, 2006). For the purpose of this study three intensive care units at a tertiary public sector hospital have been taken into account.

Critically ill patient:

Characterised by the presence of actual or potential life-threatening health problems, which includes the requirement for continuous observation and interventions in an intensive care unit to restore health where possible (Urden, et al., 2006). For the purpose of this study, a critically ill patient's health problems will encompass medical, surgical, elective and emergency diagnostic categories.

Intensive care nurse:

A person who has undergone, nursing education and training and is registered with the South African Nursing Council (SANC, 2005). Intensive care or critical care nurses are nurses who have undergone additional training to deal with actual and potential life-threatening conditions in an intensive care setting (Alspach, 2006).

Family:

A spouse or partner, parent, adult child (older than 18 years), or identified significant other who waits in the critical care waiting room (Mendonca & Warren, 1998). For the purpose

of this study a family member is anyone who states that he / she is a family member or significant other and who visits the critically ill patient regularly in the intensive care unit.

Family satisfaction:

Family satisfaction can be defined as fulfilling the needs and expectations of family members whilst their loved ones are admitted into ICU due to a critical illness (Fox-Wasylyshyn, et al., 2005). In this study a family participant's perception of satisfaction with the overall care provided to the patient and family will be measured using the FS-ICU (24) questionnaire.

Decision-making:

Medical decisions pertaining to the patient are made on a daily basis, by the healthcare team providing families with information allows the family to be included in decision-making (Stricker, et al., 2007). Decisions by the family who act as surrogate decision-makers on the withdrawal of life support or withholding treatment are dependent on the provision of information and good communication between the healthcare team and the family (Truog, Campbell, Randall Curtis, Haas, Luce, Rubenfeld, Rushton & Kaufman, 2008). In this study family participants act as surrogate decision-makers. Family participants' perception of feeling included and supported in decision making and their perception of information provided to them and the way it has been communicated will be measured using the FS- ICU (24) questionnaire.

1.7.3 Methodological assumptions

Research is a systematized investigation using a methodologically controlled approach to seek explanations to problematic questions: nursing research informs the nursing profession on pertinent nursing issues which is fundamental to nursing practice (Polit & Beck, 2008).

The holistic health model with its roots in the general systems approach, as applied to this quantitative study of family satisfaction within the intensive care context has been accepted. This research study has been undertaken to generate knowledge with the intention of improving clinical practice to benefit the care of families in the intensive care unit. Acknowledgement has been made of the researcher's objective role, without deviating from the plan, of reporting truthfully and without interference in the scientific process of data collection.

1.8 OVERVIEW OF RESEARCH METHODOLOGY

1.8.1 Research design

A quantitative descriptive research design has been used. According to Polit & Beck (2008) quantitative research is a systematic and controlled scientific method of collecting and analysing numerical information. The aim of descriptive research is to observe, describe, and document characteristic features of a situation that occurs naturally. The

purpose of using this descriptive approach has been to describe families' perception of care and decision making in the intensive care unit.

1.8.2 Population

The target population consisted of family members of critically ill adult patients who were admitted to the multidisciplinary, trauma and cardiothoracic intensive care units at a level 1 academic tertiary hospital in Gauteng. A preliminary audit undertaken in March 2010 indicated that 404 patients which is an average per month over a 3 month period were admitted to these ICUs during the period 1 January 2009-31 March 2009.

1.8.3 Sample and sampling

After consultation with a statistician a sample size was determined. Probability simple random sampling was used based on the inclusion criteria to reach the desired sample size of 100 (n=100).

1.8.4 Data collection

Data collection is the formulation of a plan on how information will be gathered. In a quantitative study an instrument is the tool used to collect data (Polit & Beck, 2008). Data collection was commenced following permission from the institution where the study took place. The family satisfaction with care in the intensive care unit FS-ICU (24) questionnaire was used to collect data by means of structured interviews. A statistician

from the Medical Research Council was consulted before data collection and thereafter to collaborate and assist with statistical analysis.

1.8.5 The instrument

In 2003 a 34 item family satisfaction questionnaire was developed and designed in Canada. This questionnaire is a modified version of the patients “Judgements of hospital” questionnaire. This is a well tested, valid and reliable instrument, developed originally in the early 1980s (Heyland & Tranmer, 2001). Based on extensive testing the 34 item questionnaire was reduced to 24 items. The FS-ICU (24) questionnaire examines all areas of families needs in ICU with the goal of improving care in the ICU. The items for this questionnaire were created from previous studies of patient satisfaction, end-of-life care, studies on family needs and literature on satisfaction with decision-making (Heyland & Tranmer, 2001). The shortened FS-ICU (24) measures two main concepts- satisfaction with care and satisfaction with decision-making. Each item uses a 5-point Likert scale (excellent, very good, good, fair, and poor), each item providing the option “not applicable”. In adherence to ethical considerations the ethics committee requested the Likert scale to be changed from a 5-point to a 4-point scale (excellent, good, poor and N/A). This was done because of the subtle differences in the grading which participants would not possibly understand in this particular setting.

1.9 VALIDITY AND RELIABILITY OF THE STUDY

The procedures and study design as stipulated in the protocol were adhered to. The researcher followed guidelines as set out by the author this was verified by every tenth sample that was checked by the same ICU nursing expert for consistency thereby ensuring reliability. A statistician from the Medical Research Council assisted and collaborated with the researcher before data collection, during data analysis and with the interpretation of the data. The researcher collected all data without assistance.

1.10 ETHICAL CONSIDERATIONS

The protocol was submitted for peer review to the Department of Nursing Education to assess the feasibility of the study. Permission to conduct the study was obtained from the University of the Witwatersrand Committee for Research on Human Subjects (Medical) (Protocol number M10421). And the Faculty of Health Sciences' Postgraduate Committee (Appendix A) Permission was granted from the Chief Executive Officer of the participating institution. Permission for the use of the Family Satisfaction with Care in the Intensive Care Unit FS-ICU (24) questionnaire was received from Heyland. (Appendix G)

Participants who met the inclusion criteria were invited to participate in the study. Written informed consent was obtained from each of them. They were assured of confidentiality and anonymity by the use of code names during data collection and reporting. The participants were reassured that participation in the study was voluntary, withdrawal from the study at any time acceptable without penalty, and they would not be harmed in any way

and privacy during the interview was ensured. The participants were given time after the interview to ask questions.

Debriefing or bereavement counselling was offered by an experienced counsellor on site if participants appeared to be distressed or if additional support was necessary.

1.11 SUMMARY

This chapter has presented an outline of the study. The problem statements, purpose of the study, research objectives and the significance of the study have been described. The paradigmatic perspectives have been discussed and the operational terms defined. A brief overview has been given of the research methodology, validity and reliability of the study and the ethical procedures adhered to.

The following chapters will include a review of the literature, the methodology, data analysis, the description and interpretation of research findings. The final chapter will present limitations of the study, as well as a summary of the research findings, conclusions and recommendations for future research.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

The measurement of family satisfaction with care in intensive care units is necessary, as meeting needs does not necessarily give the assurance that families are indeed satisfied with the process of care delivery. Insight into the opinions of family members regarding the care received and the process of decision-making is a priority in improving family-centred care for the benefit of family members and patient outcomes. Limited family satisfaction studies have been conducted and the majority of studies have focused on the identification of family needs in the ICU. This literature review discusses family needs and family satisfaction including the early work of Molter (1979) and Warren (1993) both of whom made a valuable contribution to later studies.

2.2 THE EFFECT OF CRITICAL ILLNESS ON THE PATIENT AND THE FAMILY

Critical illness associated with admission into an intensive care unit indicates a threat to patient's life. Admission into ICU is an unforeseen crisis allowing no time for the patient or the family to prepare for this stressful and anxiety-filled event in their lives (Leske, 1986; Halm, 1990; Wilkinson, 1995).

2.2.1 The critically ill patient

Critically-ill patients are characterized by the presence of actual or potential life-threatening health problems, which include the requirement for continuous observation and interventions in an intensive care unit to restore health where possible (Urden, et al., 2006). These life-sustaining interventions include mechanical ventilation to maintain breathing, highly technical equipment to monitor the patient's condition and numerous infusion pumps to administer the necessary fluids and drugs to the patient (Williams, 2005). ICU syndrome may develop as a result of the many physical, psychological and environmental stressors that the patient is exposed to. The physical, psychological and environmental stressors that the patient is exposed to in the ICU include but are not limited to, medication and immobility, psychological stressors, pre-existing anxiety and the psychological distress of the critical illness itself. Environmental stressors include alterations in sensory input because of the high noise levels from monitors and alarms and bright lights (Wesson, 1997). Dyer (1995) describes the ICU syndrome as a harrowing ordeal for the patient who experiences agitation, disorientation and symptoms of depression during critical illness in the stressful ICU environment.

Hatchett, Langley & Schollgruber (2010) conducted a prospective, quantitative, cross-sectional, descriptive design to investigate the psychological sequelae following ICU admission at a level 1 academic South African hospital, specifically determining the extent of anxiety symptoms, depressive symptoms and post-traumatic stress symptoms experienced by patients after discharge. Findings concluded that the psychological afflictions caused from an ICU admission have long term negative consequences after discharge from ICU, with the possibility of poor physical recuperation and poor

functioning within the family and the community. The emotional stressors on the patient due to critical illness and the effects of the subsequent admission to ICU can be described as an event which leaves the patient emotionally scarred for life. This will in turn have an impact on the quality of life of the patient and family.

2.2.2 The family in crisis due to stress

The family can be defined as a spouse, parent, child, or identified significant other who waits in the critical care waiting room (Mendonca, et al., 1998). In this study the family is anyone who states that he/she is a family member or significant other and who visits the critically ill patient regularly in the ICU. The traditional extended family pattern is being replaced by the nuclear family, however there are variations in the nuclear family such as single parents/persons, couples that are not married and cohabit, and reconstituted families with children from previous relationships who live together (Robb, 1998). This indicates that family is not limited to blood relatives and therefore any person who is important to the patient may be described as family.

Family members are intricate subsystems that form part of the family system (Halm, Titler, Kleiber, Johnson & Montgomery, 1993). The admission of one family member is a crisis affecting the lives of all family members (Leon & Knapp, 2008). This crisis disrupts the family system's state of equilibrium, the mobilization of family coping mechanisms, and recognition of resources available is what is required for the restoration of the equilibrium within the family system (Halm, 1990). This disequilibrium forces families to make use of previously used coping mechanisms and support systems that have proved to be effective (Leon, et al., 2008).

Kosco & Warren (2000) describe Abraham Maslow's Hierarchy of Needs which implies that every person wants to achieve his or her full potential. The comprehensive growth required to achieve full potential is conditional upon the satisfaction of basic needs or at least the belief that such needs are satisfied. This developed into the identification of the five basic needs, from the lowest to highest level: physiologic, safety, belonging, esteem and self-actualization. These needs are generally satisfied in a hierarchical manner from lowest to highest. Physiological needs are referred to as deficiency needs. The physiological needs created by the admission of a critically ill loved one and the inherent stress associated with this event, necessitates the identification and meeting of needs to allow the family to move up to the next level, to alleviate the stress experienced by the family. Furthermore needs which remain unmet increase family stress during this time of crisis (Pryzby, 2005).

2.2.2.1 Stressors in the ICU

The family's first visit with the patient is a scary experience. To see someone you love attached to machines, monitors and equipment with sounding alarms and bleeping alerts, with tubes in their nose and mouth and intravenous drips is a terrifying moment. ICU is very different to a general ward setting which is far less intimidating. Families know that if someone is admitted into ICU it is serious. It has been identified that a family experiences the highest stress levels at the time of admission, stress levels reach a plateau by day 6 and decrease by day 28 (Halm, et al., 1993). Therefore it is imperative that at this early stage families are cared for and supported, especially preparing the family before they see the patient for the first time on what they should expect when they walk into the ICU (Hupcey, 1999).

Stressors that cause anxiety for the family include the unexpected admission and critical illness of the patient, separation from their loved one, uncertainty for the future and outcomes, impending fear of the patient experiencing continuous pain and ultimately fear of death, stressors that are all difficult realities that are part of the admission into an ICU (Halm, 1990). Other possible stress factors that families are exposed to in the ICU are too numerous to mention but a few deserve mention, namely the presence of other patients who are critically ill, who are in and out of surgery or facing death or dying, and their families who are enduring obvious emotional pain (Wesson, 1997).

2.2.2.2 Communication conflict

A Canadian study conducted using the Family Needs assessment instrument to measure the ability to meet family needs in the ICU concluded that consistent communication by the same healthcare provider was significant when assessing the ICU's capability of meeting family needs (Johnson, et al., 1998).

A study by Heyland & Tranmer (2001) suggested that the healthcare team should start communicating more with each other and this may lend itself to improvement in communication with families. Davidson, Powers, Hedayat, Tieszen, Kon, Shepard, Spuhler, Todres, Levy, Barr, Ghandi, Hirsch & Armstrong, (2007) identified that inadequate communication amongst the healthcare team causes considerable tension. These authors recommend that the healthcare team which comprises physicians, consulting physicians, nurses, physiotherapists and social workers are kept abreast with the patients' treatment goals thereby ensuring consistent flow of information between the healthcare team and families. This may minimize misunderstandings and decrease the stress

associated with communication conflict in the ICU. Conflict with communication may arise between doctors and nurses as doctors speak to families using sophisticated medical terminology which they possibly don't understand, the nurse as a result is required to explain in simple terms to ensure that the families understand the information provided to them (Kirchhoff, Song & Kehl, 2004). This concurs with a recent South African study conducted in Durban which described the experiences of nurses in providing psychosocial support to families of critically ill trauma patients in intensive care units. Findings included the difficulties encountered by nurses with regards to communication. These included the identification of obstacles with communication amongst the healthcare team specifically between doctors and nurses and obstacles with communication were also identified between doctors, nurses and families (Brysiewicz & Bhengu, 2010). Disparity may therefore exist between doctors and nurses in relation to communication with family members.

2.2.2.3 Cultural support

Davidson et al. (2007) suggest that limited trust in the healthcare system and differing cultural beliefs can also cause disparity between the family and the health care team. The Chinese population believe that negative outcomes of the patient are associated with negative thoughts, being honest with families in cultures such as Asian and Middle Eastern can cause mistrust amongst themselves. In addition to different cultural beliefs Caucasians will generally choose withdrawal of life support so as not to prolong life and African Americans will choose to continue with life support to prolong life. The healthcare team is required to have an awareness of patient and family cultural beliefs and respect family wishes, as conflict may arise from cultural differences and increase the stress experienced

by the patient and the family. Schmollgruber & Bruce (2002) suggested that critical care nurses should be more sensitive to differences in family needs as a result of their culture in order to decrease the stress linked to critical illness.

2.2.2.4 Spiritual and religious support

Maintaining the spiritual well-being of patient and family during this difficult time is vital. It is during these challenging moments that families may look for meaning behind the illness in an attempt to find answers and develop an acceptance of the situation (Urden, et al., 2006). The nurse is required to respect and acknowledge a family's diverse spiritual and religious beliefs and values (Morton & Fontaine, 2009). Training in assessment and knowledge regarding the many different spiritual and religious affiliations which families may practise and believe in would be beneficial for the family. Praying with the patient and family is to be respected and carried out (Davidson, et al., 2007). Prayer may be a powerful source of strength and comfort for the patient and family.

2.2.3 Stress response in families due to the crisis

The unplanned admission of a loved one into an intensive care unit is an event which becomes an all consuming crisis in the lives of the family affected. As stated by Gilliss (1984) families may endure increased stress as compared with the patient. Warren (1993) further explains that the patient is in a physiological crisis whilst the family is in a psychological crisis. Scullion (1994) cited in Wesson (1997) states that this crisis alters the family dynamics, because of a change in environment away from home and being forced not to be close to other family members and friends who could offer family support.

Each day is lived with endless feelings of helplessness as families watch over the patient not knowing what to do (Mendonca, et al., 1998). The uncertainty of recovery and fear of death of the loved one are overriding feelings and thoughts which all create increased anxiety and emotional unrest for the family. Their present stressful circumstance can bring back painful memories of a crisis that has been endured in their life previously (Morton, et al., 2009).

This crisis acts as a stressor which activates a stress response altering a family's normal ability to cope. Activation of the fight/flight mechanism which is controlled by the sympathetic nervous system releasing catecholamines such as nor epinephrine and epinephrine into the blood stream which once released increases the heart rate, blood pressure and causes vasoconstriction. Seyle (1956) cited in Morton et al. (2009) states that this physiological response is what constitutes the alarm stage, and the resistance stage follows and describes that in our normal day-to-day life we move between these first two stages and eventually adapt. But if no adaptation occurs it will result in the third stage, which is known as the stage of exhaustion. The nurse is required to help the family through this stress response to prevent the family from reaching this final stage of exhaustion.

2.2.4 Impact of critical illness on families

Studies have clearly shown that the admission into an ICU is a crisis for both patient and their family (Kosco, et al., 2000; Fox-Wasylyshyn, et al., 2005). During this period families must deal with a magnitude of overwhelming emotions that manifest themselves as feelings of helplessness, shock, anxiety, guilt and anger (Holden, et al., 2002; Azoulay, et al., 2003). This may in turn lead to both short-and-long term consequences for families

(Paul & Rattray, 2008). Auerbach et al., (2005) showed at the time of admission there was an increase in dissociative symptoms in family members, also linked to the incidence of Acute Stress Disorder (ASD).

Van Horn & Tesh (2000) have reported behavioural responses which included sleep and eating disturbances as well as changes in roles and responsibilities. Studies have also shown an increase in consumption of over-the counter medication, alcohol and cigarettes as documented by Halm et al. (1993) as well as social and financial difficulties with work implications (Kirchhoff, et al., 2004). Responses such as these arise from the fact that families may sleep at the hospital in order to remain as close to their loved ones as possible. Collectively these responses add unexpected burdens and place risks on the health of individual family members.

Van Horn et al. (2007) quote Chesla, Fisher, Skaff et al. (2003) and Condon & McCarthy (2006) by stating that inadequate functioning of the family during the critical illness can lead to poor outcomes for the patients. These authors have concluded that providing support to family members is essential.

According to Azoulay et al. (2001) it is the responsibility of healthcare professionals to meet family needs. In addition, Kosco, et al. (2000) have reported that since nurses are in close proximity to patients they are therefore more accessible and likely to address family needs as they arise. Admittedly, practicing nurses know only too well that this is not always an easy task, especially in situations in which the patient's instability takes precedence over family needs.

2.3 FAMILY NEEDS IN THE ICU

The concept of family needs was first identified by Molter (1979). This gave rise to the development of the CCFNI as concluded by Leske (1986) cited in Maxwell et al. (2007). The CCFNI comprises a list of 45 needs statements that are categorized according to five dimensions support, comfort, proximity, information, and assurance.

Although numerous studies worldwide have used the CCFNI to identify and rank order the needs of families (Kosco, et al., 2000; Azoulay, et al., 2001; Azoulay, et al., 2003; Takman, et al. 2005; Verhaeghe, et al., 2005). Only one study (Burr, 1998) has supported the degree of confirmation of the CCFNI using semi-structured interviews on a sample of 105 families. Although many similarities were found, this study also revealed some differences that were not reflected in the CCFNI, namely the need of the family members to give reassurance and support to the patient, as well as serve to protect others.

Despite the widespread use of the CCFNI, a more recent study by Verhaeghe et al. (2005) using a systematic review found that caregivers not only underrate family members' needs, but also did not sufficiently undertake to meet these needs. They concluded that priority needs should be the focus of the nurse's overtures towards family members.

Another study undertaken by Takman et al. (2005) compared nurses' and physicians' perceptions of families' needs. They identified differences between these two groups in how they ranked family needs based on their professional experience.

In their study Azoulay et al. (2003) reported that the majority of health care professionals supported family participation in care. However, in the opinion of families only 33.4% wanted to participate in the care. From these findings it may be concluded that 66.6% of families in the study did not wish to participate in the care of their loved ones. This finding further emphasizes the fact that the CCFNI cannot be viewed as the norm.

2.3.1 Family needs not met in the ICU

Maxwell et al., (2007) quote Warren (1993) and Watson (1998) in stating that these authors further, explored family needs by asking families for their perceptions of their needs being met once they were identified. They used the “Needs Met Inventory” (NMI) which uses the same 45 items as the CCFNI ranked on a four point Likert scale, with 1 as never met 2 as sometimes, 3 as usually met and 4 as always met. From these studies, the authors referred to suggested that assurance, support and comfort were perceived as the most important needs. The findings are consistent with Molter’s (1979) original study.

A study conducted by Mendonca et al. (1998) reported their families considered their most important need items to be assurance, proximity and information, whereas support and comfort needs were less important. These findings were confirmed in a study by Kosco et al. (2000). In the Maxwell, et al. (2007) study, family needs were prioritized as assurance, comfort, proximity and accessibility. However, these authors also identified statistically significant differences for nine items on the CCFNI and 22 items on the NMI. They concluded that family members rated items higher than did the registered nurses. The above-mentioned findings are summarized in the **table 2.1**. Based on this analysis the **priority needs not met** appear to be consistently **assurance**.

Table 2.1: Needs Met Inventory in order of priority

Studies	CCFNI Dimensions				
Molter (1979) & Leske (1986)	Support No 1	Comfort No 2	Proximity No 3	Information No 4	Assurance No 5
Warren (1993) & Watson (1998)	No 2	No 3			No 1
Warren (1998)	No 4	No 5	No 2	No 3	No 1
Kosco & Warren (2000)					
Maxwell, Stuenkel & Saylor (2007)		No 2	No 3 No 4 **		No 1

Key: Subscale No 4 **= accessibility

Recently, studies suggest the need for information as the most important family need, but families often receive information that is not easily understood and inadequate as conducted by (Auerbach, et al., 2005; Verhaeghe, et al., 2005 Soderstrom, et al., 2006). If families do not understand the information given their further interaction with nurses will be compromised (Soderstrom, et al., 2006). Very often nurses feel uncomfortable or inadequate in meeting family's need for information. In order to protect themselves from difficult questions they put up a barrier. The more technical nurses appear the fewer questions a family may ask. Nurses also fear the doctors' response to information given to families. This creates conflict amongst the healthcare team. In the Van Horn et al. (2007) study it was suggested that feeling guilty or angry arose from situations that were uncontrollable and might lead to displacement by families on healthcare professionals and ultimately dissatisfaction with the care given.

2.3.2 Experiences of families in the ICU

Numerous studies have explored families' experiences in the intensive care setting from a qualitative perspective (Hupcey, 1999; Holden, et al., 2002; Williams, 2005; Soderstrom, et al., 2006; Stayt, 2007).

More specifically Holden et al. (2002) have suggested that although nurses are ideally situated to meet family needs these needs are not consistently met. In addition Hupcey (1999) reported the perspective of nurses, families and patients in the intensive care units can either take a position of "looking out for the patient, while they look out for themselves" to one of "nurses maintaining the position of power and families remaining on guard and enduring the experience". In part this study supports the additional findings that were revealed by the Burr (1998) study.

Maxwell et al. (2007) have highlighted how important the family is in the nurse-family relationship especially when a family-patient relationship is jeopardized by the patient's physiologically critical and unstable condition. This finding is supported in earlier studies. Hupcey (1999) had earlier suggested that the traditional nurse-patient relationship had been replaced by the nurse-patient-family relationship.

Furthermore Williams (2005) emphasized how families positively assist in patient care and recovery. The findings of these authors can be grouped into three themes; "getting to know the patient through the family," "family contribution to care" and "the nurses role in supporting the family". Pryzby (2005) pointed out that families can be an important source of information to nurses in enabling them to recognize the patient as a person. These

findings are consistent with the synergy model, which states that the “shift in thinking from the traditional nurses’ role towards a patient-orientated approach encompasses patients and families’ needs and forms the central focus of nursing care” (Alspach, 2006). This concurs with the findings of studies conducted by Hupcey (1999) and Maxwell, et al. (2007).

2.4 FAMILY SATISFACTION IN THE ICU

2.4.1 Family satisfaction with care in the intensive care unit FS-ICU (24) questionnaire

In 2003 a 34 item family satisfaction questionnaire was developed and designed in Canada, a modified version of the patients’ “Judgements of hospital” questionnaire. This is a well tested, valid and reliable instrument, developed originally in the early 1980s (Heyland, et al., 2001). It examines all areas of family needs in ICU with the goal of improving care in the ICU. Items for this questionnaire were created from previous studies of patient satisfaction, end-of-life care, studies on family needs and literature on satisfaction with decision-making (Heyland, et al., 2001). The questionnaire was refined, validated and shortened to 24 items in 2006 (Heyland, 2006)

The shortened FS-ICU (24) measures two main concepts: satisfaction with care and satisfaction with decision-making. Each item uses a 5-point Likert scale (excellent, very good, good, fair, and poor), each item also provides the option “not applicable.” There is one item which uses a dichotomous scale. Findings of a study to refine, score and validate

the FS-ICU (24) questionnaire demonstrated good validity in relation to other indicators of quality in the ICU (Wall, et al., 2007).

A study using the FS-ICU (24) instrument revealed that there was an increased level of satisfaction with care (associated with a higher severity of illness) as compared to satisfaction with information and decision making (Stricker, et al., 2009). This suggests that there are deficiencies in meeting family' information needs and inadequacies exist in the process of decision-making. Researchers have found that it is necessary to enhance end-of-life care specifically in terms of communication and decision making (Kryworuchko, et al., 2009).

2.4.2 Family satisfaction with care

Heyland (2001) cited in Heyland & Tranmer (2001) states that “needs assessments are not synonymous with satisfaction because unmet needs do not always translate into dissatisfaction. Nor does meeting needs guarantee satisfaction”. It is therefore important to measure family satisfaction in order to improve the quality of care in ICU (Wall, et al., 2007).

An important finding of a Canadian study suggests that in order to improve the quality of care perceived by the family. Family satisfaction with the approach used to provide care needs to be assessed (Kryworuchko et al., 2009). Conversely Crippen (2001) reported in the 30th international educational and scientific symposium of the society of critical care medicine that satisfaction surveys cannot be used to effectively gauge standards of care, as the level of satisfaction experienced by patients does not take account of the difficulties

inherent in making medical decisions. He suggests the need for objective and subjective markers.

With this in mind how could satisfaction be measured? The difficulty is that each family has its own values, beliefs and circumstances with differing coping mechanisms. Each patient presents a different diagnosis and prognosis. All these factors play a role in how the family perceives care delivery, the meeting of their needs and finally satisfaction or dissatisfaction. Despite this the healthcare team requires indicators of satisfaction to improve on their interactions with the families and care delivery.

The primary advantage of collecting family satisfaction data is to enhance the quality of care delivered to families (Dodek, Heyland, Rocker & Cook, 2004).

Interestingly, a recent family satisfaction study revealed that if a patient died in ICU the family's satisfaction with the care received was superior to those families of patients who lived. Factors that contributed to this was that family members felt included in decision-making, received emotional support and was shown respect, compassion and their needs were taken into consideration (Wall, et al., 2007). The interpretation is that families were better cared for, and more time was spent with family members when a patient died while in ICU. This emphasises the importance of equality of attention that needs to be directed to all families even if the patients are not dying. Stricker et al. (2009) in their study concurs that there is increased satisfaction with information and decision-making when a patient died in ICU.

Most importantly the Institute of Medicine of the USA emphasises that a high standard of care is characterized by an emphasis on safety, efficiency and the fair treatment of the patient who is given top priority. Thus patient-centred care includes the family in care (Wall, et al., 2007).

2.4.3 Family satisfaction with decision-making

According to Heyland et al. (2001) there is a lack of research in the assessment of families in decision-making. This area is significant in intensive care units and requires further in-depth investigation to provide insight into improving family-centred care.

In the ICU environment patients are often unable to speak for themselves and cannot make decisions as they are often mechanically ventilated, sedated or confused. Decision -making therefore becomes a difficult task for the family who act as “surrogate decision makers” (Wall, et al., 2007) which places an additional burden and stress on the family. It is for this reason that families need to be kept informed of patient progress and treatment plan as they are the best to represent the patient. Allowing families to make decisions on behalf of the patient avoids paternalism, and promotes autonomy.

The ICU environment in itself is frightening and intimidating placing the family in a further compromised and vulnerable position. Furthermore the Bill of Rights describes the patients’ right to be well informed (South African Constitution, 1996). Families are therefore automatically involved. On humane grounds families should be incorporated into every aspect of care. Inadequate care may be derived from inadequate communication/decision-making (Heyland, et al., 2001). If effective communication is

achieved between the healthcare team and family the process of decision-making will be enhanced. Providing information to patients including their families is necessary to allow families to make well informed decisions (Leske, 1986). They therefore require and are dependent on explanations, easy to understand information that is consistent and honest (Soderstrom, et al., 2006).

Furthermore a Canadian multicentre study stated that families recognize that patients who experience withdrawal of life support die in a more comfortable manner (Rocker, et al., 2004). Withholding or withdrawing therapies that sustain life is associated with death in the ICU and this process may affect family satisfaction. This is a complicated and involved process that is dependent on the many diverse features of patients and families. Studies have shown an increase in family satisfaction with stuttering withdrawal or slowly withdrawing treatment. If the patient is intubated, extubating the patient prior to death is promoted if the situation allows. Decreased family satisfaction has been found if a patient stayed in ICU for an extended period and eventually died. Since family could perceive this as prolonging life needlessly by artificial means (Gerstel, et al., 2008). However it is often the family who requests that treatment be withdrawn. This concurs with a study conducted by Gries, Randall Curtis, Wall & Engelberg, (2008) whose findings revealed that a heightened level of satisfaction with the process of decision- making is linked to the withdrawal of life support.

2.4.4 Relationship between needs and satisfaction

The question can be raised as to whether there is a relationship between needs and satisfaction! With absolute certainty there is a relationship that exists between needs and

satisfaction. If a family feels supported and satisfied that their needs are being met their ability to cope during a crisis and ability to make decisions is increased. As a result they feel in control and develop increased acceptance of the situation. Not meeting their needs will lead to dissatisfaction. When needs are not met a family's level of anxiety, stress, depression and Post Traumatic Stress Disorder (PTSD) symptoms will increase which can affect or impair their level of judgement particularly in end-of-life decision-making (Davidson, et al., 2007). In a specific study Auerbach et al. (2005) advanced that if families were not given adequate information about the patient's condition, no reason as to why things had been done, insufficient explanations of equipment used, or accommodated in an uncomfortable waiting room feelings of dissatisfaction would come to the fore. This illustrates that a direct relationship exists between needs and satisfaction. Their study also revealed that when families were optimistic they were more satisfied with needs met, and their optimism would positively affect relationship with the healthcare workers. For this optimism to be maintained health care workers are required to have similar feelings or reciprocate optimism towards the patient and the family.

With the advancement of consumerism, and the growing awareness of service delivery, the healthcare team is required to treat each family uniquely and meet their individual needs, specific to the patient and their families (Biley, Millar & Wilson, 1993). This in accordance with Batho Pele principles relating to delivering high quality public services that are ethical, fair, transparent, respectful, accountable and specific to individual needs (Department: Public Service and Administration, 2007), and the Bill of Rights contained in the Constitution which acknowledges the rights of all people and promotes dignity, equality and freedom (South African Constitution, 1996). Families have expectations and they are aware of their rights and they will exercise these rights.

2.5 PROFESSIONAL ROLE OF NURSES

2.5.1 Care and caring

Nurses show empathy and compassion to patients and their families which is a natural response to alleviate the extent of suffering endured by the family (Leavitt, 1984). To nurse a patient holistically implies looking after the patient's family too, therefore empathy, care and compassion should be extended to the family who form part of the patient (Mendonca, et al., 1998). The patient and family share an interdependent relationship, therefore the wellbeing of the family has a direct effect on the wellbeing and recovery of the patient (Leske, 1986). It has been identified that it is the nurse's role to care for the family (Hupcey, 1999). El-Masri & Fox-Wasylyshyn (2007) concur with this and explicitly state that it is the duty of nurses to meet a family's needs. Caring for families is important as this may change the stress response to the critical illness and subsequent admission into the ICU, of their loved ones which will help to decrease the level of stress experienced by the family (Pryzby, 2005).

Families require care and support from ICU nurses, which will allow families in turn to provide care and support for the patient (Burr, 1998; Price, 2004). Providing care in any form will reduce stress for both the family and the nurse and ultimately benefit the patient (Wilkinson, 1995). Families have expectations of nurses to care and support the family and if these needs are not met it will have an effect on the families' satisfaction with care (Fox-Wasylyshn, et al., 2005).

Most nurses are capable of caring for both the patient and their families, yet some stay clear of contact with the family. Questions may arise: Is this to protect themselves from getting emotionally involved, do they not know how to care and support families or is it perceived not to be a role of the nurse to care for families? Nursing is a caring profession known for making a difference. Is it easier for nurses to make a difference to the unconscious, sedated person where there is a remote chance of getting to know the person, in comparison to making a difference to conscious, frightened families?

2.5.2 Comfort and support

A nurse provides comfort by encouraging a family's "enduring behaviours" (Morse, 1992). This means that nurses encourage family behaviour which allows them to endure the situation such as allowing the family to be with the patient and providing reassurance to the family. A nurse who provides comfort to the family also shows support towards their family aiming to decrease the burden for families. By doing this families are able to save their energy so that they can use this energy to support the patient (Vandall-Walker, Jensen & Oberle, (2007). In addition Vandall-Walker et al. (2007) describes nursing support as the provision of professional support by nurses to family members during the stressful event of a loved one whom is critically ill. Nurses demonstrate support by advocating for the family. Fulfilling the role of a patient-advocate demonstrates commitment on the part of the nurse towards the patient, family members and the nursing profession.

Nurses who were participants in the Williams (2005) study highlighted the specific support that the family might require if the patient were intubated or sedated. Under these circumstances the nurse can facilitate and support the family in their attempts to

communicate with the unresponsive patient as this can be very frustrating for the family. Furthermore the nurse can support the family by allowing and encouraging the family to touch the patient to maintain a closeness and connection with their loved one. This will ensure that families have meaningful interactions with the patient (Burr, 1998)

According to the code of ethics for nurses, the function of the nurse is to do all that is reasonably necessary to protect and promote the health, well-being and fundamental rights of the patient (Urden, et al., 2006). The American Nurses Association incorporates advocacy in their definition of nursing to safeguard and improve the health of all people, preventing physical harm, reducing pain and discomfort, treating physical ailments and injury and promoting the care of all persons.

According to Lee & Lau (2003) and Price (2004) if families are supported and cared for adequately they will in turn be able to provide social support for the patient. Wilkinson (1995) conducted a study on the perceived needs of family members and found that the families felt supported by the nursing staff when they provided “soft” talk or by meeting their physical needs, such as giving them tea or coffee.

Molter’s (1979) original research identified hope as a priority need. According to the American Association of Critical-Care Nurses, providing assurance is important for the family as it instils hope for the patient’s recovery (Morton, et al., 2009). Furthermore it reassures the family that the healthcare team is doing the best they can do for the patient given the patient’s physiological condition Assurance and support needs can be achieved by taking the time to listen to families verbalize their feelings and is not dependent on

words alone but may also be portrayed by acts of kindness such as a smile, a hug or a squeeze of the hand to say we are here for you, you are not alone, and we feel your pain.

2.5.3 Interacting with the family

Hickey & Lewandowski (1988) conducted a descriptive study assessing the role of the nurse with families. Findings revealed that the nurse's interaction and involvement with families were dependent on whether patients died or if they were close to death and how the nurses felt about the patient and family. Price (2004) identified that difficulties exist for nurses in supporting the family because it is an emotionally laborious task. Interacting with families is demanding and is dependent on the individual nurse's knowledge, skill, self-efficacy experience, values and personalities (Agard & Maindal, 2009). Time constraints have also been identified as being a limiting factor in managing family issues (Hupcey, 1999). Williams (2005) argues that nurses' communication skills may positively or negatively affect interactions between nurses and the family.

Molter (1979) found that families did not expect nurses to show concern for the family. Halm (1990) put forward that a possible explanation for differing perceptions of nurse and family on caring for the family was that no specific group of health care workers recognized caring for the family as their responsibility. Fox-Wasylyshyn et al. (2005) in their study found that the family expected the nurse to interact with the family and meet their needs. On the other hand, nurses felt that it was a un-realistic expectation for them to meet the emotional needs of families. This demonstrates that nurses and families have different perceptions. In addition it has been suggested that some nurses may not possess sufficient confidence in caring for and interacting with the family (Stayt, 2007). The more

comfortable the nurse feels in interacting with the family the better able the nurse is to fulfil her role in dealing with the family for the ultimate benefit of the patient (El-Masri, et al., 2007). Furthermore El-Masri et al. (2007) suggest that there is a deficit of education for nurses in the theory and practice of family nursing and the importance of looking after families.

The Soderstrom et al. (2006) study looked at the interactions between family members and staff in intensive care units. Their findings identified two possible types of interactions; the first was “mutual understanding” and the second “mutual misunderstanding”. The first interaction between staff and family is therefore important as it may determine future interactions, which can result in either a good understanding or communication between families and staff or it can result in poor understanding and communication. Therefore a relationship needs to develop between the patient and nurse and the family and the nurse. This relationship should be based on mutual respect and trust. The family needs to trust the nurse’s judgment and believe that the nurse is acting in the patient’s best interest. Engstrom & Soderberg (2007) suggest that nurses might struggle to develop good working relationships with families as they might be required to make difficult decisions about the patient which could affect the family and place them in conflict with the needs of families.

2.5.4 Reducing family stress and helping families cope

People in crisis are more receptive to guidance which is in agreement with Leavitt’s (1984) crisis theory, which suggests that people are more amenable to accepting help and assistance during stressful times. Allowing families to express and verbalize their feelings and fears will alleviate anxiety and help families cope and come to terms with the situation

(Halm, 1990). “Not knowing was the worst part” suggests that if families are given enough information about the patient, prognosis, condition and future treatment plans their anxiety and stress were decreased (Verhaeghe, et al., 2005).

Nurses are required to assist the family in finding ways of coping in order to maintain a balance during the crisis. Redirecting the family’s focus by setting goals and prioritizing is important. Through the identification of the immediate problem, the identification of their available support systems and options is easier (Morton, et al., 2009). These actions will allow the family to feel in control of the situation. The identification and meeting of family needs and the inclusion of families reduce the stress experienced by families (Pryzby, 2005). Family members who are satisfied with the care they receive experience less stress and are therefore able to provide better support to the patient (Fox-Wasylyshyn, et al., 2005).

2.5.5 The nurse as family

In addition to the unexpected crisis of a patient who is admitted into ICU the “Nurse family member” has other unique stressors such as their need to continuously monitor the patient, be an advocate for the patient, protect the patient and the rest of the family, be the one in control and the solicitor of information. These roles put more pressure and burden on the “Nurse family member” who remains the “in charge” nurse and who finds it difficult to separate the natural nurse role from the family role (Salmond, 2010).

2.6 THE ROLE OF THE DOCTOR

ICU is based on team work therefore multidisciplinary collaboration is essential between the key team role players who support and assist each other. The role of the doctor is therefore included in this discussion. The doctor plays a curing role incorporating the traditional medical model. This entails acquiring a medical history from the patient or the family, conducting a physical examination on the patient and carrying out diagnostic tests. The focus is on the physical and biological components of disease to diagnose and treat illness in order to cure. Whereas the nurse plays a holistic caring role which differs from the medical model in that the focus is on the physical, emotional, mental and spiritual wellbeing (Mosby's, 2009). According to Azoulay et al. (2001) a fundamental role of the doctor is to provide easily understood information that is given with compassion to enable the families to make decisions on behalf of the patients.

2.7 FAMILY-CENTRED CARE

Care which is patient-centred tends to improve the recovery prospects of the patient. This is particularly important in the context of ICU, where the decisions made and results achieved can be positively influenced by the involvement of the patient and the family thereof (Davidson, et al., 2007). Care which is family-centred is founded upon the principles, objectives and physical, emotional and psychological requirements of the patient and family, and seeks to ensure that the patient and family are well informed concerning the patient's illness, the manner in which the illness is likely to develop and the options available to treat the illness. Of further importance are the expectations of the

patient and family, the treatment which they believe will be most beneficial and the manner in which they wish decisions to be made (Truog, et al., 2008).

2.7.1 Family contribution to care

Wilkinson (1995) emphasised that family centred care and the meeting of family needs, will decrease the level of stress experienced by both the nurse and family in the very stressful ICU environment.

The involvement and presence of family at the patient's bedside positively contributes to the care, recovery and outcomes of the patient (Hupcey, 1999; Williams, 2005). Tolbert (2001) recognised that whenever family members feel cared for by the ICU staff they may in turn have the ability to improve the patient's physiological and psychological state. Improving the patient's psychological state includes providing support and reassurance for the patient (Burr, 1998; Price, 2004; Pryzby, 2005)), providing emotional support for the patient (Hupcey, 1999), and reducing the anxiety experienced by the patient (Plowright, 1996 and Price, 2004)) through the family's ability to comfort the patient (Hupcey, 1999). Family familiarity with the patient may also have a very calming effect on the patient (Robb, 1998). Conversely, family members who are overly distressed or anxious may negatively affect the patient. It is important for nurses to continuously carry out assessments of families to prevent harm or setbacks for the patient, and in turn provide extra support for these families (Kosco, et al., 2000).

A family can potentially heighten the patients desire to live (Van Horn, et al., 2007). Through the family's continued presence at the patient's bedside the patient may have a

reason to fight for survival. Burr (1998) indicated that families have a need to protect the patient as well as to protect others. This suggests that despite the family's emotional state their needs are put aside, the patient becomes their priority, in ensuring that the patient receives optimum care.

Those family members who express the desire to provide care for the patient should be allowed to do so (Azoulay, et al., 2003). Van Horn et al. (2007) propose that this active interaction between the patient and the family will encourage the integrity of the family. Pryzby (2005) concurs in suggesting a family plays an integral role in providing care for the patient. They bear witness to the patient's physiological, physical and psychological fragility when feelings of helplessness dominate (Holden, et al., 2002). Participating in care may give the family a sense of purpose in being able to help the patient and feel that their hands have contributed towards the healing and recovery of the patient.

Engstrom et al. (2007) indicate that family members can be of great assistance to nurses in facilitating in the recovery of the patient. One valuable contribution families make towards patient recovery is that they allow the nurse to identify and discover the patient as a person, which has the advantage of making care more personal and less technical (Pryzby, 2005). Williams (2005) has reiterated that the family serves as a means of obtaining information about the patient in an attempt for the nurse to cultivate the ability of the patient to communicate effectively.

This inability of patients to communicate with the ICU staff results in families assuming the responsibility of decision maker and advocate on behalf of the patient (Kirchhoff, et al., 2004). The family who act as decision maker or advocate becomes automatically more

involved in interacting and discussing patient care and treatment options with the ICU staff (Hupcey, 1999).

A prospective multicentre survey in 78 ICUs in France which included 2,754 ICU caregivers and 544 family members investigated family and staff opinions of family participation in care using the CCFNI; 88.2% of staff were of the opinion that family members should participate in care and 33.4% of the family members should participate in patient care (Azoulay, et al., 2003). This illustrates the point that although there is an increasing awareness of family participation in care it is not common practice in the ICU due to either reluctance of caregivers to encourage such involvement or family reluctance to be part of the process of care (Azoulay, et al., 2003).

2.7.2 Family visitation

Since the early work of Molter (1979) the family's need for proximity has been identified as a priority family need in numerous studies (Leske, 1986; Wilkinson, 1995; Mendonca, et al., 1998; Verhaeghe, et al., 2005). Plowright (1996) in an empirical study reviewing visiting in intensive therapy units emphasized that visiting within the ICU has always been a controversial subject, but suggests that it is crucial to meet family needs especially in relation to unrestricted visiting. The organisation was the initial beneficiary in respect of visiting in the ICU, later the patient and then the patient and family. This progression is a result of focusing nursing care on the individual, the development of consumerism with regards to health provision and family needs studies which have contributed to the existing wealth of knowledge on family-centred care (Plowright, 1996).

A common theme identified in family needs studies are that families want to be close to the patient (Mendonca, et al., 1998; Williams, 2005). With the advancement of a “family friendly” healthcare environment, the recommendation of an open visiting policy that is dependent on individual circumstances, the decision of visitation is made between the patient, family and the nurse for the benefit of the patient (Davidson, et al., 2007). This is in accordance with clinical practice guidelines for support of the family in the patient-centred intensive care unit promulgated by the: - American College of Critical Care Medicine Task Force in 2004-2005.

Vandall-Walker et al. (2007) describe restricted visiting policies as the separation between the ICU and the waiting room which was not merely physical, in that members of the patient were denied access to the patient and the healthcare team, and to information concerning the patient, to the extent that the fears of the family members were increased and trust in the healthcare team diminished. These restrictions limit access to the patient and prevent the meeting of the family need for proximity. They result in families having to wait for extended periods which is frustrating and adds to the stress experienced by family members. For a family member to be allowed to be present at the patient’s bedside means access to the patient and access to information (Vandall-Walker, et al., 2007). Van Horn et al. (2007) suggest that open visitation has advantages such as improving family participation in care as well as communication with the nurse and decreasing the number of complaints by the family. Agard et al. (2009) suggest that open visitation allows the family to visit whenever they want to on condition that it has no detrimental effects on the patient’s safety or routine and that the trusting relationship between the staff and the patient is not jeopardised.

2.7.3 Family presence during ward rounds

Having the family present during ward rounds meets the needs of families by their involvement in discussions regarding the care and treatment of the patient and further provides the family access to information, an opportunity to ask questions which may prevent misunderstandings, and it also improves communication between the family and the healthcare team (Pryzby, 2005). These findings are consistent with the clinical practice guidelines for support of the family in the patient-centred intensive care unit: American College of Critical Care Medicine Task Force 2004-2005 (Davidson, et al., 2007).

2.7.4 Family presence at resuscitation

Families are becoming more aware of their rights and are increasingly expressing their desire to witness resuscitation of their loved ones. Clinical practice guidelines for support of the family in the patient-centred intensive care unit as outlined in the American College of Critical Care Medicine Task Force 2004-2005 recommends that family presence at resuscitation should be part of a formal process and families should be supported during the resuscitation efforts (Davidson, et al., 2007). In a survey on preferences regarding family member presence during resuscitation, 75.0% of family members would want to witness resuscitation if given the option and a similar percentage of patients if given the option would want their families to witness their resuscitation (Benjamin, Holger & Carr, 2004). A large study conducted involving 984 ICU and emergency nurses revealed that a limited number of hospitals have FPR policies, but despite this fact many hospitals allowed families to be present during resuscitation (Maclean, Guzzetta, White, Fontaine, Eichhorn, Meyers & Desy, 2003).

The humane care of patients is a necessity in providing for the holistic nursing of patients and one which includes caring for the family. The family acts as surrogate decision-makers and plays a significant role in the progress of patient's recovery. Encouraging a more humane approach in the care of patients and their families will create a therapeutic environment enhancing healing and improving patient recovery and outcomes. The vast technological environment of an ICU may limit a humane and holistic environment but a holistic and humane environment can be maintained if the healthcare team work together and allow the active participation of the family in care and decision-making (Harvey, Ninos, Adler, Goodnough-Hanneman, Kaye & Nikas, 1993).

2.8 SOUTH AFRICAN RESEARCH

As far as has been established, there is insufficient literature on family satisfaction in the ICU from a South African perspective. Extensive research of this kind has been conducted in Canada, (Heyland, et al., 2001; Rocker, et al., 2003; Wall, et al., 2007; Kryworuchko, et al., 2009) Switzerland (Stricker, et al., 2009), France (Azoulay, et al., 2001) and the USA (Wall, et al., 2007; Gerstel, et al., 2008; Gries, et al., 2008).

Two family needs studies were conducted in South Africa in the same ICU setting as this study. Firstly, Schmollgruber et al., (2002) looked at the professional support needs of culturally diverse families of critically ill adult patients. This quantitative study revealed that regardless of the socio-economic and cultural differences that exist between population groups there were no statistically significant differences in the professional support needs as perceived by families. Furthermore ICU nurses were not able to identify

the expectations of families in relation to the provision of professional support from ICU nurses during the first three days post admission to the ICU.

Secondly, Gundo, Langley & Schmollgruber (2010) conducted a quantitative study in the same setting comparing nurse and family 'perceptions of family needs in the ICU. Findings from this study showed that a greater number of both nurses and families were in agreement with 42 of 45 needs statements, with high scores recorded for assurance and information. Further revealed was that higher scores were recorded by families for the assurance and proximity. Gundo et al., (2010) concluded that nurse and family perceptions of family needs were generally the same.

Ever since 1979 when Molter first identified the concept of family studies and introduced the CCFNI. Family needs studies have been conducted extensively. However, these studies have consistently identified the same un-met priority needs of families. Despite this plethora of knowledge, no new insights have been added to existing knowledge on family needs. Numerous researchers have repeatedly identified assurance and information as the most important needs of families. Yet, they are repeatedly not being met. Admittedly the first and most valuable step is to identify needs but a few steps beyond identifying needs to be taken. The next step as ICU nurses would be to meet these needs. As the literature so suggests it is the nurses' role to provide holistic nursing both to the patient and the family. Furthermore following these steps measuring how satisfied families are with how their needs are being met needs to be done.

Studies on family satisfaction in the ICU from a South African perspective would be interesting and would contribute towards the introduction of new, unknown insights into

family needs. This research aims to bridge the gap by using data collected to convert it into providing quality care, improving the process of decision-making for families and to enable ICU nurses to take the next few steps following the identification of family needs.

2.9 FUTURE DIRECTIONS FOR FAMILY CENTRED CARE

Future planning focuses and emphasises family centred care, as attested by the following:

- **Shared decision-model**

Literature suggests that families are often not given sufficient information and the necessary tools to be able to make decisions. A new shared decision-making model has therefore been introduced one which presupposes a partnership between the healthcare team, patient and family. This will allow patient preferences to be established and it will attempt to decrease family anxiety and increase family coping abilities. Their ability to make decisions will be enhanced at a time when the family is faced with the responsibility of making decisions (Davidson, et al., 2007).

- **Family advocates**

Tolbert (2001) states that family advocates have been introduced, whose focus is solely on the family at a time of crisis. This serves to support, comfort, and improve communication and the provision of information between the family and healthcare workers. Family advocates will ensure that family needs are met especially their need for honest and

consistent information as well as effective communication to assist in their decision-making ability. The advantages are that more time can be spent with families explaining the patient's condition and possible treatment options. And also engaging in discussions when necessary and answering questions. Most importantly the patient's treatment and care will not be compromised but rather enhanced. Families will feel cared for, they will find a safe place and ultimately form good relationships, improve patient outcomes, increase acceptance and coping abilities. In short, needs will be met, satisfaction will increase and complaints will decrease.

- **Critical care assistance programme (CCFAP)**

This programme was developed by the AACN together with the chest foundation, Eli Lilly and company foundation. Its aim is to ensure that family needs are met, information, sharing improved decision making bettered and ultimately satisfaction increased (Morton, et al., 2009).

Table 2.2: Summary of factors that contribute towards family satisfaction or family dissatisfaction

Factors known to contribute to family satisfaction	Factors known to contribute to dissatisfaction
Overall higher satisfaction with care	Overall lower satisfaction with information and decision-making especially with end-of-life care
	Inadequate pain management
	Inconsistent communication by different healthcare providers
	Insufficient provision of information and the way in which information is communicated
If patients died in ICU their satisfaction with care was superior	If patients survived in ICU their satisfaction with care was inferior
	Extended length of stay in hospital and eventual death
Feeling supported during decision-making	
Feeling included in decision making	
Withdrawal of life support increases comfort	
Stuttering withdrawal is associated with satisfaction, extubation before death is encouraged	
Flexible visiting policy	
	Lack of a waiting room

2.10 SUMMARY

The literature studies have shown that admission to an intensive care unit is a potential crisis situation for families. During this period families must deal with a number of overwhelming emotions, which carries the risk of both short and long term consequences for families and patient outcomes. Provision of family support is vital in helping families cope and come to terms with this experience. It has been promoted that nurses are ideally positioned to provide family support more so than any other healthcare professional.

There is a scarcity of current empirical evidence relating to the impact of critical illness on families as identified in the literature. In addition, in family needs studies there has been a shift away from the predominance of quantitative studies in earlier years to an increasing number of qualitative studies in later years. While the focus of these studies is predominantly on developed, first world countries, the need for information has nevertheless been identified as the most important family need, while the family need that is consistently not met appears to be assurance.

Earlier studies have primarily focused on quantitative approaches to rank the importance of family needs using the Critical Care Family Needs Inventory (CCFNI) (Molter, 1979). Only a few studies have addressed family needs by using the Needs Met Inventory (NMI) (Warren, 1993) to establish whether family needs are met by healthcare professionals in the intensive care units. Moreover, these latter studies highlight discrepancies in the rank order of importance of the five main categories compared to those initially proposed by Molter (1979) and subsequent studies.

Despite the extensive use of the CCFNI, a more recent study (Verhaeghe, et al., 2005) recorded that caregivers underestimate family needs and do not do enough to meet these needs. This finding was based on a review of all the CCFNI studies during the period 1979-2008. These findings suggest that families have other needs which were not incorporated or adequately addressed by the CCFNI. Research shows that due to the limitation of survey instruments the tendency is to generalize findings and exclude the subjective experiences of participants.

More recently, studies have focused on exploring family needs using a qualitative approach. Collectively, these studies introduce new findings such as the family's importance in providing support to patients, the family's role in contributing to patient care and the nurses' role in supporting the families, none of which are incorporated in the CCFNI or NMI.

Family needs and expectations are often unmet in the intensive care units and this may lead to an unsatisfactory experience for the family, limiting their ability to support their loved one. This can negatively affect patient recovery and patient outcomes. There is a direct relationship between the meeting of family needs and their level of satisfaction. In order to improve the quality of care in the ICU measuring whether families are indeed satisfied with how their needs are met in the ICU needs to be done. Conclusions can be made for the need to find tools to measure satisfaction because meeting needs does not guarantee that families are indeed satisfied with how their needs are met. A Family's overall satisfaction with care is perceived as being higher than their satisfaction with information and decision-making. The literature highlights a gap in the provision of information and communication which ironically has been shown to be the most important need.

Nurses play a significant role in identifying and meeting family needs. They are best placed to care for and support the families in coping with having a critically ill loved one in ICU thereby reducing their stress.

Patient-centred care includes family-centred care. Families can contribute positively towards the patient's care, recovery and outcomes. However despite the awareness of the benefits of family-centred care and a family's need for proximity, restricted visiting hours continue to be practised. Family presence during ward rounds and family presence at resuscitation are giant leaps forward in favour of family-centred care for the ultimate benefit of the patient.

There is a paucity of similar studies in South Africa. The identification of family needs in SA is a necessary first step, followed by an assessment of family satisfaction as to how their needs are being met. Further studies on family satisfaction in the ICU from a South African perspective would be beneficial to the advancement of family care and could bridge the gap in information, communication and decision-making in intensive care units.

The next chapter provides a detailed discussion on the research methods used in this study.

CHAPTER THREE

RESEARCH DESIGN AND RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter presents the research methodology and includes research design, the research setting, population, sample and sampling, the inclusion and exclusion criteria, data collection, a description of the instrument used in data collection including the reliability and validity of the instrument and the ethical procedures followed.

3.2 RESEARCH DESIGN

A research design is the overall plan for acquiring answers to the research questions. It addresses problems that may arise during the research process (Polit & Beck, 2008). A quantitative, descriptive research design was used to accomplish the study's objectives. This design was appropriate as it allowed data to be collected which described the opinions of families regarding care and decision-making in the intensive care units.

Quantitative research- Quantitative research is a systematic and controlled scientific method of collecting and analysing numerical information (Polit & Beck, 2008). The Family Satisfaction with care in the Intensive Care Unit FS-ICU (24) questionnaire was used to collect numeric information for analysis and interpretation.

Descriptive design – Descriptive research entails making observations, with the intention of describing, and documenting features characteristic of naturally occurring events (Polit & Beck, 2008). The purpose of using a descriptive approach was to describe family perceptions and opinions of care and decision-making in the intensive care unit.

3.3 RESEARCH SETTING

Research setting is defined as the place where the collection of data will occur (Polit & Beck, 2008). This study was conducted in three intensive care units at an academic tertiary public sector hospital. This public sector hospital accommodates approximately 1088 beds of which the ICU makes up at least 6% of the total patient admissions. From the period 01/09/2010-30/09/2010 there were approximately 120 admissions in the three ICU units. Patients who make use of this facility generally have no medical aid and make use of this public service provided by the government for their health care. In the recent years there has been an increased influx of patients from Francophone countries.

Intensive care unit (ICU) A consists of 9 rooms, with 1 bed in each room, ICU B can accommodate 4-5 adult patients and 4 paediatric patients, ICU C can accommodate 12 patients. The type of admissions into these three wards includes patients, who have been involved in motor or pedestrian vehicle accidents and victims of assault such as stab wounds or gunshot wounds, cardiothoracic surgery such as coronary artery bypass grafting (CABG) and valve replacements and post-operative complications, pneumonia and sepsis. These ICU patients are usually admitted following a sudden and most unexpected traumatic event. This often leaves the patient and the family in a sudden crisis situation.

Cardiothoracic patients generally have elective surgery and they have been prepared for some time before being admitted to the ICU. Preparation of the family and the patient for the admission is most often carried out prior to admission. Staff in these three units comprises an intensivist who manages and co-ordinates patient care. Intensivists are medical specialists who have an intensivist qualification in the speciality of intensive care medicine. Nursing staff includes a unit manager, and nurses who have general nursing qualifications of which there are those with an additional qualification in critical care and those without. Nurse-patient ratio in the ICU is one nurse to one patient, however it needs to be noted that sometimes sub-professional nurses are working in the capacity of registered nurses due to staff shortages.

The institution's visiting policy is for two hours a day from 15h00-17h00. A private, suitable interview site was selected that was close to the respective ICUs.

3.4 POPULATION

A population is the whole group of individuals who share the same characteristics (Polit & Beck, 2008). The population in this study included family members of critically ill adult patients who were admitted to intensive care units at this tertiary public sector hospital in Gauteng. A preliminary audit undertaken in March 2010 indicated that 404 patients were admitted to these ICUs during the period 1 January 2009-31 March 2009.

3.5 SAMPLE AND SAMPLING

A sample is a subset of the population that is selected for participation in a particular research study (Polit & Beck, 2008). In collaboration with a statistician a sample size of 100 (n=100) was decided upon. As stated in the preliminary audit 404 patients were admitted into these ICUs which is on average 25% of the total admissions over a 3 month period. In this study, all families of critically ill patients were included as they were representative of the population, provided they met the inclusion criteria and provided their written consent to be a participant in the study was given.

The inclusion criteria included:

- A family member or significant other of a patient who was admitted to a level 1 multidisciplinary, trauma or cardiothoracic adult ICU.
- With an admission period greater than 72 hours and less than 3 weeks at the selected study site.
- Family members were required to be 18 years or older, who were able to speak, understand and reply in English.

Family members had to have visited the ICU at least twice and had to have provided consent before the interview was conducted. Polit & Beck (2008) describe inclusion criteria as the specific characteristics which determine which people from the target population may be included as participants in a research study.

If the patient died in ICU the family was contacted 3-4 weeks after the death of their loved one. Exclusion criteria excluded family members of patients who were admitted to the selected study sites for a period less than 24 hours, as the family would not have been exposed to the ICU for a sufficient length of time to adequately answer the FS-ICU (24) questionnaire. Probability simple random sampling was utilised until the desired sample size of 100 was reached. In order to ensure, that each person had an equal opportunity of being sampled, the ICU register was used as the sample frame and every third admission (*kth*) i.e.; patients' family member was approached to participate in the study. In total 29 participants were drawn from ICU A, 31 participants were drawn from ICU B and 40 participants were drawn from ICU C.

Table 3.1: Participants sampled in the study (n=100)

Intensive Care Unit	Family participants
ICU A	29
ICU B	31
ICU C	40
Total	100

3.6 DATA COLLECTION

On receipt of approval from the participating institution, data collection commenced from the three intensive care units. Structured interviews were decided upon to be a suitable means to collect data, as it was at a time when the family found themselves in an unexpected crisis, and the questions were emotionally sensitive. A structured interview is a

more personal approach, as opposed to impersonal self-administered questionnaires. According to Polit & Beck (2008) structured interviews have a higher response rate, any misunderstandings can be explained and it also allows the researcher to obtain a more comprehensive picture through observation of the participant's verbal and non-verbal behaviour. The researcher can also probe for more information if required. This further allows the researcher to understand the extent of satisfaction or dissatisfaction of care and decision-making as families of patients who are critically ill in ICU. Data collection was conducted over a three month period from September 2010 to November 2010.

3.6.1 Instrument

The Family Satisfaction in the Intensive Care Unit (FS-ICU [24]) questionnaire was used as the data collection instrument. The instrument measured two main concepts: family satisfaction with care and satisfaction with decision-making in the ICU. The instrument required patient demographic data to elicit socio-demographic information, which was completed by means of a prospective review. Items used included age, gender, date of admission and diagnosis on admission. The instrument also included participant demographic data to elicit socio-demographic information, which was completed by means of an interview schedule. Items used included gender, age, home language, population group, and educational level, relationship to the patient, if involved as a family member of a patient in ICU before, if they lived with the patient, if they lived in the city or out of town and the distance they travelled to the hospital.

The instrument is divided into two parts: The first part assessed satisfaction with care and the second part assessed satisfaction with decision-making. Satisfaction with care consisted of 14 items namely:-

- Care of the patient – four items.
- Care of the family – four items.
- Professional care related to nurses – two items.
- Professional care related to doctors – one item.
- The ICU environment including the atmosphere of the ICU and the atmosphere of the waiting room – two items.
- The participants overall level of satisfaction – one item.

Satisfaction with decision-making consisted of ten items: According to Heyland & Tranmer (2001) “this sections questions stem from Charles et al and Tilden et al, who have used the following categories: decision-making, information exchange, deliberation and deciding about which treatment option”.

This section focused on information needs comprising six items, and the process of decision-making comprising four items. If the patient died during their ICU stay a further three questions were asked and the family member had to choose which statement best described their views. This was followed by three open-ended questions. An open-ended question allows the participants to answer in their own words and it does not restrict their responses (Polit & Beck, 2008).

The three open ended questions included:

- Suggestions on how to make care provided in the ICU better
- Comments on things that were done well and
- Comments and suggestions that may be helpful to the staff of the hospital.

Each item uses a 5-point Likert scale (excellent, very good, good, fair, and poor) and also provides the option “not applicable.” According to Polit & Beck (2008) a Likert scale consists of several declarative items that express a viewpoint on a topic. This means that a statement is given and the participant is requested to choose an item that best describes their feelings/views/opinions. Some variation is provided within the questionnaire: Item 1.14 uses a three point Likert scale, which provides the option of very dissatisfied, most satisfied and completely satisfied. Item 2.7 also uses a three point Likert scale which provides the options of feeling excluded, feeling neither included nor excluded or feeling included in the decision-making process. Similarly, item 2.8 provides the options of feeling overwhelmed, feeling neither overwhelmed nor supported or feeling supported during the decision-making process. Item 2.9 provides the options of feeling out of control, feeling neither in control nor out of control or feeling in control over the care of the patient. Additionally, item 2.10 is a dichotomous response option. Items 2.11 -2.13 asks which of the following best describes the participants views and was applicable only if the patient died whilst in ICU. Item 2.11 provides the option of: was the patient’s life prolonged unnecessarily, was the patient’s life neither prolonged nor shortened or was the patient’s life shortened unnecessarily. Item 2.12 provides the options of was the patient uncomfortable, mostly comfortable or totally uncomfortable. Item 2.13 provides the

options of feeling abandoned, feeling neither abandoned nor supported and feeling supported.

There is one item which uses a dichotomous scale. Polit & Beck (2008) describes a dichotomous question as a categorical variable that has only two values or categories from which to make a choice.

The questionnaire took 10-15 minutes to complete and was designed to be self-administered. It was administered within an admission period of greater than 72 hours and less than 3 weeks. The instrument hasn't been used in South Africa. Minor alterations were recommended by the Human Research Ethics Committee to make it more suitable and more appropriate for South Africa's unique ICU setting. This will be discussed under ethical considerations.

3.6.2 Procedure

Upon receipt of the Ethics clearance certificate from the Health Research Ethics Committee of the University of the Witwatersrand (Appendix B) approval was sought from the Chief Executive Officer of the institution and the Gauteng Department of Health (Appendix C) to commence with the research. Data were collected from the adult intensive care units over a 3 month period from September 2010 to November 2010. Family members who met the inclusion criteria of the study were contacted and met in a private designated room where the purpose of the study was explained, what the study entailed and what was required of each participant. Family members were invited to participate in the study. Families were given an information letter (Appendix D) which they read and

verbalized their understanding of the study and the information letter. Participant were assured of their absolute voluntary participation, that strict confidentiality and anonymity would be maintained and that it would be acceptable for them to withdraw from the study at anytime without penalty. They were also informed that if after the interview they felt distressed, debriefing counselling would be made available for them by an experienced counsellor. The consent form (Appendix E) was then signed. The FS-ICU (24) questionnaire was used to collect data. The structured interview took between 10-15 minutes to complete. The participant was given time afterwards to ask questions and to verbalize their feelings freely while being observed and notes were taken that were thought to be of interest or importance.

If patients had died families were contacted telephonically, the information letter was read to the family member and consent was obtained verbally. Telephonic interviews were conducted using the same FS-ICU (24) questionnaire. Telephonic interviews were conducted instead of mailing the questionnaires to families, this was done after discussion with supervisors and the HREC representative. Reasons for doing this was due to the possibility of a low response rate, no interaction with bereaved families whilst in the clinical areas, reluctance on the part of bereaved families to meet in person and the majority of bereaved families lived far from the hospital which made personal contact difficult.

3.7 VALIDITY AND RELIABILITY

The FS- ICU (24) questionnaire was the instrument used to collect data. This questionnaire was developed by Heyland & Tranmer for the Kingston General Hospital ICU research working group in Canada and validated for the purpose of measuring family satisfaction with care and decision-making in the intensive care unit. Heyland & Tranmer (2001) conducted a study to determine the feasibility of using this questionnaire on family members to assess their satisfaction with care. They concluded that the FS-ICU (24) questionnaire used to collect data from family members of critically ill patients was valid, reliable and feasible. The correlation coefficient for satisfaction with care and satisfaction with decision-making was .64 and overall the correlation coefficient with care was .85 indicating a reliable result. A multiple-centre study conducted by Rocker et al., (2004) which included six tertiary hospitals in five provinces within Canada indicated positive usage of this questionnaire in other countries (Wall, et al., 2007).

In 2006 the original 34 item questionnaire was refined, validated and shortened to 24 items (Heyland, 2006). A study conducted with a sample size of 1,038 in six university-affiliated hospitals in Canada and one university-affiliated hospital in the United States to refine, score and validate the FS-ICU (24) found that scores showed good validity in relation to other evidence of ICU quality. The internal consistency (Cronbach's alpha) ranged from 0.74-0.95. It was also concluded that the FS-ICU (24) successfully measured the two constructs of care and decision-making (Wall, et al., 2007). This instrument has been used extensively in Canada, USA and parts of Europe. The FS- ICU (24) questionnaire has been adapted to be used in various settings and has been translated into Canadian-French, German, Chinese, Portuguese, Spanish, Swedish and Hebrew (Heyland, 2006). This

demonstrated the questionnaire's adaptability and usability in other settings. The content validity of this questionnaire is based on the fact that the questions were formulated from existing literature on family satisfaction and good correlation exists between satisfaction with care and satisfaction with decision-making. (Heyland & Tranmer, 2001) Content validity is the extent to which each item of the questionnaire appropriately and sufficiently addresses the concept being measured (Polit & Beck, 2008).

To achieve rigorous and truthful research the measuring tools used are to be psychometrically sound (De Von, Block, Moyle-Wright, Ernst, Hayden, Lazzara, Savoy & Kostas-Polston, 2007). Psychometric assessment determines the quality of an instrument based on its validity and reliability (Polit & Beck, 2008). Validity is the extent to which an instrument measures what it is intended to measure (Polit & Beck, 2008). In this study validity was maintained by using a valid instrument, FS- ICU (24). This questionnaire has been used in similar family satisfaction studies in various countries and has being translated into different languages. A pilot study was conducted before the main study to test the understanding of the information letter and the questionnaire. Patients were assured that they could withdraw from the study at any time, that their participation was voluntary and that their identity would be protected at all times. During data analysis assistance was sought from an expert statistician.

Reliability is the extent of consistency or accuracy with which an instrument measures an attribute. The higher the reliability of an instrument, the lower the amount of error in obtained scores (Polit & Beck, 2008). Reliability was maintained by using the same questionnaire and the same researcher at each interview, the researcher collected all data without assistance to ensure consistency with data collection. The procedures and study

design as stipulated in the protocol were adhered to. Guidelines as set out by the author was followed and verified by every tenth sample that was checked by the same ICU nursing expert for consistency thereby ensuring reliability. The reliability of an instrument can be increased by using a group that is homogenous i.e. the family members (participants) of critically ill patients. According to Polit & Beck (2008) homogeneity refers to the ability of the instrument to consistently measure the same crucial characteristics. A statistician from the Medical Research Council assisted and collaborated with the researcher before data collection, during data analysis and with the interpretation of the data to ensure statistical accuracy.

3.8 PILOT STUDY

A pilot study was conducted before the commencement of the main study from 09 September 2010-12 September 2010 using the information letter and the adapted FS (ICU) questionnaire to test the understanding of the wording used. Participants (n=10) who met the inclusion criteria were included in the pilot study. This was 10% of the sample. Ethical considerations were followed. The results of which were not used in the main study. A pilot study is a small scale test of what has been planned. It serves to test feasibility, it determines whether the chosen methodology is adequate and appropriate, assesses the length of time it takes to complete the questionnaire and checks clarity and understanding of the language of statements used in the questionnaire (Polit & Beck, 2008).

3.9 ETHICAL CONSIDERATIONS

The protection of human rights, honesty and integrity is necessary for sound ethical research. The risk/benefit ratios for the participant have to be assessed objectively therefore permission from the necessary authorities and ethical clearance is required before the commencement of research studies. Polit & Beck (2008) according to the Belmont Report describe the three principles of beneficence, respect for human dignity and justice as essential to conducting ethically acceptable research studies. The following ethical requirements were taken into consideration:

- To obtain permission to conduct research, the research proposal and instrument were submitted to the Post Graduate Committee (Faculty of Health Sciences) of the University of the Witwatersrand. Permission was granted in writing (Appendix A).
- To ensure compliance with ethical standards, the research proposal and instrument were submitted to the Medical Human Research Ethics Committee of the University of the Witwatersrand. Approval was obtained and the committee issued a clearance certificate (Appendix B) ensuring beneficence to protect the participant from physical or psychological harm.
- Permission was granted for the accessibility to the hospital and records of patients by the Chief Executive Officer and the Deputy Director of Nursing Services of the institution.

- Permission to conduct the research was obtained from the Deputy Director of Gauteng Health Department (Appendix C)
- Each participant was given an information letter to read before considering participation in the study. This ensured justice and fair treatment of participants. (Appendix D).
- Written informed consent was obtained from the participating family members (Appendix E). The participant was assured that the use of code names would ensure confidentiality and anonymity, that their participation was voluntary and that they were able to withdraw from the study at any given point without penalty. The participants were given the assurance that in no way would they be harmed and their privacy would be strictly maintained. This ensured respect for human dignity.
- Debriefing or bereavement counselling was offered by an experienced counsellor on site if and when participants appeared to be distressed or requested additional support.
- Permission of the use of the FS- ICU (24) was obtained from the author (Appendix G)

Minor alterations to the questionnaire as recommended by the Human Research Ethics included altering the use of words such as us and we to remove all references to the

researcher as being part of hospital staff, Patient demographic data added to the questionnaire included: age, gender, date of admission and diagnosis on admission.

A question was also included to ask the participant to describe their understanding of the patients diagnosis, prognosis and if there were any complications.

Participant demographic data that was added included: home language, population group, education level, and distance to the hospital.

A question was included to ask the participant to describe the patients' diagnosis, and if there were any complications and their prognosis, in order to determine their understanding of the patients' condition. The 5-point Likert scale was collapsed to a 4-point Likert scale (1.excellent, 2.good, 3.poor and 4. N/A) preventing the potential problem of the participants becoming confused with having so many options to choose from.

3.10 SUMMARY

This chapter described the research methodology. The research design was selected to appropriately meet the study's purpose and objectives. An in-depth description is given of the instrument that was used for data collection. A pilot study was conducted at the main study site using the adapted interview schedule. The interview schedule successfully met the study's objectives. The following chapter presents data analysis and research findings.

CHAPTER FOUR

RESULTS AND DISCUSSION OF FINDINGS

4.1 INTRODUCTION

Data files were set within the computer statistical package 'STATA' version 10, data entered once and then verified during the second direct data entry. Descriptive and comparative statistics were used to achieve the study objectives. The descriptive tests (frequency, mean and standard deviation) were used to synthesize patient and family participant's socio-demographic data and interview schedule. Whereas comparative statistics were employed to describe and synthesize total questionnaire scores to compare the socio-demographic data of family participant's with obtained levels of measurements to test for statistical significance. Statistical tests included the Cronbach's reliability coefficient alpha and Fisher's exact test. Testing was done at the 0.05 level of significance ($p < 0.05$) and insured a power of at least 95 % accuracy in findings. 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 clinical data of patients: age, gender and diagnosis and family participants' socio-demographic data inclusive of gender, age, home language, population group, education level, relationship to patient, prior exposure to intensive care, their living arrangement in relation to the patient, where they live, and travelling distance to the hospital. Frequency distributions and cross tables were used to provide an overall coherent presentation and description of the data. Percentages in these findings were taken to the nearest whole number.

The Cronbach's reliability coefficient alpha was applied to assess the reliability of the summative rating scale (Likert scale) composed of total questionnaire scores for satisfaction with care and satisfaction with decision making (construct variables). When comparing item scores the Fisher's exact test was applied to test for significance of differences in the frequencies of responses for satisfaction with care and satisfaction with decision making. Testing was done on item level to further explore the data. When comparing categorical variables the response was like the latter, the Fisher's exact test was used to test for significance of differences in the frequencies of participants responses for satisfaction with care and satisfaction with decision making and selected socio-demographic (gender, age, education, previous exposure to intensive care) variables. Frequency distributions and cross tables were used to provide an overall summary of the data. Collapsing of the categories on the Likert scale was done to facilitate presentation of the data, however, it was noted that a larger percentage of participants answered strongly satisfied and moderately satisfied or poor in the itemised analysis. Measurement of central tendency and variation (mean and standard deviation) were used to summarize the data.

The level of statistical significance was set at the level of $p < 0.05$. A bio-medical statistician from the Medical Research Council (MRC) analysed the data using the statistical package 'STATA' version 10.

Because of the homogeneity of the sample the findings may be of interest to other public sector intensive care units, clinical practice and education of intensive care nurses.

4.3 RESULTS AND FINDINGS

4.3.1 Questionnaire Section 1: Patient Socio-demographic Data

This section related to the critically ill patients demographic data which comprised of four (4) items. Items included are age, gender, date of admission and diagnosis on admission, which were obtained by the researcher through prospective record review. Results of this process are summarized in **table 4.1** for the total sample (n=100). Items were combined to form coherent groups to facilitate discussion of the data.

Table 4.1 Socio-demographic data for patient participants for the total sample (n=100)

Item	Demographic data	Frequency	Percent
1.1	Age in years		
	< 20	6	6.0%
	20 – 39	36	36.0%
	40 – 59	32	32.0%
	60 – 79	19	19.0%
	> 79 years	7	7.0%
1.2	Gender		
	Male	53	53.0%
	female	47	47.0%
1.3	Date of admission	-	-
1.4	Diagnosis on admission		
	Medical	35	35.0%
	Surgical	65	65.0%
	- emergency surgery	35	35.0%
	- elective surgery	30	30.0%

Males accounted for 53.0% (n=53) and females 47.0% (n=47) of the total patient sample (n=100). The majority (68.0%; n=68) was between the ages of 20 to 59 years, and 26.0% (n=26) were in the 60 to 79 age categories. It can be extrapolated from these findings that male patients predominate in the total sample (n=100). However, between ages categories indicated opposite higher and lower frequencies in the 20 to 59 and 60 to 79 age categories, implying that in terms of age distributions this is a young patient population. In this study, gender distribution trends are consistent with similar studies conducted overseas (Europe and the United States of America). Findings in this study indicate a younger age distribution than similar overseas studies, where Johnson et al. (1998) indicated majority

(57%) of their sample were between the ages of 60 to 79 years and mean age of 62.84 years was observed in the Mendonca et al. (1998) study.

The majority (65.0%; n=65) of the total sample (n=100) were surgical and 35.0% (n=35) were medical cases. For statistical purposes the surgical cases were subdivided into elective and emergency cases, as it was assumed that this difference would impact on the satisfaction with care and decision making of family members. Findings indicated emergency cases having a slightly higher (35.0%; n=35) surgical case load than a lower (30.0%; n=30) in elective surgical cases. In terms of diagnosis this study's findings are not consistent with other similar studies. In the Johnson, et al. (1998) study they indicated a 53.0% surgical and 47.0% medical case load in their sample. In this study, the higher surgical case load was not surprising as two of the intensive care units accept critically ill patients in the cardiothoracic and surgical specialities and one accepts only trauma-related injuries. Findings are displayed in **figure 4.1**.

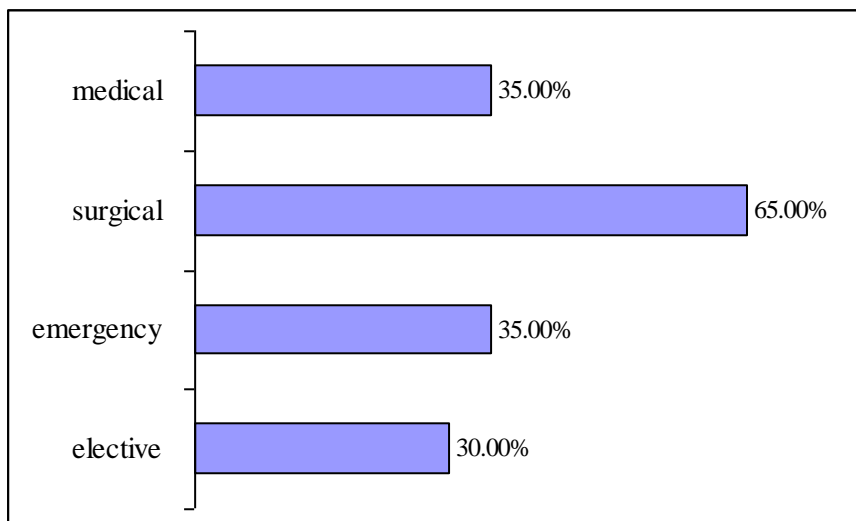


Figure 4.1 Frequency distributions obtained for patient's diagnosis in ICU

4.3.2 Questionnaire Section 1 : Participants Socio-demographic Data

This section related to the participant demographic data, which comprised of ten (10) items. Items included: gender, age, home language, population group, level of education, relationship to the patient, previous ICU experience, living status (if no, then on average how often they see the patient), where they live and the distance to the hospital. This information was obtained by means of a structured interview within the admission period between three days to three weeks, after consent was obtained.

A total of 100 (n=100) family members or significant others made up the sample size. Results of this process is summarised in **table 4.2**. Items were grouped together to allow ease of discussion.

Table 4.2 Socio-demographic data of participants for the total sample (n=100)

Item	Demographic data	Frequency	Percent
2.1	Gender		
	Male	39	39.0%
	Female	61	61.0%
2.2	Age in years		
	< 20	1	1.0%
	20 – 39 years	44	44.0%
	40 – 59 years	40	40.0%
	60 – 79 years	14	14.0%
	> 79 years	1	1.0%
2.3	Home language		
	English	31	31.0%
	Zulu	24	24.0%
	Afrikaans	10	10.0%
	European descent	2	2.0%
	Other African	33	33.0%
2.4	Population group		
	Black	60	60.0%
	White	29	29.0%
	Indian	8	8.0%
	Coloured	3	3.0%
2.5	Education level		
	< high school	37	37.0%
	High school	37	37.0%
	Some college	20	20.0%
	University	6	6.0%

Females accounted for 61.0% (n=61) and males 39.0% (n=39) of the total sample (n=100).

The highest (84%; n=84) responses were between the ages of 20 to 59 years, followed by 14.0% (n=14) in the 60 to > 79 and 1.0% (n=1) in > 79 and < 20 age categories,

respectively. It can be extrapolated from these findings that majority (61.0%) participants were females and majority (84.0%) were between the ages of 20 to 59 years.

In terms of home language, the prevalent home language amongst participants was English at 31% (n=31) followed by Zulu at 24% (n=24) and Afrikaans at 10% (n=10), whereas the balance comprised of other European languages at 2% (n=2) and other African languages at 33% (n=33). English, one of the official languages, is the *lingua franca*, whilst Zulu is the most widely spoken of the nine official African languages. It is a well known and established fact, Isizulu is home language to twenty four percent of South Africans and fifty percent of South Africans understand the language. In summary the adoption by South Africa of eleven official languages demonstrates the diversity of cultures and languages that constitute the population in Gauteng and the country as a whole.

In this study, an analysis in terms of population groups indicated a higher (60.0%; n=60) response in the Black group, followed by 29.0% (n=29), 8.0% (n=8) and 3.0% (n=3) as White, Indian and Coloured population groups, respectively. These findings are congruent with population estimates of Statistics SA (South Africa) in terms of which the 2010 mid-year population estimates were indicated as follows: 79.4% African, 8.8% Coloured, 2.6% Indian/Asian and 9.2% white (StatsOnline, 2010). Findings are displayed in **figure 4.2**.

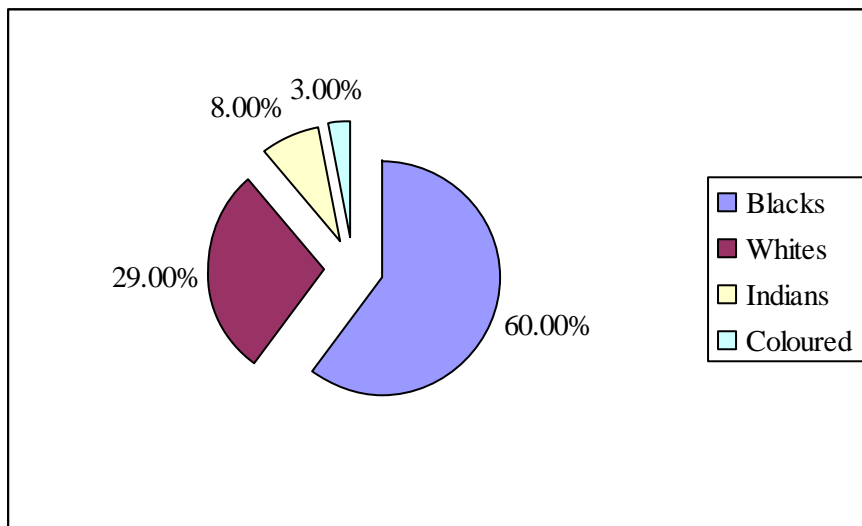


Figure 4.2 Population demographical distribution of the total sample (n=100)

In the total sample (n=100) between education levels indicated a higher (74.0%; n=74) frequency response as less than high school and high school, whereas a slightly lower (26.0%; n=26) was noted in further and higher education. It can be extrapolated from these findings that majority (74.0%; n=74) participants had education less than high school and high school level and one quarter (26.0%; n=26) had further and higher education level. It was assumed that these factors would generate significant differences in level of satisfaction with care and decision making based on differences in educational level distributions between participants. Findings are displayed in **table 4.2**

Table 4.3 provides an overview of demographic responses of participants related to patient relationships, prior experience of intensive care, living arrangements and travelling distance to the hospital. Items were grouped together to allow ease of discussion.

Table 4.3 Demographic responses of participants related to selected variables

Item	Demographic data	Frequency	Percent
2.6	Relationship to patient		
	Sibling	30	30.0%
	Spouse	21	21.0%
	Parent	16	16.0%
	Child	14	14.0%
	Significant other	19	19.0%
2.7	Involved in ICU before		
	Yes	44	44.0%
	No	56	56.0%
2.8	Live with patient		
	Yes	54	54.0%
	No	46	46.0%
2.9	Where live		
	City	48	48.0%
	Out of town	52	52.0%
2.10	Distance to the hospital		
	< 1 hr drive	82	82.0%
	1 – 3 hr drive	11	11.0%
	> 3 hr drive	7	7.0%

In the total sample (n=100) the majority (56.0%; n=56) had no previous intensive care experience and only a minority (44.0%; n=44) had prior experience. Participants relationship to the patient was slightly higher (30.0%; n=30) as siblings, followed by spouse (21.0%; n=21), significant other (19.0%; n=19), parent (16.0%; n=16) or child (14.0%; n=14). In terms of the relationship to patients the study by Mendonca et al. (1998) indicated a majority (40.81%) as son and daughters and minority (4.1%) as brothers and

sisters, whereas Warren (1998) reported significant others as highest (27.8%) followed by spouses (25.0%) and a minority (8.3%) response as parents.

In this study, an analysis between participants revealed a majority (54.0%; n=54) participants shared a living arrangement with the critically ill patients, a minority (46.0%; n=46) had no shared living arrangements with patients. Majority (52.0%; n=52) lived out of town and a minority (48.0%; n=48) lived in the city. The majority (82.0%; n=82) of participants lived less than one hour drive to the hospital, 11.0% (n=11) residing one to three hours distance and only a minority (7.0%; n=7) more than a three hour distance from the hospital. The distribution of participant visitation were highest (37.0%; n=17) responses for visited the patient more than weekly, followed by 28.3% (n=13) weekly, 23.9% (n=11) visited monthly and 10.9% (n=5) visited the patient yearly. These findings are displayed in **figure 4.3**.

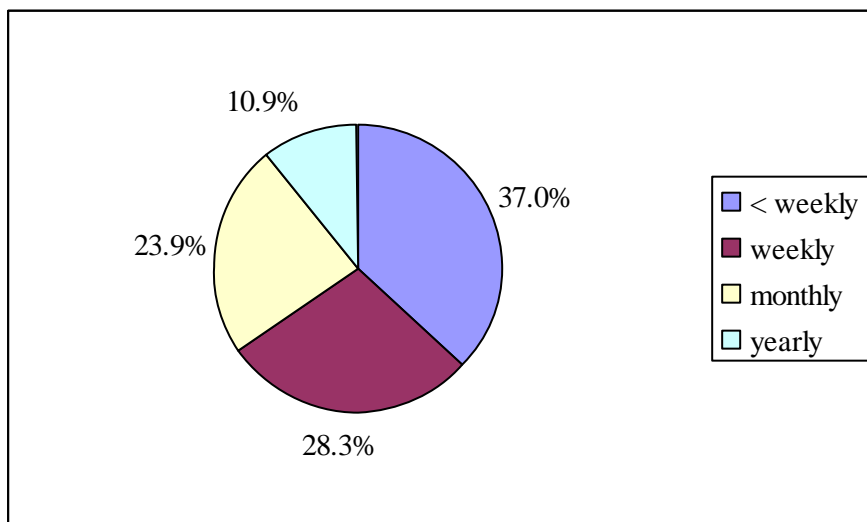


Figure 4.3 Frequencies obtained for how often participants saw the patient (n=46)

4.3.3 Questionnaire Section 2: Satisfaction with care and decision making items

This section comprised of twenty four items to which responses were obtained from the participants by the researcher through a structured interview process, specifically within an admission period of the patient > 72 hours and < than three weeks, to determine the level of satisfaction with care and decision making around the care of the critically ill patient. Descriptive and comparative statistics were used to analyse the data on scale, construct and item levels.

The total sample comprised of 100 participants who were family or significant others of adult patients admitted to one of three selected intensive care units. The instrument used in this study is the Family Satisfaction with Care in the Intensive Care Unit FS-ICU (24) Questionnaire. This questionnaire measures satisfaction with care and satisfaction with decision making, as the major construct variables on a four point Likert scale, with the rating option of 1, 2, 3 or 4 reflected as excellent, good, poor or not applicable (NA), respectively. Some variation is provided within the questionnaire for example, Item 1.14 uses a three point Likert scale, which provides the option of very dissatisfied, most satisfied and completely satisfied. Item 2.7 uses a three point Likert scale which provides the options of feeling excluded, feeling neither included nor excluded or feeling included in the decision-making process. Similarly, item 2.8 provides the options of feeling overwhelmed, feeling neither overwhelmed nor supported or feeling supported during the decision-making process. Item 2.9 provided the options of feeling out of control, feeling neither in control nor out of control or feeling in control over the care of the patient. Additionally, item 2.10 has a dichotomous response option. Items 2.11 -2.13 asks which of the following best describes the participants views and was applicable only if the patient

died whilst in ICU. Item 2.11 provided the option of: was the patient's life prolonged unnecessarily, was the patient's life neither prolonged nor shortened or was the patient's life shortened unnecessarily. Item 2.12 provided the options of was the patient uncomfortable, mostly comfortable or totally comfortable. Item 2.13 provided the options of feeling abandoned, feeling neither abandoned nor supported and feeling supported. The end of the questionnaire includes three (items 2.14 to 2.16) open-ended questions to obtain suggestions on how to improve care in the intensive care unit (item 2.14); comments on things that were done well (item 2.15) and comments or suggestions that would be helpful to the staff of the hospital (item 2.16).

Data were analysed to determine level of satisfaction with care using frequency responses for total questionnaire scores after collapsing one of the categories of the Likert scale, where 1 and 2 were used as excellent and good, respectively to form the satisfaction with care and decision making categories, and 3 as poor, was used to form dissatisfaction with care and decision making 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 participants answered moderate satisfaction with care in the itemized analysis. The decision for collapsing the categories was informed by the statistician and in consultation with the researcher's supervisor.

4.3.3.1 Satisfaction with care

Satisfaction with care formed the first part of the questionnaire (Appendix F), which comprised fourteen questions. Items were combined to form coherent groups to facilitate discussion of data. Findings are displayed in **tables 4.4 to 4.7**.

Table 4.4 Frequencies obtained for satisfaction with care (items 1.1 to 1.4)

Item	Statement	Satisfaction with care							
		1 Excellent		2 Good		3 Poor		4 Not applicable	
		n	%	n	%	n	%	n	%
1.1	How was your family member treated. Concern caring by staff the courtesy, respect and compassion your family member was given?	53	53.0%	44	44.0%	3	3.0%	-	-
1.2	Symptom management. How well the ICU staff addressed and treated your family member's symptoms? - Pain	33	33.0%	65	65.0%	1	1.0%	1	1.0%
1.3	- Breathlessness	24	24.0%	73	73.0%	2	2.0%	1	1.0%
1.4	- Agitation	12	12.0%	85	85.0%	1	1.0%	2	2.0%

Items 1.1 to 1.4 on the data collection instrument inquired about how the participants perceived the treatment of their family members. Findings related to item 1.1 revealed

majority (53.0%; =53) of participants were slightly more satisfied with the treatment their family members received, and compared with forty four (44%; n=44) responses indicated as good. Whereas higher response for symptom management (items 1.2 to 1.4), was indicated as good for pain, breathlessness and agitation (65.0%, 85.0%, 73.0%, respectively). It can be extrapolated from these findings that participants are satisfied with the treatment and symptom management their family members received. Findings are displayed in **table 4.4**.

Table 4.5 Frequencies obtained for satisfaction with care (items 1.5 to 1.7)

Item	Statement	Satisfaction with care							
		1 Excellent		2 Good		3 Poor		4 Not applicable	
		n	%	n	%	n	%	n	%
1.5	How were you treated? Consideration of your needs: How well the ICU staff showed an interest in your needs?	31	31.0%	52	52.0%	17	17.0%	-	-
1.6	Emotional support. How well the ICU staff provided emotional support?	19	19.0%	56	56.0%	22	22.0%	3	3.0%
1.7	Coordination of care; The teamwork of all the ICU staff who took care of your family member.	28	28.0%	65	65.0%	5	5.0%	2	2.0%
1.8	Concern and caring by ICU staff: the courtesy, respect and compassion you were given?	26	26.0%	63	63.0%	11	11.0%	-	-

Items 1.5 to 1.8 on the data collection instrument inquired about how the participants perceived treatment, support and care received from staff members. These findings are displayed in **table 4.5**. Findings in this study indicated on average (>50.0%) participants were satisfied with treatment, support and care received from staff members. Furthermore, findings indicated that level of disagreement across these items varied from 5.0 % to 22.0%. It can be extrapolated from the level of disagreement that there are areas for improvement by staff members across these items. Findings are displayed in **table 4.5**.

Table 4.6 Frequencies obtained for satisfaction with care (items 1.9 to 1.11)

Item	Statement	Satisfaction with care							
		1 Excellent		2 Good		3 Poor		4 Not applicable	
		n	%	n	%	n	%	n	%
1.9	Nurses: Skill and competence of ICU nurses: How well the nurses cared for your family member	35	35.0%	58	58.0%	7	7%	-	-
1.10	Frequency of communication with ICU nurses: How often nurses communicated to you about your family member's condition?	16	16.0%	48	48.0%	36	36.0%	-	-
1.11	Physicians: Skill and competence of ICU doctors: How well doctors cared for your family member?	45	45.0%	52	52.0%	3	3.0%	-	-

Items 1.9 to 1.11 on the data collection instrument inquired how the participant's perceived communication and care received from the nurses and doctors. Findings indicated participants were slightly more satisfied (45.0%; n=45) with competence and skills of doctors (item 1.11), compared with only thirty five (35.0%; n=35) percent indicated for nurses (item 1.9). Furthermore, over one third (36.0%; n=36) responses of participants were indicated as poor for frequency of communication with nurses (item 1.10). It can be extrapolated from these findings that participants are more satisfied with care received from doctors than nurses. Findings are displayed in **table 4.6**.

Table 4.7 Frequencies obtained for satisfaction with care (items 1.12 to 1.14)

Item	Statement	Satisfaction with care							
		1 Excellent		2 Good		3 Poor		4 Not applicable	
		n	%	n	%	n	%	n	%
1.12	The ICU: Atmosphere of the ICU was?	27	27.0%	65	65.0%	8	8.0%	-	-
1.13	The waiting room: the atmosphere in the ICU waiting room was?	1	1.0	6	6.0%	93	93.0%	-	-
1.14	Overall satisfaction	1	1.0%	91	91.0%	8	8.0%	-	-

Items 1.12 to 1.14 on the data collection instrument inquired how the participants rated the overall satisfaction with care received in the intensive care unit. Findings indicated majority (65.0%; n=65) were mostly satisfied with the atmosphere of the intensive care unit (item 1.12), whereas majority (93.0%; n=93) participants were satisfied with the

waiting room area. Of the total sample majority (91.0%; n=91) participants indicated overall satisfaction as mostly satisfied (good). It can be extrapolated from these findings that there are also areas for improvement, particularly related to the issue of waiting room area. Findings are displayed in **table 4.8**.

4.3.3.2 Satisfaction with decision making

Satisfaction with decision making formed the second part of the questionnaire (Appendix F), which comprised ten questions. In this part of the questionnaire provision is made for inclusion of three items, particularly for bereaved participants. This is followed by three open ended responses which concludes the questionnaire. Items were combined to form coherent groups to facilitate discussion of data. Findings are displayed in **tables 4.48 to 4.9**.

Table 4.8 Frequencies obtained for satisfaction with decision making (items 2.1 to 2.6)

Item	Statement	Satisfaction with decision making							
		1 Excellent		2 Good		3 Poor		4 Not applicable	
		n	%	n	%	n	%	n	%
2.1	Information needs: Frequency of communication with ICU doctors: How often doctors communicated to you about family members condition?	27	27.0%	48	48.0%	25	25.0%	-	-
2.2	Ease of getting information: willingness of ICU staff to answer your questions?	20	20.0%	70	70.0%	10	10.0%	-	-
2.3	Understanding of information: How well ICU staff provided you with explanations that you understood?	17	17.0%	71	71.0%	12	12.0%	-	-
2.4	Honesty of information: The honesty of information provided to you about your family members condition?	21	21.0%	69	69.0%	8	8.0%	2	2.0%
2.5	Completeness of information: How well ICU staff informed you about what was happening to your family member and why things were being done?	17	17.0%	58	58.0%	25	25.0%	-	-
2.6	Consistency of information: The consistency of information provided to you about your family members condition (did you get a similar story from the doctor, nurse etc.)?	12	12.0%	70	70.0%	18	18.0%	-	-

Items 2.1 to 2.6 on the data collection instrument inquired how the participants rated the satisfaction with decision making process in the intensive care unit. Findings indicated

higher majority (>70.0%) participants responses were rated as good for ease of information (70.0%; n=70), understanding information (71.0%; n=71) consistency of information (70.0%; n=70) reflected as item 2.1, item 2.3 and item 2.6, respectively. However, findings indicated that a quarter of participants responses were rated poor for frequency of communication with doctors (25.0%; n=25), and similarly for completeness of information (25.0%; n=25), reflected as item 2.1 and item 2.5.

Table 4.9 Frequencies obtained for satisfaction with decision making (items 2.7 to 2.10)

Item	Statement	Satisfaction with decision making							
		1 Excellent		2 Good		3 Poor		Not Applicable	
		n	%	n	%	n	%		
2.7	Did you feel included in the decision-making process?	13	13.0%	22	22.0%	65	65.0%	-	-
2.8	Did you feel supported during the decision making process?	9	9.0%	28	28.0%	63	63.0%	-	-
2.9	Did you feel you had control over the care of your family member?	14	14.0%	59	59.0%	27	27.0%	-	-
2.10	When making decision, did you have adequate time to have your concerns addressed and questions answered?	34	34.05	66	66.0%	-	-	-	-

Items 1.7 to 1.10 on the data collection instrument inquired how the participants rated the process of decision making regarding the health care their family member received. Findings indicated majority (>50.0%) responses were indicated for item 2.9 and 2.10, whereas more than sixty (n= > 60) participants rated poor for items 2.7 and 2.8. These findings are displayed in **table 4.9**.

4.3.3.3 Results of bereaved participants

Table 4.10 Frequencies obtained for satisfaction with decision making for the total sample (n=9)

Item	Statement	Satisfaction with decision making							
		1 Excellent		2 Good		3 Poor		Not Applicable	
		n	%	n	%	n	%		
2.11	Which of the following best describes your view?	-	-	5	55.6%	4	44.4%	-	-
2.12	During the final hours of your family members life which best describes your views?	3	33.3%	4	44.4%	2	22.2%	-	-
2.13	During the last hours before your family members death, which best describes your views?	-	-	5	55.6%	4	44.4%	-	-

Items 2.11 to 2.13 of the data collection instrument inquired how the participants rated their perceptions after their family member died during the intensive care stay. Findings indicated that the majority (55.6%; n=5) of responses of participants indicated that they

were overall satisfied with the decision making process, whereas 44.4% (n=4) percent indicated overall satisfaction during the final hours of their family members life and 55.6% (n=5) indicated overall satisfaction during the last hours before their family members death. Findings are displayed in **table 4.10**. Items that were negatively worded were adjusted and reversed by the statistician during data analysis.

4.3.3.4 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 the construct scores and individual item scores were used. Results of the process are summarised in **table 4. 10**.

Table 4.11: Summary Cronbach's reliability coefficient for items Q 1.1 to Q1. 14 and items 2.1 to 2.10

Test	Items included	Reliability Coefficient
Test 1	Q1.1 ;Q1.2 ;Q.13 ;Q1.4 ;Q1.5 ;Q1.6 ;Q1.7 ; Q1.8 ;Q1.9 ;Q.10 ; Q1.11 ; Q1.12 ; Q1.13	0.850
Test 2	Q1.1 ;Q1.2 ;Q.13 ;Q1.4 ;Q1.5 ;Q1.6 ;Q1.7 ; Q1.8 ;Q1.9 ;Q.10 ; Q1.11 ; Q1.12 ; Q14	0.855
Test 3	Q2.1 ;Q2.2 ;Q2.3 ;Q2.4 ;Q2.5 ;Q2.6 ;Q2.7 ;Q2.8 ; Q2.9 ; Q2.10	0.832

Findings were based solely on the reliability coefficient, and some items (test 1) were omitted to maximise reliability of the coefficient alphas. Findings yielded Cronbach's

alphas of 0.832 to 0.855 (test 2 and test 3) for construct and total questionnaire scores. These findings meet the standard 0.80 – 0.85 for reliability (Polit & Beck, 2008), they suggest a positive relationship exists between the variables of the total item scores. Results of this process are summarised in **table 4.11**.

Measurement of central tendency and variation (mean and standard deviation were used to summarise that data. Findings for selected participant socio-demographic categorical variables, namely gender, education, population and prior exposure to intensive care are discussed in the next section. Summary of the mean scores for comparison of satisfaction with care and satisfaction with decision making are provided in **tables 4.12 to 4.15**.

Table 4.12 Summary mean total scores of gender for comparison of satisfaction with care and satisfaction with decision making

Gender	Satisfaction with care			Satisfaction with decision making		
	n	Mean	SD	n	Mean	SD
Male	39	26.79	4.58	39	20.74	2.58
Female	61	26.05	4.52	61	20.59	2.24

Table 4.12 presents the summary of total mean scores for comparison of satisfaction with care and satisfaction with decision making by gender. Of the total sample (n=100) the mean score obtained for gender for satisfaction with care was 26.79 (SD 4.58) for male participants, with contrast of 26.05 (SD 4.52) for female participants. This is an observed difference of 0.74. Similarly, the mean score for satisfaction with decision making was

20.74 for male participants, contrasted by a 20.59 score for female participants. This is an observed difference of 0.20.

Table 4.13 Summary mean total scores of education for comparison of satisfaction with care and satisfaction with decision making

Education	Satisfaction with care			Satisfaction with decision making		
	n	Mean	SD	n	Mean	SD
< high school	37	25.81	4.24	37	20.57	2.09
High school	37	25.68	4.61	37	20.65	2.64
Some college	20	28.20	4.58	20	20.85	2.60
University	6	27.50	4.93	6	20.50	2.43

Table 4.13 presents the summary of total mean scores for comparison of satisfaction with care and satisfaction with decision making by education. Marginal differences in mean scores in the sub-group categories were observed.

Table 4.14 Summary mean total scores of population for comparison of satisfaction with care and satisfaction with decision making

Population	Satisfaction with care			Satisfaction with decision making		
	n	Mean	SD	n	Mean	SD
Black	60	26.30	4.23	60	20.93	2.16
White	29	27.14	4.69	29	20.62	2.43
Indian	6	25.00	4.73	6	19.83	3.43
Coloured	3	23.33	8.08	3	19.00	3.61

Table 4.14 presents the summary of total mean scores for comparison of satisfaction with care and satisfaction with decision making by population group. A cut off point was set statistically and population in Black and White groups were considered for further analysis. Of the total sample (n=100) the mean score obtained for population for satisfaction with care was 26.30 (SD 4.23) for participants categorised as Black, with contrast of 27.14 (SD 4.69) for responses in White group. This is an observed difference of -0.84. Similarly, the mean score for satisfaction with decision making was 20.93 (SD 2.16) for participants categorised as Black, contrasted by a 20.62 (SD 2.43) score for responses in White group. This is observed difference of 0.31.

Table 4.15 Summary mean total scores of previous exposure in intensive care for comparison of satisfaction with care and satisfaction with decision making

Exposure to ICU	Satisfaction with care			Satisfaction with decision making		
	n	Mean	SD	n	Mean	SD
Yes	44	26.64	4.64	44	20.89	2.23
No	56	26.11	4.48	56	20.46	2.52

Table 4.15 presents the summary of total mean scores for comparison of satisfaction with care and satisfaction with decision making by exposure to intensive care. Of the total sample (n=100) the mean score obtained for exposure to intensive care for satisfaction with care was 26.64 (SD 4.64) for participants that tested positively, with contrast of 26.11 (SD 4.48) for negative responses. This is an observed difference of 0.53. Similarly, the mean score for satisfaction with decision making was 20.89 (SD 2.23) for participants that tested positively, contrasted by a 20.46 (SD 2.52) score for negative responses. This is observed difference of 0.43.

Based on an observed difference in the mean scores in the sub-groups for gender, education, population and prior exposure to intensive care, the item scores were then tested to determine whether they are significant or not. Collapsing of the categories of the Likert scale was done to facilitate presentation of the data, where 1 = excellent, 2 = good and 3 = poor. The Fisher's exact test was employed to proportionate the data by categorical variables. An overview of this process is provided in **tables 4.16 to 4.23**, and followed by a summary of significant findings of Fisher's exact test for categorical variables in **table 4.24**

Table 4.16 Summary for Fisher’s exact test for frequencies obtained for satisfaction with care by gender

Item	Statement	Gender						Fisher’s exact test
		Male			Female			
		1	2	3	1	2	3	
1.1	How was your family member treated. Concern caring by staff the courtesy, respect and compassion your family member was given?	46.15	51.20	2.56	57.38	39.34	3.28	0.559
1.2	Symptom management. - Pain	25.64	74.36	-	1.64	37.70	59.02	0.354
1.3	- Breathlessness	17.97	79.49	2.56	27.87	68.42	1.64	0.558
1.4	- Agitation	5.13	87.18	2.56	16.39	83.61	-	0.038*
1.5	How were you treated? Consideration of your needs:	28.21	53.85	17.95	32.79	50.82	16.39	0.889
1.6	Emotional support. How well the ICU staff provided emotional support?	17.95	58.97	17.95	19.67	54.20	24.59	0.721
1.7	Coordination of care; The teamwork of all the ICU staff who took care of your family member.	3.33	61.54	5.13	24.59	67.21	4.92	0.666
1.8	Concern and caring by ICU staff: the courtesy, respect and compassion you were given?	28.21	61.54	10.26	24.59	63.93	11.48	0.952
1.9	Nurses: Skill and competence of ICU nurses: How well the nurses cared for your family member	25.64	64.10	10.26	40.98	54.10	4.92	0.237
1.10	Frequency of communication with ICU nurses: How often nurses communicated to you about your family member’s condition?	15.38	43.59	41.03	16.39	50.82	32.79	0.730
1.11	Physicians: Skill and competence of ICU doctors: How well doctors cared for your family member?	38.46	58.97	2.56	49.18	47.54	3.28	0.561
1.12	The ICU: Atmosphere of the ICU was?	30.77	64.10	5.13	24.59	65.57	9.84	0.612
1.13	The waiting room: the atmosphere in the ICU waiting room was?	-	-	100.0	1.64	9.84	88.52	0.079
1.14	Overall satisfaction	5.13	94.87	-	9.84	88.52	1.64	0.679

Key: * = statistical significance

Table 4.17 Summary for Fisher’s exact test for frequencies obtained for satisfaction with decision making by gender

Item	Statement	Gender						Fisher’s exact test
		Male			Female			
		1	2	3	1	2	3	
2.1	Information needs:: Frequency of communication with ICU doctors: How often doctors communicated to you about family members condition?	25.64	43.59	30.77	27.87	50.82	21.31	0.599
2.2	Ease of getting information: willingness of ICU staff to answer your questions?	17.95	69.23	12.82	21.13	70.49	8.20	0.723
2.3	Understanding of information: How well ICU staff provided you with explanations that you understood?	17.95	66.67	15.38	16.39	73.77	9.84	0.652
2.4	Honesty of information: The honesty of information provided to you about your family members condition?	20.51	64.10	10.26	21.31	72.13	6.56	0.324
2.5	Completeness of information: How well ICU staff informed you about what was happening to your family member and why things were being done?	20.51	53.85	25.64	14.75	60.66	24.59	0.719
2.6	Consistency of information: The consistency of information provided to you about your family members condition (did you get a similar story from the doctor, nurse etc.)?	7.69	74.36	17.95	14.75	67.21	18.03	0.656
2.7	Did you feel included in the decision-making process?	15.38	23.08	61.54	11.48	21.31	67.21	0.829
2.8	Did you feel supported during the decision making process?	7.69	25.64	66.67	9.84	29.51	60.66	0.815
2.9	Did you feel you had control over the care of your family member?	23.08	48.72	28.21	8.20	65.57	26.23	0.080
2.10	When making decision, did you have adequate time to have your concerns addressed and questions answered?	28.21	71.79	-	37.70	62/30	-	0.390

Key: * = statistical significance

Table 4.18 Summary for Fisher's exact test for frequencies obtained for satisfaction with care by education

Item	Statement	Education												Fisher's exact test
		< higher education			Higher education			Further education			Higher education			
		1	2	3	1	2	3	1	2	3	1	2	3	
1.1	How was your family member treated.	59.46	40.54	-	51.35	43/24	5/41	45.00	55.00	-	50.00	33.33	16.67	0.356
1.2	Symptom management. - Pain	24.76	70.26	2.70	-	40.54	59.46	-	35.00	65.00	33.33	66.67	-	0.746
1.3	- Breathlessness	27.03	72.97	-	18.92	78.38	2.70	25.00	70.00	-	33.33	50.00	16.67	0.243
1.4	- Agitation	13.51	83.78	-	10.81	86.46	-	10.00	90.00	-	16.67	66.67	16.67	0.470
1.5	How were you treated? Consideration of you needs:	27.03	64.86	8.11	35.14	51.35	13.51	30.00	35.00	35.00	33.33	33.33	33.33	0.124
1.6	Emotional support. How well the ICU staff provided emotional support?	24.32	52.16	10.81	21.62	62.16	13.51	10.0	30.0	60.0	-	66.67	16.67	0.003*
1.7	Coordination of care;	24.32	75.68	-	37.84	56.76	2.70	25.00	60.00	15.00	-	66.67	16.67	0.023*
1.8	Concern and caring by ICU staff:	27.03	70.27	2.70	27.03	64.86	8.11	25.00	45.00	30.00	16.67	66.67	16.67	0.102
1.9	Nurses: Skill and competence of ICU nurses:	29.73	64.86	5.41	40.54	54.05	5.41	40.0	50.0	10.0	16.67	66.67	16.67	0.672
1.0	Frequency of communication with ICU nurses:	16.67	59.46	24.32	21.62	45.95	32.43	5.00	30.00	65.00	16.67	50.00	33.33	0.093
1.11	Physicians: Skill and competence of ICU doctors:	40.54	59.46	-	56.76	43.24	-	30.0	60.0	10.0	45.00	52.00	3.00	0.047*
1.12	The ICU: Atmosphere of the ICU was?	30.00	60.00	10.00	56.76	43.24	-	30.00	60.00	10.00	50.00	33.33	16.67	0.047*
1.13	The waiting room: the atmosphere in the ICU waiting room was?	29.73	64.56	5.41	27.03	70.27	2.70	25.00	55.00	20.00	16.67	66.67	16.67	0.354
1.14	Overall satisfaction	2.70	8.11	89.19	-	5.41	94.59	-	5.00	95.00	-	-	100.00	0.935

Key: * = statistical significance

Table 4.19 Summary for Fisher’s exact test for frequencies obtained for satisfaction with decision making by education

Item	Statement	Education												Fisher’s exact test
		< higher education			Higher education			Further education			Higher education			
		1	2	3	1	2	3	1	2	3	1	2	3	
2.1	Information needs:: Frequency of communication with ICU doctors: How often doctors communicated to you about family members condition?	24.32	62.16	13.51	35.41	43.54	21.62	20.00	25.00	35.00	16.67	66.67	16.67	0.024
2.2	Ease of getting information: willingness of ICU staff to answer your questions?	18.92	78.38	2.70	16.22	70.27	13.51	20.00	60.00	20.00	50.00	50.00	-	0.178
2.3	Understanding of information: How well ICU staff provided you with explanations that you understood?	18.92	75.68	5.41	18.92	64.86	16.22	10.00	70.00	20.00	16.67	83.33	-	0.591
2.4	Honesty of information: The honesty of information provided to you about your family members condition?	21.62	75.68	2.70	15.00	60.00	20.00	16.67	66.67	16.67	21.00	69.00	8.00	0.352
2.5	Completeness of information:	18.92	64.86	16.22	24.32	62.16	13.51	5.00	30.00	65.00	-	83.33	16.67	0.001*
2.6	Consistency of information:	10.81	83.78	5.41	10.81	78.38	10.81	20.00	30.00	50.00	-	66.67	33.33	0.000*
2.7	Did you feel included in the decision-making process?	5.41	21.62	72.97	8.11	21.62	70.27	35.00	20.00	45.00	16.67	33.33	50.00	0.071
2.8	Did you feel supported during the decision making process?	2.70	32.43	64.86	5.41	24.32	70.27	30.00	30.00	40.00	-	16.67	83.33	0.046*
2.9	Did you feel you had control over the care of your family member?	8.11	59.46	32.43	13.51	51.35	35.14	25.00	65.00	10.00	16.67	83.33	-	0.152
2.10	When making decision, did you have adequate time to have your concerns addressed and questions answered?	29.73	70.27	-	29.73	70.27	-	50.00	50.00	-	33.33	66.67	-	0.425

Key: = * statistical significance

Table 4.20 Summary for Fisher’s exact test for frequencies obtained for satisfaction with care by population

Item	Statement	Population						Fisher’s exact test
		Black			White			
		1	2	3	1	2	3	
1.1	How was your family member treated. Concern caring by staff the courtesy, respect and compassion your family member was given?	53.33	46.67	-	48.28	41.38	10.34	0.062
1.2	Symptom management. How well the ICU staff addressed and treated your family member’s symptoms? - Pain	30.00	66.47	1.67	31.03	68.97	-	1.000
1.3	- Breathlessness	20.00	80.00	-	20.69	72.41	6.90	0.143
1.4	- Agitation	-	10.00	90.00	13.79	79.31	3.45	0.156
1.5	How were you treated? Consideration of you needs: How well the ICU staff showed an interest in your needs?	33.33	53.33	13.33	24.14	48.24	27.59	0.249
1.6	Emotional support. How well the ICU staff provided emotional support?	21.67	66.67	11.67	10.34	48.28	37.93	0.009*
1.7	Coordination of care; The teamwork of all the ICU staff who took care of your family member.	23.33	73.33	3.33	24.14	62.07	6.90	0.166
1.8	Concern and caring by ICU staff: the courtesy, respect and compassion you were given?	28.33	63.33	8.33	24.14	58.62	17.24	0.470
1.9	Nurses: Skill and competence of ICU nurses: Howe well the nurses cared for your family member	35.00	60.00	5.00	31.03	58.62	10.34	0.628
1.10	Frequency of communication with ICU nurses: How often nurses communicated to you about your family member’s condition?	15.00	55.00	30.00	13.79	37.93	48.28	0.238
1.11	Physicians: Skill and competence of ICU doctors: How well doctors cared for your family member?	38.33	60.00	1.67	62.07	34.48	3.45	0.044*
1.12	The ICU: Atmosphere of the ICU was?	28.33	63.33	8.33	20.69	72.41	6.90	0.719
1.13	The waiting room: the atmosphere in the ICU waiting room was?	1.67	6.67	91.67	-	6.90	93.10	1.000
1.14	Overall satisfaction	5.00	93.33	1.67	6.90	93.10	-	1.000

Key: * statistical significance

Table 4.21 Summary for Fisher’s exact test for frequencies obtained for satisfaction with decision making by population

Item	Statement	Population						Fisher’s exact test
		Black			White			
		1	2	3	1	2	3	
2.1	Information needs:: Frequency of communication with ICU doctors: How often doctors communicated to you about family members condition?	21.67	51.67	26.67	34.38	41.38	24.14	0.484
2.2	Ease of getting information: willingness of ICU staff to answer your questions?	15.00	75.00	10.00	20.69	65.52	13.79	0.625
2.3	Understanding of information: How well ICU staff provided you with explanations that you understood?	15.00	73.33	11.67	13.79	72.41	13.79	1.000
2.4	Honesty of information: The honesty of information provided to you about your family members condition?	16.67	71.67	8.33	17.24	75.86	6.90	1.000
2.5	Completeness of information: How well ICU staff informed you about what was happening to your family member and why things were being done?	11.67	60.00	28.33	17.24	65.52	17.24	0.488
2.6	Consistency of information: The consistency of information provided to you about your family members condition (did you get a similar story from the doctor, nurse etc.)?	6.67	76.67	16.67	13.79	65.52	20.69	0.393
2.7	Did you feel included in the decision-making process?	13.33	18.33	68.33	13.79	31.03	55.17	0.362
2.8	Did you feel supported during the decision making process?	10.00	28.33	61.67	6.90	31.03	62.07	1.000
2.9	Did you feel you had control over the care of your family member?	13.33	60.00	26.67	17.24	55.17	27.59	0.902
2.10	When making decision, did you have adequate time to have your concerns addressed and questions answered?	35.00	65.00	-	24.14	75.86	-	0.340

Key: * = statistical significance

Table 4.22 Summary for Fisher’s exact test for satisfaction with care by previous exposure to intensive care

Item	Statement	Exposure to ICU						Fisher’s exact test
		Yes			No			
		1	2	3	1	2	3	
1.1	How was your family member treated. Concern caring by staff the courtesy, respect and compassion your family member was given?	52.27	43.18	4.55	53.57	44.64	1.79	0.754
1.2	Symptom management. How well the ICU staff addressed and treated your family member’s symptoms? - Pain	38.64	59.09	-	28.57	69.94	1.79	0.306
1.3	- Breathlessness	22.73	70.45	4.55	25.00	75/00	-	0.301
1.4	- Agitation	13.64	79.55	2.27	10.71	89.29	-	0.211
1.5	How were you treated? Consideration of you needs: How well the ICU staff showed an interest in your needs?	27.27	47.73	25.00	33.93	55.36	10.71	0.191
1.6	Emotional support. How well the ICU staff provided emotional support?	11.36	52.27	29.55	25.00	58.93	16.07	0.355
1.7	Coordination of care; The teamwork of all the ICU staff who took care of your family member.	29.55	25.09	9.09	26.79	69.94	1.79	0.344
1.8	Concern and caring by ICU staff: the courtesy, respect and compassion you were given?	25.00	56.82	18.18	26.79	63.00	11.00	0.137
1.9	Nurses: Skill and competence of ICU nurses: Howe well the nurses cared for your family member	38.64	50.00	11.36	32.14	64.29	3.57	0.203
1.10	Frequency of communication with ICU nurses: How often nurses communicated to you about your family member’s condition?	11.36	45.45	43.18	19.64	50.00	30.36	0.340
1.11	Physicians: Skill and competence of ICU doctors: How well doctors cared for your family member?	50.00	45.45	4.55	41.07	57.14	1.79	0.451
1.12	The ICU: Atmosphere of the ICU was?	22.73	68.18	9.09	30.36	62.50	7.14	0.725
1.13	The waiting room: the atmosphere in the ICU waiting room was?	-	4.55	95.45	1.79	7.14	91.07	0.826
1.14	Overall satisfaction	13.64	86.36	-	3.57	94.64	1.79	0.133

Key: * = statistical significance

Table 4.23 Summary for Fisher’s exact test for satisfaction with decision making by previous exposure to intensive care

Item	Statement	Exposure to ICU						Fisher’s exact test
		Yes			No			
		1	2	3	1	2	3	
2.1	Information needs:: Frequency of communication with ICU doctors:	27.27	47.73	25.00	26.79	48.21	25.00	1.000
2.2	Ease of getting information: willingness of ICU staff to answer your questions?	20.45	68.18	11.36	19.64	71.43	8.93	0.949
2.3	Understanding of information: How well ICU staff provided you with explanations that you understood?	15.91	70.45	13.64	17.84	71.43	10.71	0.901
2.4	Honesty of information: The honesty of information provided to you about your family members condition?	18.18	70.45	9.09	23.21	67.86	7.14	0.898
2.5	Completeness of information:	13.64	54.55	31.82	19.64	60.71	19.64	0,340
2.6	Consistency of information:	11.36	56.82	31.82	12.50	80.36	7.14	0.006*
2.7	Did you feel included in the decision-making process?	18.18	22.73	59.09	8.93	21.43	69.84	0.379
2.8	Did you feel supported during the decision making process?	6.82	27.27	65.91	10.71	28.57	6.071	0.823
2.9	Did you feel you had control over the care of your family member?	15.91	54.55	29.55	12.50	62.50	25.00	0.744
2.10	When making decision, did you have adequate time to have your concerns addressed and questions answered?	36.36	63.64	-	32.14	67.86	-	0.676

Key: * = statistical significance

Table 4.24 Summary of significant findings of Fisher’s exact test for categorical variables

Categorical variable	Item number	Fisher’s exact test
Gender	Q1.4	0.038
Education	Q1.6	0.003
	Q1.7	0.024
	Q1.11	0.047
	Q2.1	0.024
	Q2.5	0.001
	Q2.6	0.000
	Q2.8	0.046
Population	Q1.11	0.044
Prior exposure to ICU	Q1.6	0.035

Table 4.24 presents the summary of significant findings of Fisher’s exact test for selected categorical variables for gender, education, population and previous exposure to intensive care.

Data were then analysed to determine whether the difference in the construct scores and total questionnaire scores were statistically significant by population. A Fisher’s exact test was employed to proportionate the data by categories (male and female). Findings indicated that of the twenty four satisfaction with care and decision making items, only one item (item 1.4) was statistically significant ($p=0.038$). No significant difference was observed in the remaining satisfaction with care and decision making items. Results of this process are summarised in **table 4.24**.

Data were analysed to determine whether the difference in the construct scores and total questionnaire scores were statistically significant by education. A Fisher's exact test was employed to proportionate the data by categories (< high school, high school, some college and higher education). Findings indicated that of the total twenty four satisfaction with care and decision making items, seven items namely, item 1.6 ($p=0.003$), item 1.7 ($p=0.024$), item 1,11 ($p=0.047$), item 2.1 ($p=0.024$), item 2.5 ($p=0.001$), item 2.6 ($p=0.000$) and item 2.8 ($p=0.046$) was statistically significant. No significant difference was observed in the remaining satisfaction with care and decision making items. Results of this process are summarised in **table 4.24**.

Data were analysed to determine whether the difference in the construct scores and total questionnaire scores were statistically significant by population group. A Fisher's exact test was employed to proportionate the data by categories (Black and White). Findings indicated that of the total twenty four satisfaction with care and decision making items, only one item (item 1.11) was statistically significant ($p=0.044$). No significant difference was observed in the remaining satisfaction with care items. Results of this process are summarised in

table 4.24.

Data were analysed to determine whether the difference in the construct scores and total questionnaire scores were statistically significant by exposure to intensive care group. A Fisher's exact test was employed to proportionate the data by categories (yes and no). Findings indicated that of the total twenty four satisfaction with care and decision making items, only one items (item 1.6) was statistically significant ($p =0.035$). No significant

difference was observed in the remaining satisfaction with care and decision making items. Results of this process are summarised in **table 4.24**.

4.3.3.5 Responses from open ended questions (items 2.14 to 2.16)

Items 2.14 to 2.16 on the data collection instrument inquired whether the participants wished to make additional comments or recommendations for intensive care. Findings in item 2.14 indicated that 49.0% of participants suggested that better provision of information and enhanced communication between the doctor, nurses and family would improve care in the ICU. Further, results in item 2.16 showed that 12.0% (n=12) of participants felt that patient care was good. And according to 7.0% (n=7) of participants the operation/surgery was satisfactory. Related to specific recommendations (item 2.16), participants suggested the following:

- Rigid visiting hours were a grievance for 27.0% (n=27) of participants, suggesting that twice a day would be more convenient.
- The provision of a comfortable waiting room in close proximity to the patient was suggested by 17.0% (n=17) of participants.
- A quarter of participants, 26.0% (n=26) commented on unsatisfactory conduct of nurses and in particular their "bad attitude", unfriendliness", and inapproachability. Participants expressed that they "were scared to ask nurses about the patient".

As the above-mentioned findings are already incorporated into the items of the FS-ICU (24) questionnaire they were not subjected to further analysis. However, the findings in

this study are not unique and have been reported on in similar more recent studies conducted at the same institution (Gundo, et al., 2010; Herbert & Harris, 2011). It is the intention of this researcher to incorporate these findings in the recommendations arising from the study.

4.4 DISCUSSION OF MAIN FINDINGS

The purpose of this study was to describe family member's opinions regarding their satisfaction with care and decision making during the patients admission to the intensive care units (ICUs).

In this study, the first part of the questionnaire elicited participants' perceptions of their level of satisfaction with care in the intensive care unit. Ten items supported the results and discussion of findings in this part of the questionnaire.

Participants perceived the treatment and care their family member received as more than satisfactory (**items 1.1 to 1.4**). The majority of participants (53.0%; n=53) responses were slightly more than satisfied with the treatment their family member received and 44.0% (n=44) rated this item as good. Similarly, a high score was noted as participants rated symptom management (items 1.2 to 1.4) for their family member as good for pain (65.0%; n=65), breathlessness (85.0%; n=85) and agitation (73.0%; n=73). These findings indicated that participants were **more satisfied with treatment and symptom management** their family member received. This finding is similar to studies conducted overseas (Canada and Switzerland) where Heyland et al. (2001) reported 70.0% of participants were highly

satisfied with the treatment their family member received. The management of pain, breathlessness and agitation was rated as excellent (58.0%, 55.0% and 54.0% respectively). Another study which consistently shares these findings is a study by Stricker et al. (2007) the majority (58.0%) responses were satisfied with the treatment their family member received. The management of pain, breathlessness and agitation was rated as good (66.0%, 63.0% and 65.0% respectively). These findings from both studies indicate increased satisfaction with patient care and symptom management.

Participants perceived the treatment they received from intensive care staff (**items 1.5 to 1.7**) as less satisfactory. Participants were mostly satisfied (>50.0%) for consideration of their needs, emotional support, coordination of care and concern and caring as 52.0%, 56.0%, 65.0% and 63.0%, respectively. However, some participants were also dissatisfied with the level of emotional support (22.0%; n=22) and interest shown by staff members (17.0%; n=17) towards their needs. These findings indicated that participants rated their satisfaction with the treatment they received **less than satisfactory**. These findings have both consistent and inconsistent findings with similar studies conducted overseas. Heyland et al. (2001) reported that 74.0% of family participants were highly satisfied with the treatment they received from intensive care staff in relation to the consideration of their needs. Emotional support, coordination of care and concern and caring by ICU staff were rated as excellent 64.0%, 58.0% and 72.0% respectively. Stricker et al. (2007) reported that 65.0% of family participants were satisfied with the treatment they received from intensive care staff in relation to the consideration of their needs. Emotional support, coordination of care and concern and caring by ICU staff were rated as good 68.0%, 68.0% and 58.0% respectively. Consistent findings are related to co-ordination of care and concern and caring by ICU staff. Inconsistent findings are related to consideration of

family members' needs and the provision of emotional support which were rated higher in comparison with this study's findings.

Participants perceived competence and skills of doctors and intensive care nurses as more satisfactory (**items 1.8 to 1.11**). Family were mostly satisfied (> 50.0%) for nurses and doctors skill and competence, and it was noted that family were **more satisfied with doctor competence and skills than those of nurses** (45.0% vs. 35.0%). However, some participants were also more dissatisfied with intensive care nurses frequency of communication (36.0%; n=36). The strength of this finding is further supported by comments in the open ended items, where it was suggested by participants that some nurses have a '**bad attitude**' towards family. These findings indicated that participants rated more satisfaction with doctors than intensive care nurses. However, participants were also **dissatisfied with frequency of nurse's communication** with them. These findings are inconsistent with Heyland et al. (2001) study where 62% of participants' scores were for excellent demonstrating their satisfaction with the nurse's communication other inconsistent findings in this study included increased satisfaction with both doctor and nurses competence and skills (63.0% vs.72.0%) respectively this illustrates that in this study the nurses competence and skills were rated higher than the doctors competency and skill. In addition Stricker et al. (2007) findings also suggest increased satisfaction with both doctors and nurses skills (60.0% vs 56.0%) respectively. Furthermore 59.0% of participants were satisfied with the frequency of nurses' communication and 65.0% of participants were satisfied with the frequency of the doctors' communication.

Participants had mixed views on the intensive care atmosphere (**items 1.12 to 1.14**), where the intensive care unit itself was rated higher than the waiting room. Findings indicated

participants were more satisfied (65.0%, n=65) with the intensive care unit atmosphere, whereas they were more **dissatisfied with the waiting area (93.0%; n=93). The strength of this finding was further supported by 49.0% (n=49) participants** as additional comments in the open ended items (item 2.14 to 2.16) of the data collection instrument. **Overall participants were more satisfied (91.0%; n=91)** with the care received in intensive care. In this study, this finding is consistent with Heyland et al. (2001) these authors conducted a study in Canada, where they reported overall satisfaction with care as 93.0% in addition consistent with this study's findings a similar study was conducted in Switzerland where the authors reported overall satisfaction with care as 83.0% (Stricker, et al., 2007).

In this study, the second part of the questionnaire aimed to elicit participants' perceptions of their level of satisfaction with decision making in the intensive care unit. Fourteen items supported the results and discussion in this part of the questionnaire. In addition, a further three items supported the bereaved participant of patients who had died in intensive care.

Participants perceived the **information for decision making as more satisfactory** than excellent (**items 2.1 to 2.6**), where the highest (>70.0%) scores were obtained for ease of getting information (70.0%; n=70), understanding of information (71.0%; n=71), consistency of information (70.0%; n=70) and honesty of information (69.0%; n=69). Some participants were **dissatisfied (25.0%; n=25) with frequency of communication with doctors (item 2.1), and completeness of information (item 2.5)**. These findings indicated that participants rated **more satisfaction (for four of six items) with decision making**. Findings indicated that participants were **more satisfied with the information received** in the intensive care unit. However it is notable that **frequency of**

communication with doctors and completeness of information was perceived as less satisfactory. Some of these findings are consistent with a similar study which was conducted by Heyland et al. (2001). Participants in their study were least satisfied with the frequency of communication with ICU doctors (score=67). Another study conducted had consistent findings and reported that participants in their study also expressed least satisfaction with the frequency of communication with ICU doctors (62 ± 27) (Stricker, et al., 2007).

Participants perceived the process for inclusion in decision making as less than satisfactory (**items 2.7 to 2.10**), where the highest (>60.0%) scores were **obtained for excluded (65.05; n=65) and unsupported (63.0%; n=63)** during the decision making process (63.0%; n=63). Of the remaining two items participants perceived their satisfaction with decision making process between 59.0% and 66.0% as **having control over the care** of the patient (item 2.9) and **adequate time to have concerns addressed** (item 2.10). Findings indicated that participants were **dissatisfied with the degree of exclusion and support** received during the decision making process. However, participants were **more satisfied with control and adequacy of time** taken to address their concerns in intensive care. These findings are inconsistent with two studies conducted overseas. Firstly, Heyland et al. (2001) reported that in their study 66.0% of participants felt included in decision-making, 64.0% felt supported during decision-making, 49.0% had control over care. Secondly, Stricker et al. (2007) reported that in their study 60.0% of participants felt included in decision-making, 76.0% of participants felt supported during decision-making and 54.0% of participants had control over care the patient received. Findings from these two studies show that family members were less satisfied with the amount of control they had over the care the patient received.

Bereaved participants perceived decision making process as a more mixed view, with aspects of more satisfied and dissatisfied (**items 2.11 to 2.13**). Bereaved participants perceived as being more satisfied (>50.0%) with decision making process for two items, namely overall view (55.6%; n=5) and views during the last hours of family member death (55.6%; n=5), whereas some participants perceived as markedly satisfied (33.3%; n=3) during the final hours of their loved ones life (item 2.12). These findings suggest **bereaved participants are more satisfied with decision making process than other family members of patients** in intensive care. However, as the sample size (n=9) was small these findings cannot be generalised to include all bereaved families opinions in intensive care. Consistent with these findings Wall et al. (2007) conducted a study in the USA and reported that when a patient died in ICU family's satisfaction with the care received was superior to those families of patients who lived. Factors that contributed to this was that family members felt included in decision-making, received adequate emotional support and was shown respect, compassion and their needs were taken into consideration. These findings are also consistent with Stricker et al. (2009) study which was conducted in Switzerland. These authors' findings revealed increased satisfaction with the provision of information and decision-making when a patient died in ICU.

Of the total questionnaire, **ten of twenty four items** were found to be statistically significant ($p < 0.05$). Six of fourteen items comprised satisfaction with care (part one) and four of ten items were related to satisfaction with decision making (part two). Total questionnaire scores were utilised to compare selected family demographic categorical variables, namely gender, education, population and prior exposure to intensive care. Related to gender, findings indicated that of the twenty four satisfaction with care and decision making items, only one item (item 1.4) was statistically significant ($p = 0.038$) for

gender. **This item related to participants perception of satisfaction with symptom management specifically related to management of agitation.** Related to education, findings indicated that of the total twenty four satisfaction with care and decision making items, seven items namely, item 1.6 ($p=0.003$), item 1.7 ($p=0.024$), item 1,11 ($p=0.047$), item 2.1 ($p=0.024$), item 2.5 ($p=0.001$), item 2.6 ($p=0.000$) and item 2.8 ($p=0.046$) was statistically significant ($p<0.05$) for education. **These items related to how participants were treated, particularly related to emotional support provided by intensive care staff, and coordination of care by the intensive care team (item 1.7), skill and competence of intensive care doctors (item 1.11), completeness of information (item 2.5), consistency of information (item 2.6) and degree of support during decision making process (item 2.8).** Related to population, findings indicated that of the total twenty four satisfaction with care and decision making items, **only one item (item 1.11) was statistically significant ($p=0.044$).** **This item related to participants perception of skills and competence of intensive care doctors.** Related to prior exposure to intensive care, findings indicated that of the total twenty four satisfaction with care and decision making items, **only one item (item 1.6) was statistically significant ($p =0.035$).** **This item related to how participants were treated, particularly related to emotional support provided by intensive care staff.**

4.5 SUMMARY

This chapter discussed the descriptive and comparative statistics that were used to describe and analyse the data collected. The data and interpretation of findings were presented.

Overall satisfaction with care for the patient and family member was rated by participants as slightly higher than satisfaction with decision-making. However participants rated the care provided to the patient as superior than the care and treatment that they received from the ICU staff.

Overall the study showed that 91.0% (n=91) of participants were mostly satisfied with the care provided to them and the patient, by the ICU staff. Of the 24 items the items that were most highly rated by participants, was that of symptom management of the patient. The symptom management of agitation satisfied 85.0% (n=85) of participants, while the treatment of the symptom of breathlessness satisfied 73.0% (n=73) of participants. Other highly rated areas were the understanding of information which rated 71.0% (n=71) satisfactory. Both consistency of information and the ease of getting information were rated as 70.0% (n=70) good.

The least satisfied item in the study related to the waiting room which was rated as 93.0% (n=93) dissatisfactory by participants. This was either due to an inadequate waiting room or lack of a waiting room.

Other items that were identified as less than satisfactory were the frequency of communication by the ICU nurses', rated as poor by 36.0% (n=36) of participants. Frequency of communication with ICU doctors and the completeness of information, both rated as poor by 25.0% (n=25) of participants. The emotional support provided by the ICU staff was rated as 22.0% (n=22) poor by participants.

The process of decision making was rated as dissatisfactory in terms of 65.0% (n=65) of participants feeling excluded and 63% (n=63) feeling unsupported during the process.

Bereaved participants were more satisfied with the process of decision-making than participants whose family member had survived.

The results from the open ended questions highlighted some areas for improvement, which included:

- flexible visiting hours or visiting hours twice daily preferably in the afternoon and at night to suit working hours
- provision of an adequate waiting room
- In respect of the nurses' recommendations a change in their attitude to be friendlier and more approachable.

Ten of twenty four items were found to be statistically significant ($p < 0.05$)

- Six of fourteen items comprised satisfactions with care were found to be statistically significant.
- Four of ten items comprised satisfactions with decision-making were found to be statistically significant.

The following chapter will discuss the limitations of the study, summary of research findings, conclusions and recommendations for further research.

CHAPTER 5

SUMMARY AND CONCLUSIONS

5.1 INTRODUCTION

This concluding chapter of the research report presents the summary of the study, main findings are discussed and the limitations are described. This is followed by recommendations for clinical nursing practice, education, the institution and future research based on the findings of this study.

5.2 SUMMARY OF THE STUDY

5.2.1 Purpose of the study

The purpose of the study was to describe family members' opinions regarding the quality of care and decision-making in the intensive care unit.

5.2.2 Objectives of the study

The objectives of the study were to describe families' satisfaction with care provided in the intensive care units, and families' satisfaction with decision-making in the intensive care units.

5.2.3 Methodology

The Committee for Research on Human Subjects (Medical) of the Witwatersrand (protocol number M10421) (Appendix B) granted ethical clearance before commencement of the study. Permission was further obtained prior to commencement of the study from the Faculty of Health Sciences Postgraduate Committee (Appendix A), the Deputy Director of Gauteng Health Department (Appendix C) and the Chief Executive Officer of the Hospital.

Three adult intensive care units at a tertiary public sector hospital were used to conduct the study. A statistician was consulted prior to data collection and a sample size of 100 was decided to be acceptable, this ensured a power of at least 95% accuracy in findings which was acquired to achieve 0.05 level of significance ($p < 0.05$) testing.

To test the feasibility of the study, understanding of the information letter, informed consent form and questionnaire a pilot study was conducted. The pilot study consisted of 10 participants, who were interviewed prior to the commencement of the main study. Structured interviews were conducted with 91 of the participants and telephonic interviews were conducted on 9 bereaved participants. The instrument used for both the structured and telephonic interviews was the FS-ICU (24) questionnaire. The questionnaire comprises 24 items with a predominant 4 point Likert scale. Satisfaction of care consisted of 14 items and satisfaction with decision-making consisted of 10 items. To elicit suggestions and comments from participants three open ended questions were included at the end of the questionnaire.

To meet the study's objectives a quantitative, descriptive research design was used. Data was collected over a three month period during the months of September, October and November 2010. Descriptive and comparative statistics were used to analyse the data which was done in consultation with a statistician.

5.3 SUMMARY OF RESEARCH FINDINGS

The purpose of this study was to describe family members' opinions regarding the quality of care and decision-making, during their loved ones admission to one of the three adult intensive care units. In this study structured interviews were conducted with 91 participants. The 9 bereaved participants were interviewed telephonically using the same FS-ICU (24) questionnaire. Interviews were done with the admission period of the patient >72 hours and < than three weeks.

The first objective of the study was to describe families satisfaction with care provided in the intensive care units. The first part of the questionnaire measured satisfaction with care. The majority (more than 50.0%) of participants scored their satisfaction with care as predominantly good to excellent. Overall participants reported a higher level of satisfaction with patient care whilst a lower level of satisfaction was reported with regard to family care. Participants were satisfied with the amount of care received but the level of satisfaction varied dependant on the aspect of care in question. Participants perception of concern, care, courtesy, respect, compassion afforded to the patient scored 53.0% (n=53) indicating that such treatment was excellent. In comparison, the same question was asked

in relation to the family, and 26.0% (n=26) indicated that such treatment was excellent. This highlights the differing perceptions of patient care in comparison to family care.

The provision of emotional support to the family, consideration of the family's needs and frequency of communication with the family by the ICU nurses was for the most part regarded as good. However a significant portion (22.0%; n=22, 17.0%; n=17 and 36%; n=36) respectively of participants gave poor scores. Results showed that 65.0% (n=65) of participants rated the teamwork as good. Families rate doctors skill and competence higher than nurses skill and competence 45.0% (n=45) excellent and 35.0% (n=35) for excellent respectively. Of the participants 65.0% (n=65) rated the atmosphere of the ICU as good.

The vast majority (91.0% n=91) of participants felt mostly satisfied with the amount of care received in the ICU. This finding concurs with a study conducted in Canada by Heyland et al. (2001) using the FS-ICU (24) questionnaire. Their finding for overall care was 93.0%.

Participants were mostly satisfied with the management of patient symptoms and patient care. The highest rating for satisfaction was for the management of patients' symptoms of agitation (85.0%; n=85), breathlessness (73.0%; n=73) and pain (65.0%; n=65). Participants were least satisfied with the atmosphere of the ICU waiting room and the frequency of communication with ICU nurses, 93.0% (n=93) of participants reported that the atmosphere of the waiting room was poor and 36.0% (n=36) of participants reported that the frequency of communication with ICU sisters was poor. These findings of been mostly satisfied with patient care and least satisfied with the atmosphere of the ICU waiting room, are consistent with the Stricker et al. (2007) study.

The second objective of the study was to describe family's satisfaction with decision-making in the intensive care units. The second part of the questionnaire measured satisfaction with decision-making. Overall the majority (more than 50.0%) of participants scored their satisfaction with decision-making as predominantly good.

Participants were mostly satisfied with the understanding of information from the ICU staff; the consistency of information, ease of getting information and the honesty of information reportedly scoring 71.0% (n=71), 70.0 % (n=70), 70.0 % (n=70) and 69.0% (n=69) for good. Of the participants 59.0 % (n=59) felt neither in control nor out of control with regard to the care the patient received and 66.0% (n=66) of participants felt that they had adequate time to make decisions. Participants were least satisfied with the frequency and completeness of information. Both scoring 25.0% (n=25) for poor. In addition, 65.0% (n=65) of participants felt excluded and 63.0% (n=63) felt unsupported during decision-making.

In this study findings suggest that family members have an increased level of satisfaction with care as compared to their satisfaction with the provision of information and feeling included and supported during decision-making processes. This concurs with two other family satisfaction studies conducted overseas where participants rated their overall satisfaction with care as been higher than their satisfaction with decision-making. One of which was conducted in Canada (Heyland, et al., 2001). The other of which was conducted in Switzerland (Stricker, et al., 2007).

Bereaved participants were more satisfied with the decision-making process than other participants of patients. However the sample size was small to generalise these findings.

Of the open ended questions close to half 49.0% (n=49) of the sample suggested the need to improve information and communication between the doctor, nurses and family as this would improve care in the ICU. Suggestions were made from 27.0% (n=27) of participants to have more flexible visiting hours and preferably visiting hours twice a day. A quarter 26.0% (n=26) of the sample commented on unsatisfactory conduct of nurses.

Fisher's exact test was applied to test for significance of differences in the frequencies of responses for satisfaction with care and satisfaction with decision-making. Ten of twenty four items were found to be statistically significant ($p < 0.05$) using the Fisher's exact test to compare item scores. Comparison of participants' demographic variables included gender, education, population and prior ICU exposure. Six of fourteen items comprised satisfaction with care (part one) were found to be statistically significant and four of ten items were related to satisfaction with decision-making (part two) were found to be statistically significant.

5.4 LIMITATIONS OF THE STUDY

The researcher acknowledges the following as limitations in this study:

- A small sample size
- Three intensive care units at one public sector tertiary hospital
- It was at the time of the biggest strike experienced in South Africa
- The inclusion of only nine bereaved participants.

- The researcher's presence during the interview may have limited the participants' disclosure or honesty of problems for possible fear of patient victimization.
- Study did not include families as participants once patients were discharged.
- No consideration was given to the severity of illness.

Generalisation of findings is restricted by the above mentioned limitations, however replication of the study in other intensive care units of other public sector hospitals should be undertaken to support or oppose these findings.

5.5 CONCLUSION

This study is based on the family systems theory (McClowry, 1992) and the crisis theory (Haber, 1982) with the belief that the patient cannot be nursed monastically; the family forms an integral part of holistic nursing care. Needs arise from the crisis and if these needs are met family satisfaction increases thereby involving the family in care and decision-making will in turn enhance patient recovery and outcomes. The purpose of this study was to describe family members' opinions regarding the quality of care and decision-making in the intensive care unit.

The results of this study showed that family members have an increased level of satisfaction with care as compared to their satisfaction with the provision of information and feeling included and supported during decision-making processes. This study provides insight into the experiences of family and their level of satisfaction in the intensive care units. Areas for improvement have been identified especially in the areas of information,

communication, and decision-making. This suggests that there are deficiencies in meeting family' information needs and inadequacies exist in the process of including and supporting family' in decision-making. Findings from this study also suggest that the family's need for proximity is not been met as evidenced by the grievance of rigid visiting hours and the suggestion from family members to have visiting times twice a day.

This study highlights that family needs are not met across all need areas and the ability to meet these needs can only be achieved with a team work approach with doctors and nurses working together in the best interest of the patient, and including family in care and decision-making.

To improve family-centred care and enhance information, communication and decision-making continuous measurement of family satisfaction in the intensive care unit is necessary, as meeting needs does not necessarily give the assurance that families are indeed satisfied.

Results of this study have supported the existing evidence in literature on family satisfaction with care and decision-making in the ICU. However, there are limited family satisfaction studies that have been conducted in South Africa. Most studies were conducted in western countries which cannot be compared to South Africa's unique ICU setting and the diversity of cultures, languages that constitute the population in Gauteng and the country as a whole.

5.6 RECOMMENDATIONS OF THE STUDY

There is insufficient literature on family satisfaction in the ICU from a South African perspective. Further research needs to be conducted in South Africa to examine family satisfaction with care and decision-making in intensive care units. Heyland et al. (2001) indicate that there are many studies that have been done which have focused on family needs but only a few studies have been done assessing family satisfaction with care in the ICU. Patient-centred care has progressively advanced with nursing practice focussing on patient and family needs in synchrony to ultimately benefit the patient, encourage optimal recovery and promote positive outcomes (Alspach, 2006). Holistic nursing care implies that the patient is not cared for in isolation but that the family is included in care and is cared for in an empathetic and compassionate manner (Mendonca, et al., 1998). Thus patient-centred care should encompass family-centred care which means that families are involved in care and decision-making. Especially given the fact that families assume the responsibility of decision makers on behalf of the patient (Wall, et al., 2007). Meeting family's needs and practicing family-centred care reduces the stress experienced by the family and nurse during critical illness and subsequent admission into ICU (Wilkinson, 1995). The positive contribution that family members make is beneficial to the patients' recovery and wellbeing. The findings of this study forms the platform on which the following recommendations are made.

5.6.1 Recommendations for nursing practice

Information and communication

Numerous studies have identified the need for information as the most important family need, but families often receive information that is not easily understood and inadequate (Auerbach, et al., 2005; Verhaeghe, et al., 2005; Soderstrom, et al., 2006). Leske (1986) suggests that the provision of information is essential to enable families to make informed decisions. Azoulay et al. (2001) identified that an association exists between the provision of adequate information and family satisfaction. Findings in this study suggest that 36.0% (n=36) of participants were dissatisfied with the frequency of communication with ICU nurses and 25.0% (n=25) were dissatisfied with the frequency of communication with ICU doctors. In addition 25.0% (n=25) of participants were given incomplete information. These findings suggest paternalism and lack of information, and inconsistent communication by nurses and doctors. This is contrary to the shift to a family-centred approach and inclusion of families in care and decision-making. Findings from the open ended questions indicated that 49.0% (n=49) of participants suggested that better provision of information and enhanced communication between the doctor, nurses and family would improve care in the ICU.

Furthermore areas that were perceived by participants as dissatisfactory were the process of decision-making. Findings revealed that 65.0% (n=65) of participants felt excluded in decision-making and 63.0% (n=63) felt unsupported during decision-making. This study highlights that family needs are not met across all need areas and the ability to meet these needs can only be achieved with a team work approach with doctors and nurses working together in the best interest of the patient, and including family in care and decision-making. In this study the level of education was 74.0 % for less than high school and high school 37.0% respectively. This highlights the need to simplify the information provided to

family members and the necessity for the nurse to act as a mediator between the doctor and the family. The implementation of a shared decision-making model encourages the development of a partnership between doctors, nurses and family members (Davidson, et al., 2007). This emphasizes the importance of frequent and effective communication and the provision of adequate and complete information. Previous studies have shown that providing complete and adequate information will enhance communication (Heyland, et al., 2001). Thus increased communication and the exchange of adequate information between the healthcare team and the patient-family unit could alleviate the stress and anxiety that is associated with critical illness and admission to ICU. Furthermore, Johnson et al. (1998) point out that communication between the healthcare team and the family is the main factor which determines family satisfaction in the ICU. Implication of findings for the practice of critical care nurses are the following:

The exchange of increased information and effective communication can be provided in the following ways:

- Family members could join doctors' ward rounds daily to give the family an opportunity to ask questions with regards to medical procedures, treatment goals, condition and prognosis of the patient. This will ensure that family members have frequent access to doctors and nurses. And it will encourage the exchange of information and prevent misunderstanding between the doctors, nurses and family. In addition this will allow family members to feel included and supported during decision-making processes.
- Collaboration between the healthcare team to improve communication between themselves and the patient-family unit in order to better the channels of

communication amongst doctors and nurses, nurses and nurses, doctors and family and nurses and family. The purpose would be to ensure the provision of consistent and complete information to family members.

- On admission families receive an information booklet containing pertinent information about the ICU. The benefits of a information booklet for the family is that the family can read it in their own time, any additional questions to nurses can be alleviated, it can be one source of dependable and consistent information about the ICU procedures, routines, visiting times, contact details, ways in which the family can participate in care and preferred channels of communication available to them.

Care and emotional support for the family

The role of the nurse is to care for the family (Hupcey, 1999) and to meet the needs of family's (El- Masri, et al., 2007). Caring for the family in crisis, meeting family's needs and including family's in care reduces the amount of stress associated with the critical illness of a loved one (Pryzby, 2005). If families feel cared for and supported they in turn will be in a better position to care for and support the patient (Burr, 1998). It is necessary for nurses to ultimately help families cope with this stressful event (Morton & Fontaine).

This study's findings revealed that 22.0% (n=22) of participants were dissatisfied with the emotional support provided to them by the ICU nurses and 17.0% (n=17) of participants were less than satisfied with the consideration of their needs.

The implication of findings for the practice of critical care nurses are the following:

- emphasize the need for family-centred care. Encourage a more humane approach in the care of patients and their families to enhance healing in a therapeutic environment.
- nurses to recognize the impact of emotional support on families and consideration of families' unique needs in a sensitive manner. Families make positive contributions to the outcome of the patient, particularly if they in turn are supported by the health care team. This results in benefits for both the patient and the family.
- the importance of the nurse's role in reducing family stress and helping families cope with the crisis

In the open-ended questions of this research study, participants emphasized the unsatisfactory conduct of nurses in particular their "bad attitude", unfriendliness, inapproachability and general fear of enquiries about the patient. This is a great concern partly because it does not involve all nurses and partly because it is difficult to quantify the empirical evidence on the exact behavioural issues at hand. Participants highlighted particular behavioural traits such as unfriendliness, inapproachability and bad attitude but this is exactly what makes this a challenging conundrum as attitude cannot necessarily be "trained" or improved upon by external factors. Instead it is driven by an individual's disposition and or willingness to recognise a need for change or improvement in conduct.

Family's need for proximity has being identified as a priority need in numerous studies (Leske, 1986; Wilkinson, 1995; Mendonca, et al., 1998; Verhaeghe, et al., 2005) Yet despite this family members are denied access to the patient unless during visiting times as evidenced in this study by the responses from the open ended questions. Acknowledgment is made of the fact that nurses cannot change the institutions' visiting policy, however

recommendations for clinical nursing practice would be to encourage nurses to make appropriate judgement calls where applicable in certain given circumstances such as a deteriorating condition of the patient this should be assessed and be dependent on the individual needs of the patient and family. Van Horn et al. (2007) suggest that open visitation has advantages such as improving family participation in care as well as communication with the nurse and it decreases the number of complaints by the family.

5.6.2 Recommendations for nursing education

El-Masri et al. (2007) suggests that there is a deficit of education for nurses in the theory and practice of family nursing and the importance of looking after families. Recommendations for nursing education would be for critical care nurses to receive further education and training on the following:

- holistic nursing care which encompasses body, mind and spirit of both the patient and the family
- communication skills to ensure effective communication between nurses and families
- assessment of families coping abilities to refer to counsellors for de-briefing or social workers if necessary.
- assessment of families during decision-making process ensuring that families understand the information been provided to enable the family to make informed decisions.
- the identification and meeting of needs that are unique to each family

- Family advocates who assist families during times of crisis and who can spend more time with the family. This will serve as an additional source of support and comfort for the family, improve communication, improve the provision of information and assist in the decision-making process and ensure that families' needs are met (Tolbert, 2001).
- Shared decision-model which allows a partnership between the doctors, nurses, patient and family. This will ensure sufficient information and the family will gain the necessary tools to make decisions. Its aim is to decrease family anxiety and enhance family coping abilities (Davidson, et al., 2007)
- Critical care assistance programme (CCFAP) to ensure that family needs are met, information sharing is improved and informed decision-making enhanced (Morton, et al., 2009).

5.6.3 Recommendations for nursing research

The study was conducted at one institution a replication of this study from a larger population in other public sector intensive care units is necessary to support findings in this study. Data collected from further research on family satisfaction may provide indicators to improve the quality of care and decision-making experienced by family members of patients admitted into intensive care units. Furthermore additional research is required to recognize new approaches to improve family's experiences in the event of critical illness and admission into ICU.

5.6.4 Recommendations for the institution

Suggestions made from the open ended questions by participants were specifically directed at the institution to improve families' experiences in the intensive care unit:

- Make provision for a comfortable waiting room in close proximity to the ICU for the family members of patients who are admitted into the ICU.
- To revise the current visiting policy, open visiting times and individualized visiting policies in the best interest of the patient and family. Exceptions could be made for the ICU's of the hospital given the nature of critical illness and high incidence of death associated with admission into the ICU.
- The provision of an information booklet about the ICU for family members.

This chapter concludes the research report. To expand literature on family satisfaction from a South African perspective the continual assessment and measurement of families' experiences, opinions and perceptions of care and decision-making in intensive care units is required to use the data collected to improve the process of quality care delivery and informed decision-making for optimal family-centred care.

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Reference: Ms Tania van Leeve
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03 June 2010
Person No: 328641
PAG

Ms G Rodrigues
P O Box 73454
Fairlands
Johannesburg
2030
South Africa

Dear Ms Rodrigues

Master of Science in Nursing: Approval of Title

We have pleasure in advising that your proposal entitled "*Families opinions regarding care in adult intensive care units at a public sector tertiary hospital in Gauteng*" has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

A handwritten signature in cursive script, appearing to read 'S Benn'.

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX B

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ms Gaynor Rodrigues

CLEARANCE CERTIFICATE

M10421

PROJECT

Families' Opinions Regarding Care in Intensive
Care Units at a Tertiary Hospital in Gauteng

INVESTIGATORS

Ms Gaynor Rodrigues.

DEPARTMENT

Department of Nursing Education

DATE CONSIDERED

30/04/2010

DECISION OF THE COMMITTEE*

Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 04/06/2010

CHAIRPERSON



(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Dr G Langley

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

 15.07.2010

CONDITIONS OF APPROVAL OF RESEARCH CONDUCTED GAUTENG DEPARTMENT OF HEALTH
AND SOCIAL DEVELOPMENT (GDHSD)

For approval by Director: Policy, Planning and Research



HEALTH AND SOCIAL DEVELOPMENT
(GDHSD)
POLICY, PLANNING AND RESEARCH (PPR)
Enquiries: Sue le Roux
Tel: +2711 355 3212
Fax: +2711 355 3675
Email: Sue.LeRoux@gauteng.gov.za

CONTACT DETAILS OF THE RESEARCHER	
Date	24 August 2010
Tel number	+27-11-469-5547 (Office), +27-83-208-6265 (mobile)
Email	shelley.schmollgruber@wits.ac.za
Researcher /Principal investigator (PI)	Gaynor Rodrigues
Supervisor	Shelley Schmollgruber
Institution	Nursing Department of University of Witwatersrand
Research title	Families opinions regarding care in adult intensive care units at a public sector tertiary hospital in Gauteng

ONLY FOR APPROVAL OF THE RESEARCH STUDY TO BE CONDUCTED BY GAYNOR RODRIGUES ENTITLED "FAMILIES OPINIONS REGARDING CARE IN ADULT INTENSIVE CARE UNITS AT A PUBLIC SECTOR TERTIARY HOSPITAL IN GAUTENG"

Approval is hereby granted by the Gauteng Department of Health and Social Development for the above research project to be conducted. Approval is limited to compliance with the following terms and conditions:

1. All principles and South African regulations pertaining to ethics of research are observed and adhered to by all involved in the research project. Ethics approval is only acceptable if it has been provided by a South African research ethics committee which is accredited by the National Health Research Ethics Council (NHREC) of South Africa; this is regardless of whether ethics approval has been granted elsewhere.

Of key importance for all researchers is that they abide by of all research ethics principles and practice relating to human subjects as contained in the Declaration of Helsinki (1964, amended in 1983) and the constitution of the Republic of South Africa in its entirety. Declaration of Helsinki upholds the following principles when conducting research, respect for:

- Human dignity;
 - Autonomy;
 - Informed consent;
 - Vulnerable persons;
 - Confidentiality;
 - Lack of harm;
 - Maximum benefit;
 - and justice
2. The GDHSD is indemnified from any form of liability arising from or as a consequence of the process or outcomes of any research approved by HOD and conducted within the GDHSD domain;
 3. Researchers commit to providing the GDHSD with periodic progress and a final report; short term projects are expected to submit progress reports on a more frequent basis and all reports must be submitted to the Director: Policy, Planning and Research of the GDHSD;
 4. The Principal Investigator shall promptly inform the above mentioned office of changes of contact details or physical address of the researching individual, organisation or team;
 5. The Principal Investigator shall inform the above office and make arrangements to discuss their findings with GDHSD prior to dissemination;
 6. The Principal Investigator shall promptly inform the above mentioned office of any adverse situation which may be a health hazard to any of the participants;
 7. The Principal Investigator shall request in writing authorization by the HOD via PPR for any intended changes of any form to the original and approved research proposal;
 8. If for any reason the research is discontinued, the Principal Investigator must inform the above mentioned office of the reasons for such discontinuation;
 9. A formal research report upon completion should be submitted to the Director: Policy, Planning and Research of the GDHSD with recommendations and implications for GDHSD, the Directorate will make this report available for the HOD.

AGREEMENT BETWEEN THE GAUTENG DEPARTMENT OF HEALTH AND SOCIAL DEVELOPMENT (GDHSD)
AND THE RESEARCHER

Ms. S le Roux

Director: Policy, Planning and Research

Date: 24/08/2010

Signature:



Name and surname of Principal Researcher

Research/Academic Institution

Date:

Signature:

Information Letter

Good day

My name is Gaye Rodrigues and I am currently a Master of Science (Nursing) student at the University of the Witwatersrand. A requirement as part of my course is that I conduct clinical research.

I am investigating families' opinions of the care provided to them by the healthcare team in the Intensive Care Unit. You have been selected as a potential participant for this research study as your loved one has recently been admitted to the adult general ICU. I would therefore be grateful for a few moments of your time to voice your opinion of what you have experienced thus far, and may I invite you to consider participation. Your thoughts and feelings will contribute towards a valuable and meaningful study and the results will be used to improve family centered care in ICU.

My reason for doing this research is that it is a time of crisis when someone you love is admitted unexpectedly into ICU and families need to receive support during this time. Family satisfaction surveys have been studied extensively in other countries such as the USA, Canada and Europe. However few such studies have been conducted in South Africa.

You as the family member or significant other play a very important part as you provide care, love, comfort and protection for your loved one. Your loved one may be unable to speak for him or herself and you may be faced with the most overwhelming decisions. The provision of adequate information, being cared for and feeling supported through this difficult time is vital.

If you chose to participate I will sit with you in a private room and ask you some questions related to your satisfaction with care (14 questions) and decision making (10 questions) in the ICU. You will need to select what is most appropriate for you i.e.: excellent, good and poor or not applicable. The interview will take between 10-15 minutes of your time.

Sharing your experience in completing the questionnaire will allow us to take the necessary measures to improve family-centered care in the ICU. Future families who find themselves in a similar position as you will benefit through improved care and support during this emotionally traumatic time in their lives. If after this interview you feel anxious and distressed an experienced and qualified counselor will be made available for debriefing.

The choice to participate is entirely yours. There will be no negative consequences for you or your loved one if you refuse to participate. If you do agree to be part of the study you may withdraw at any given time. Your identity will be protected at all times i.e. numbers will be used to identify each participant; your name will not appear on any of the research forms or on the research report. A record of the names will be kept by me in a notebook under strict lock and key. A copy of the final research report can be made available on request. Please supply your postal address if necessary. If you completely understand the information above and if you are willing to be a participant in this research report please could you sign the attached consent form.

Thank you for your interest and for considering participation in this meaningful and valuable study. Please contact me should you have any further questions on 083 208 6265 or 011 469 5547.

Yours Faithfully
Gaye Rodrigues

Consent Form

Families' opinions of care in the intensive care unit

MSC Nursing University of Witwatersrand-Student: G Rodrigues 328641

I agree to participate in this research project investigating the families' opinions of care in the Intensive Care Unit.

I have read the information letter and understand what the study is all about. I also understand that my participation is voluntary and that I can withdraw at any given time without any consequences.

I agree to answer the questions honestly. All information will remain confidential and my name will not appear anywhere on the questionnaire or the research report.

Number assigned: 7

Signature: M. Rodrigues

Study ID number _____

**Family satisfaction with Care in the Intensive Care Unit
FS-ICU (24)**

Your family member is/was a patient in this ICU. The questions that follow ask **you** about your family member's most recent ICU admission. There were probably many doctors, nurses and other staff involved in caring for your family member. There may be exceptions but of interest to this study is **your overall assessment** of the quality of care that was delivered to you and your family member. This was probably a very difficult time for you and your family. It would be appreciated if you would take the time to provide your opinion about what was done well and what can be done to make the ICU better. Please be assured that all responses are confidential. The Doctors and Nurses who looked after your family member will not be able to identify your responses.

1. PATIENT DEMOGRAPHIC DATA

1.1	Age	<20	20-39	40-59	60-79	>79
1.2	Gender	Male		Female		
1.3	Date of admission					
1.4	Diagnosis on admission					

Could you please describe the patients (Your family members) condition, include any complications and the prognosis?

2. PARTICIPANT DEMOGRAPHIC DATA

Please complete the following about yourself and your relationship to the patient.

2.1 Gender: Male Female

2.2 Age: years old

2.3 Home language:

2.4 Population group:

2.5 Education level:

<input type="checkbox"/> <High School	<input type="checkbox"/> High School	<input type="checkbox"/> Some College	<input type="checkbox"/> University	<input type="checkbox"/> Advance Degree
---------------------------------------	--------------------------------------	---------------------------------------	-------------------------------------	---

2.6 Relationship to patient:

<input type="checkbox"/> Wife	<input type="checkbox"/> Husband	<input type="checkbox"/> Partner	<input type="checkbox"/> Mother	<input type="checkbox"/> Father
<input type="checkbox"/> Sister	<input type="checkbox"/> Brother	<input type="checkbox"/> Daughter	<input type="checkbox"/> Son	

Other (please specify):

2.7 Before this most recent event, have you been involved as a family member of a patient in an ICU (intensive care unit)?

Yes No

2.8 Do you live with the patient?

Yes No

If no, then on average how often do you see the patient?

<input type="checkbox"/> More than weekly	<input type="checkbox"/> Weekly	<input type="checkbox"/> Monthly	<input type="checkbox"/> Yearly	<input type="checkbox"/> Less than once a year
---	---------------------------------	----------------------------------	---------------------------------	--

2.9 Where do you live?

City Out of town

2.10 Distance to the hospital?

<input type="checkbox"/> < 1 hr drive	<input type="checkbox"/> 1-3 hr drive	<input type="checkbox"/> > 3 hr drive
---------------------------------------	---------------------------------------	---------------------------------------

PART 1: SATISFACTION WITH CARE

Please tick one box that best reflects your views. If the questions does not apply to your family members stay then tick the not applicable box (N/A)

HOW WAS YOUR FAMILY MEMBER TREATED (THE PATIENT)

1. **Concern and Caring by ICU staff:**

The courtesy, respect and compassion your family member (the patient) was given

Excellent	Good	Poor	N/A
-----------	------	------	-----

Symptom Management:

How well the ICU staff assessed and treated your family members Symptoms

2. **Pain**

Excellent	Good	Poor	N/A
-----------	------	------	-----

3. **Breathlessness**

Excellent	Good	Poor	N/A
-----------	------	------	-----

4. **Agitation**

Excellent	Good	Poor	N/A
-----------	------	------	-----

HOW WERE YOU TREATED?

5. **Consideration of your needs:**

How well the ICU staff showed an interest in your needs

Excellent	Good	Poor	N/A
-----------	------	------	-----

6. **Emotional Support**

How well the ICU staff provided Emotional support

Excellent	Good	Poor	N/A
-----------	------	------	-----

7. **Co-ordination of care:**

The teamwork of all the ICU staff who took care of your family member

Excellent	Good	Poor	N/A
-----------	------	------	-----

8. **Concern and Caring by ICU Staff:**

The courtesy, respect and compassion **you** were given

Excellent	Good	Poor	N/A
-----------	------	------	-----

NURSES:

9. **Skill and Competence of ICU**

Nurses:

How well the nurses cared for your family member

Excellent	Good	Poor	N/A
-----------	------	------	-----

10. **Frequency of communication with ICU nurses:**

How often nurses communicated to you about your family members

Excellent	Good	Poor	N/A
-----------	------	------	-----

condition

PHYSICIANS (All doctors)

11. Skill and competence of ICU

Doctors:

How well doctors cared for your Family member

Excellent	Good	Poor	N/A
-----------	------	------	-----

THE ICU

12. Atmosphere of ICU was

Excellent	Good	Poor	N/A
-----------	------	------	-----

THE WAITING ROOM

13. The atmosphere in the ICU Waiting room was

Excellent	Good	Poor	N/A
-----------	------	------	-----

14. Some people want everything done for their health problems

While others do not want a lot

done. How satisfied were you

with the LEVEL or amount of

health care your family member

received in the ICU?

Very Dissatisfied	Mostly Satisfied	Completely Satisfied
-------------------	------------------	----------------------

PART 2: FAMILY SATISFACTION WITH DECISION-MAKING AROUND CARE OF CRITICALLY ILL PATIENTS

INSTRUCTIONS FOR FAMILY OF CRITICALLY ILL PATIENTS

This part of the questionnaire is designed to measure how you feel about YOUR involvement in decisions related to your family members' health care. In the intensive care unit, your family member may have received care from different people. Please think about all the care your family member received when you are answering the questions.

PLEASE TICK ONE BOX THAT BEST DESCRIBES YOUR FEELINGS

INFORMATION NEEDS

1. Frequency of Communication with ICU Doctors:

How often doctors communicated to you about your family members condition

Excellent	Good	Poor	N/A
-----------	------	------	-----

2. Ease of getting information:

Willingness of ICU staff to answer your questions

Excellent	Good	Poor	N/A
-----------	------	------	-----

3. Understanding of information:

How well ICU staff provided you with explanations that you understood

Excellent	Good	Poor	N/A
-----------	------	------	-----

4. Honesty of information:

The honesty of information provided to you about your family members condition

Excellent	Good	Poor	N/A
-----------	------	------	-----

5. Completeness of information:

How well ICU staff informed you about what was happening to your family member and why things were being done

Excellent	Good	Poor	N/A
-----------	------	------	-----

6. Consistency of information:

The consistency of information provided to you about your family members condition (did you get a similar story from the doctor, nurse, etc.)

Excellent	Good	Poor	N/A
-----------	------	------	-----

PROCESS OF MAKING DECISIONS:

During your family members stay in the ICU, many important decisions were made regarding the health care she or he received. From the following questions, pick one answer from each of the following set of ideas that best matches your views:

7. Did you feel included in the decision making process?

1. I felt excluded.

2. I felt neither included nor excluded.

3. I felt included

8. Did you feel supported during the decision making process?

1. I felt totally overwhelmed.

2. I felt neither overwhelmed nor supported.

3. I felt supported.

9. Did you feel you had control over the care of your family member?

1. I felt really out of control and that the health care system took over and dictated the care my family member received.

2. I felt neither in control nor out of control.

3. I felt that I had good control over the care my family member received.

10. When making decisions, did you have adequate time to have your concerns addressed and questions answered?

1. I could have used more time.

2. I had adequate time.

If your family member died during the ICU stay, please answer the following questions (11-13). If your family member did not die please skip to question 14.

11. Which of the following best describes your views:

1. I felt my family member's life was prolonged unnecessarily.

2. I felt my family member's life was neither prolonged nor shortened unnecessarily.

3. I felt my family member's life was shortened unnecessarily.

12. During the final hours of your family member's life, which of the following best describes your views?

1. I felt that he/she was very uncomfortable.

2. I felt that he/she was mostly comfortable.

3. I felt that he/she was totally comfortable.

13. During the last few hours before your family members death, which of the following best describes your views:

1. I feel very abandoned by the health care team.

2. I felt neither abandoned nor supported by the health care team.

3. I felt supported by the health care team.

14. Do you have any suggestions on how to make care provided in the ICU better?

15. Do you have any comments on things that were done well?

16. Please add any comments or suggestions that you feel may be helpful to the staff of this hospital.

Thank you very much for your participation and your opinions.

APPENDIX G

From: Daren Heyland [<mailto:dkh2@queensu.ca>]
Sent: 24 January 2011 07:01 PM
To: Gaynor
Subject: Re: permission to use the FS-ICU 24 questionnaire

Sure
No problem
Please keep me informed about your results
Daren heyland

Sent from my iPhone

On 2011-01-24, at 7:56 AM, Gaynor <gaynor@vibe.co.za> wrote:

Dear Dr Heyland

My name is Gaynor Rodrigues, I am a postgraduate nursing student at the University of the Witwatersrand in Gauteng South Africa.

I am currently completing a research report for a masters degree specialising in ICU.

I am conducting a quantitative study on family satisfaction of care and decision making in the ICU. My research supervisors are Shelley Schmollgruber and Dr Gayle Langley from the nursing department of the University of the Witwatersrand.

Please may I have your permission to use the FS-ICU 24 questionnaire as my data collection instrument?

Thank you

Yours Sincerely

Gaynor Rodrigues

Gaynor Rodrigues
Department of Nursing Education
Faculty of Health Sciences
University of Witwatersrand
7 York Road
Park town 2193

The Chief Executive Officer
Charlotte Maxeke Johannesburg Hospital
Private Bag x21
Johannesburg

Dear Sir/Madam

I am presently registered as an MSc student at the University of the Witwatersrand in the Department of Nursing Education.

I hereby request your permission prior to the commencement of my research study. The studies primary goal is to improve family centered care in the Intensive care units. The study will involve describing family member's opinions of care and decision making in the adult general Intensive care unit.

The instrument that will be used for data collection is the FS-ICU 24. This instrument was designed in Canada and has never been used in South Africa. It will therefore be validated by a panel of experts. Families will be invited to participate in the study 3 days post admission once their stress levels have declined. If the families loved one has died in ICU a pack of letters will be mailed to the families 3-4 weeks after their loved ones death which will include: a letter of condolence, a information letter and a consent letter. Debriefing and bereavement counseling will also be offered by an experienced counselor.

If the families agree to participate written signed consent will be obtained, and structured interviews will be conducted by me in a private room. Confidentiality will be strictly maintained. No name or identifying information will be written on the any of the data collection forms. Participants will be informed of their rights to withdraw at any point without negative consequences. All data will be kept by me in a locked cabinet. All ethical obligations will be adhered to and the results of the study will be distributed to the adult general ICU and participants if they request a copy of the research report.

Families play such a vital role for their critically ill loved ones. They provide patients with care, love, familiarity, protection and the difficult responsibility of being "surrogate decision makers" Families therefore need to be supported with care, compassion, good communication and easy to understand and accessible information in order to cope optimally with this unforeseen crisis.

We need a tool that can measure family satisfaction as meeting families' needs in ICU does not automatically mean that families are satisfied with the process of care and decision making. Family satisfaction data can be valuable in targeting interventions to improve the quality of family centered care in the ICU. It is essential for the hospital to provide a supportive environment for the family as they form an integral part of patient care and recovery. Attached please find a copy of my research proposal

Yours Faithfully

Gaynor Rodrigues
MSc Nursing student