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PERCEPTIONS OF STAKEHOLDERS ON FAMILY-CENTRED CARE IN THE INTENSIVE CARE UNIT: AN ASSOCIATIVE GROUP ANALYSIS

by

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DEDICATION

To every family member that has sat or will sit in wait. Waiting for results, waiting for an outcome, waiting for information, waiting for that little piece that sustains hope for one more day.

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DECLARATION

I, Rachele Lara Pretorius, declare that this dissertation, titled **“Perceptions of stakeholders on family-centred care in the intensive care unit: an associative group analysis**, is my own work. All sources referenced and quoted have been mentioned and acknowledged in a full reference list. Furthermore, I declare that this work has not been submitted for any other degree at any other institution.

Researcher signature	Date
Witness signature	Date

ABSTRACT

Introduction and background: Family-centred care in the intensive care unit has increased steadily over the past three decades, based on the premise that the illness and health of an individual family member affects the whole family unit. Although widely researched there are still inconsistencies in implementing family-centred care, which influences the ability to transfer research findings into practice. Research has shown that recognising the role of family members in the critical care environment should be considered an essential component to caring for the critically ill patient. Although recommendations have been made for the implementation of family-centred care, it is not feasible for all recommendations to be adopted by nurses and healthcare professionals in a single ICU. Nurses and healthcare professionals need to customise strategies to an individual intensive care unit to improve family-centred care.

Aim: The aim of the study was to explore and describe nurses, healthcare professionals and family members' perceptions of family-centred care in the intensive care unit.

Research design and methods: A quali-quanti research design was used. Participants included nurses, healthcare professionals and family members in the intensive care unit of a private hospital in Gauteng, South Africa. There were a total of sixty (60) participants who took part in the study. Nurses were selected using stratified random sampling, healthcare professionals were selected using total population sampling and family members were selected using purposive, maximum variation and convenience sampling. Data was collected over a period of one month by means of structured interviews using an associative group analysis technique. Participants were asked to write down free word associations in relation to the stimulus word "family-centred care" in order to explore and describe their perceptions of family-centred care in the intensive care unit as it is currently, as it could be in the "ideal world" and any gaps that exist around these perceptions.

Results: Five themes were derived from the data: communication, environment, continuum of feelings, reflections and spiritual care.

Conclusion: The implementation of family-centred care should involve all stakeholders in the intensive care unit in order to address inconsistencies in perceptions around family-centred care.

Keywords: Associative group analysis, intensive care unit, family-centred care, healthcare professionals, nurses, perceptions, stakeholders

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LIST OF ABBREVIATIONS

AGA	Associative group analysis
ICU	Intensive care unit
FCC	Family-centred care
FM	Family member
HCP	Healthcare professional
N	Nurse

CHAPTER 1
ORIENTATION TO THE STUDY

1.1 INTRODUCTION

The intensive care unit (ICU) is an overwhelming, unfamiliar environment for family members (Christensen & Probst, 2015:67). Seeing a loved one lying in a bed connected to machines leaves them feeling disconnected and fearful for their loved one's life (Christensen & Probst, 2015:67). When a patient is admitted into the ICU, their family members are at risk of emotional and psychological upset, which may lead to post-traumatic stress disorder. Post-traumatic stress disorder has been reported in a vast number of family members following the demise or discharge of a patient from the ICU (Mayer, Rosenfeld, & Gilbert, 2013: 172; Probst, Gustin, Goodman, Lorenz & Wells-Di Gregorio, 2015: 391; Kentish-Barnes et al., 2015:1342; Wong, Liamputtong, Koch & Rawson, 2015:51). The family members' interaction with the nurses and healthcare professionals in the ICU may positively or negatively influence the risk of the development of post-traumatic stress disorder (Wong et al*.,* 2015:51).

The environment in which nurses and healthcare professionals work, influences their engagement with family members at the bedside. The ICU environment is becoming increasingly demanding, patient acuity is high, technology is becoming more complex and more than ever regulations and documentation are dominating practice (Moloney-Harmon, 2010:2). Nurses and healthcare professionals need to deal with these complexities, whilst recognising the overwhelming psychological impact on family members of the critically ill patient (Petrinec & Daly, 2016:72). McConnel and Moroney (2015:995) state that family engagement in the ICU varies according to the individual beliefs of the nurses, the healthcare professionals and the family members. Family-centred care is an approach to healthcare that is rooted in mutually beneficial partnerships amongst patients, family members and healthcare professionals (Institute for Patient and Family Centred Care, 2014).

Most nurses and healthcare professionals recognise the importance of family-centred care, but consider themselves unprepared and unable to optimise family-centred care, leaving a feeling of frustration and dissatisfaction amongst nurses and healthcare professionals (Hamric & Blackhall, 2007:428; Arbour & Wiegand, 2014:216; Hetland, McAndrew, Perazzo & Hickman, 2018:74). Conversely some nurses and healthcare professionals feel that there are instances when family members hinder their work in caring for patients (Rippen, Zimring, Samuels & Denham, 2015:92). Furthermore, some evidence suggests that family-centred care carries the risk of increasing the workload and stress amongst nurses and healthcare professionals (Gerritsen et al., 2017:552). Nurses, healthcare professionals and administrators in individual ICU's need to identify strategies for implementing family-centred care according to priorities and available resources (McConnell & Moroney, 2015: 996; Davidson et al., 2017:118; Hetland et al., 2018:74).

Balint and colleagues introduced patient-centred care for the first time in 1969 (Institute for Patient and Family Centred Care, 2014). The term was coined by the Picker Commonwealth Program for Patient-Centred Care. Family-centred changes were pioneered in the 1960's to 1970's in the United States of America with regard to maternity care. In the 1980's the practice of child-focused, family-centred care extended into hospitals, homes, community care and public health programs. By the end of the 1980's family-centred care extended into the adult population. Patient-and-family-centred care is grounded in mutually beneficial partnerships amongst nurses, patients and families and redefines the relationships in healthcare (Institute for Patient and Family Centred Care, 2014). Family-centred care is a natural extension of this concept, which acknowledges the essential contribution that family members make to healthcare and is recognised as a vital part of the healthcare team's approach that is essential to the patients' health and wellbeing (Davidson et al., 2017:106; Goldfarb et al., 2017:1751). Advantages of family-centred care are that family members: (a) provide emotional support to the patient in illness, thereby decreasing the patients' anxiety; (b) keep the patient connected to society and that which is familiar to them during their illness; (c) provide essential cultural and ethnic preferences which may influence treatment approach (Brysiewicz & Emmamally, 2017:1), and (d) are actively involved in decision-making regarding patient care and treatment options (Gerritsen et al., 2017: 550).

Family-centred care improves patient and family experiences (Goldfarb et al., 2017:1751; Cypress & Frederickson, 2017: 201; Shay, 2018:1), improves the nurses' and healthcare professionals' emotional wellbeing (Siffleet et al., 2015:307) and decreases the risk of psychological upset and potential post-traumatic stress disorder in family members (Davidson et al., 2017: 112; Shay, 2018:1). Family-centred care is an approach in healthcare that respects and is receptive to the family members' needs and values (Davidson et al., 2017:1751).

Family-centred care in the ICU has increased steadily over the past three decades, based on the premise that the illness and health of an individual family member affects the whole family unit (Brysiewicz & Emmamally, 2017:1). Research has shown that recognising the role of family members in the critical care environment should be considered an essential component in caring for the critically ill patient (Gerritsen et al., 2017:55). According to De Beer and Brysewicz (2016:21), with the diverse culture in South Africa, patients and family members in the ICU can have a range of cultural beliefs. In many instances these beliefs may differ from those of the nurses and healthcare professionals caring for them, which may lead to conflicting opinions and practices. Nurses and healthcare professionals should attempt to improve partnerships with the families to improve the diverse understanding of family-centred care. Cultural diversity in South Africa may lead to the needs of families being overlooked. However, nurses and healthcare professionals should develop action plans to ensure that family members' individual needs are met (Hlahlatsi et al., 2017: 52). Each ICU has variable institutional, professional and patient dynamics, emphasising the need to identify specific hospital barriers prior to the implementation of new strategies (Furquan & Zakaria., 2017: 366). Perceptions of family-centred care vary amongst healthcare professionals, adding to the unique challenge of improving family-centred care in the ICU (Hetland et al., 2018:73). These variations make each ICU unique, as they differ with regard to the available resources, needs of family members and interests of nurses and healthcare professionals. If individual ICUs were to review current practices in family-centred care, sustainable, feasible interventions could be identified according to their unique situations (Davidson et al., 2017: 118).

1.2 PROBLEM STATEMENT

Family-centred care in the ICU has been widely researched internationally, yet there are still misconceptions, varying opinions and weak evidence of the most effective way of implementing these in practice (Davidson et al., 2017: 120; McConnell & Moroney, 2015:996; Zaforteza et al., 2015:336). Family-centred care principles have been agreed upon, but a consensus definition has not yet been established (Kuo et al., 2012:297). Insufficient formal policies and written guidelines about family-centred care make the implementation of family-centred care a challenge in the ICU (Cypress & Frederickson, 2017: 213; Davidson et al., 2017: 118; Hetland et al., 2018:73). Recommendations have been made for the implementation of family-centred care. However, these recommendations cannot be standardised across all ICU's. Nurses and healthcare professionals in individual ICU's need to customise strategies to implement family-centred care (Davidson et al., 2017:118). Current research identifies family-centred care in ICUs to remain an inconsistent practice. The organisational culture and professional practice environment influence the delivery of family-centred care (Hetland, 2018: 74).

Neglecting the opportunity to improve family-centred care in ICUs may result in family distress, the inability to cope and an increase in the risk of post-traumatic distress syndrome (Christensen & Probst, 2015:67; Kentish-Barnes, 2015:1342; Wong et al., 2015:51). It may lead to an increased emotional burden on healthcare professionals, leading to a feeling of decreased job satisfaction (Siffleet et al., 2015:307), in addition to dissatisfaction with the care by the family members and patients (Cypress & Frederickson, 2017: 231); and may influence patient outcome negatively (Brysievicz & Emmally, 2016:1).

Within the South African context, cultural diversities need to be taken into consideration, as limited research has been done on family-centred care in South Africa (De Beer & Brysievicz, 2017: 26). There are conflicting opinions and beliefs amongst nurses, healthcare professionals and family members regarding family-centred care, how to implement this and how to determine family-centredness in healthcare (Kuo et al., 2012:297). To date the implementation of family-centred care remains a challenge. Due to the uniqueness of each ICU setting and the elements within this setting, limited research has been identified in South Africa exploring the nurses, healthcare professionals and family members' perceptions of family-centred care in the ICU within this unique cross-cultural environment.

1.3 SIGNIFICANCE OF THE PROPOSED STUDY

Family-centred care in the ICU remains an inconsistent practice. These inconsistencies are related to individual perceptions and expectations around family-centred care, unit and organisational factors and the availability of resources (Hetland et al., 2018:74). Research findings may be used to gain a deeper understanding of how family-centred care is perceived by the nurses, healthcare professionals and family members. Nurses and healthcare professionals may gain a better understanding of how family members perceive family-centred care and how these perceptions may differ from their own. By enhancing family-centred care, patient outcome may improve; patient and family satisfaction may increase, and it may lead to improved job satisfaction amongst the nurses and healthcare professionals.

1.4 RESEARCH QUESTIONS

Based on the research problem, the following questions are posed:

- How do nurses, healthcare professionals and family members perceive family-centred care in the intensive care unit?
- How do nurses, healthcare professionals and family members perceive ideal family-centred care in the intensive care unit?
- What is the gap between nurses', healthcare professionals' and family members' perceptions of family-centred care in the intensive care unit?

1.5 AIM AND OBJECTIVES

The aim of this study is to explore and describe the stakeholders' perceptions of family-centred care in the intensive care unit. To address the aim of the research, the objectives are to:

- describe nurses', healthcare professionals' and family members' perceptions of family-centred care in the intensive care unit;
- explore nurses', healthcare professionals' and family members' perceptions of ideal family-centred care in the intensive care unit, and
- describe the gap between nurses', healthcare professionals' and family member's perception of family-centred care in the intensive care unit.

1.6 CONCEPT CLARIFICATION

In the context of this research, and for simplicity and consistency throughout this dissertation, the following key concepts were defined:

- **Associative group analysis:** A research method that uses continuous free word associations to access and compare the dispositions of different groups of respondents. It is a method that measures perceptions, attitudes and beliefs (Kovalcikova & Lacny, 2016: 82).
- **Critically ill patient:** The patient who has a life-threatening illness requiring supportive treatments and meticulous monitoring to avoid complications which could lead to the patient's demise (De Beer & Brysiewicz, 2017:22). In this study, the critically ill patient refers to the adult patient who is currently admitted in the ICU.
- **Family-centred care:** Patient and family-centred care is grounded in mutually beneficial partnerships amongst healthcare providers, patients and their families and redefines the relationships in healthcare (Institute for Patient and Family Centred care, 2014). In this study family-centred care focuses on the needs, wants and desires of family members of the critically ill patient. The family member is seen as an integral part of the healthcare team.
- **Family member:** In this study, the family is a person or persons who have a close, meaningful relationship with the critically ill patient, not necessarily blood related (De Beer & Brysiewicz, 2017:22). This person offers emotional support to the critically ill patient, for example a relative, partner or friend.
- **Healthcare professionals:** A healthcare professional is a person associated with either a specialty or a discipline and who is qualified and allowed by regulatory bodies to provide a healthcare service to a patient (Segan's Medical Dictionary online, 2011). In this study the healthcare professionals are those people who are currently working in the ICU where the study will be conducted. They include dieticians, physiotherapists, infection-prevention specialists and doctors, and are registered with the Health Professions Council of South Africa (HPCSA).
- **Intensive care unit (ICU):** A unit in the hospital filled with specialized equipment for the care of critically ill patients, who require continuous monitoring and treatment by specifically trained healthcare professionals (Weller, 2014:18). In this study an ICU refers to an adult ICU in a private hospital in Pretoria, South Africa, where nurses care for patients and their family members.

- **Nurses:** A professional nurse and an enrolled nurse are persons registered as nurses in terms of section 31 of the Nursing Act 33 of 2005. Enrolled nurses work under the direct supervision of professional nurses. In this study, the nurse refers to professional nurses and enrolled nurses involved in caring for the patient and family members in the ICU where the study will be conducted.
- **Perceptions:** Perceptions refer to an individual's or group's unique way of viewing a phenomenon. It involves processing stimuli and incorporating memories and experiences towards understanding a specific situation (McDonald, 2012:8). In this study perceptions refer to the unique way in which nurses, healthcare professionals and family members view family-centred care in the ICU.
- **Stakeholder:** Stakeholders are persons, groups or institutions with interests in a project or policy, or who may be directly or indirectly affected by the process or the outcome (World Health Organisation, 2005:2). In this study stakeholders include nurses, healthcare professionals and family members in the ICU where the study has been conducted. Stakeholders influence and are influenced by family-centred care.

1.7 PHILOSOPHICAL ASSUMPTIONS

A paradigm is a worldview, a general perspective on the complexities of the real world. A constructivist paradigm, also known as a naturalistic paradigm deals with issues of human complexity by exploring them directly. Constructivist researchers emphasise the dynamic, holistic and individual aspects of human experience and try to capture aspects in their entirety, within the context of those who experience them. The integration of information occurs to develop a theory or describe the phenomenon under observation, through inductive reasoning. The collection of information is done thus in a natural setting. Constructivist studies yield rich, comprehensive information that may potentially reveal varied dimensions of complex phenomena (Polit & Beck, 2017:11).

1.7.1 Ontological assumptions

Within the constructivist paradigm, there are multiple realities. Reality is subjective as it is mentally constructed by individuals (Polit & Beck, 2017:10). The free word associations foremost in people's minds reflect their perceptual construct in relation to a specific theme or concept (Diaz-Guerrero & Szalay, 1991:22). The reality of family-centred care as perceived by the nurse, healthcare professionals and family members in the ICU may differ.

1.7.2 Epistemological assumptions

Epistemology has to do with the very base of knowledge, including its nature and forms, how it can be acquired and how it is communicated to other human beings. It denotes the relationship between the knower, the would-be knower and what can be known (Mustafa, 2011:24; Polit & Beck, 2017:10). The researcher acknowledged that the participants' knowledge of family-centred care was constructed by their own previous experiences, their values, beliefs and interactions.

1.7.3 Methodological assumptions

Methodology refers to the strategy, plan of action and process or design underlying the choice and use of a particular method (Mustafa, 2011:24; Polit & Beck, 2017:10). The researcher aimed to gain insight into the participants' perceptions of family-centred care in the ICU. Results were contextual with a small sample. Quali-quantitative analysis was used; the research design was Associative Group analysis. Free word associations were collected from participants and were quantitatively weighted and plotted by numerical value on a semantograph (Schutte, 2016:7).

1.8 CONTEXT

The research was conducted in a 23 bedded ICU in a 360-bed capacity urban private hospital in Pretoria, Gauteng Province. The ICU admits critically ill patients under the following disciplines: neurosurgery, general surgery, orthopaedic surgery, maxilla-facial surgery, internal medicine and neurology patients. Patients admitted to the ICU are fully dependent on nursing care. Mostly patients are nursed on a nurse-to-patient ratio of 1:1. From the period October 2017 to April 2018 bed occupancy was 85% on average, the unit admitted 838 patients and the average length of stay per patient was 4,95 days (The Hospital, 2018).

Visiting hours for family members are from 15h00-16h00 and 19h00-20h00 daily. Only 2 visitors are allowed at a time at the patient's bedside and no children under the age of twelve are allowed in the ICU. The waiting area for family members is situated outside the ICU. There are 5 chairs placed in the passage for visitors to sit and wait.

There are 2 large glass doors at the entrance of the ICU; these doors are only opened during visiting hours. If a family member wishes to enter outside of visiting time they need to ring a bell in order to be let into the ICU. When first entering the ICU, before going to the patient's bedside, family members are expected to adhere to contact precautions as part of infection control, which entails putting on a plastic apron, a surgical face mask, spraying their hands with alcohol disinfectant and then wearing disposable gloves. There is usually a careworker at the door to meet the family members and ensure that they apply these infection control practices.

On arrival at the bedside of the patient, nurses taking care of the patient are expected to meet family members, introduce themselves and provide information on the patient's condition. If a family member would like to see the doctor treating the patient, they are expected to make an appointment by contacting the receptionist working at that doctor's consulting rooms.
Healthcare professionals involved in the care of all ICU patients include nurses, specialist physicians, dieticians, physiotherapists, pharmacists and radiographers. Other allied healthcare professionals that may be involved in the care, depending on the patient's condition, include speech therapists and occupational therapists.

1.9 DELINEATION

The sample population who participated in the study were limited to one ICU in a private hospital in Gauteng. In addition, only the nurses and healthcare professionals working in the ICU and family members who had a family member admitted as a patient in the ICU were included.

1.10 RESEARCH DESIGN AND METHODS

The researcher used a quali-quanti research design. Qualitative and quantitative data were collected concurrently and analysed together, the qualitative data being transformed into quantitative data (Harwell, 2011:156). Qualitative data formed the baseline of the research design, using free word associations given by participants in response to the stimulus word "family-centred care". These free word associations were then coded and transformed into quantitative data to be presented on a semantograph. Quantitative data provided a visual representation of results to allow for a comparison of findings amongst nurses, healthcare professionals and family members.

The research methods will be discussed in terms of the population, sampling and sample size, data collection, data analysis and data interpretation. The research methods are summarised in Table 1.1.

Table 1.1: Summary of the research methods

Research methods applied in this study	
Population	In this study the population consisted of nurses, healthcare professionals and family members in the ICU.
Sample	The research sample in this study consisted of nurses, healthcare professionals and family members in the ICU where the study was conducted. The inclusion criteria for each sample group will be discussed separately.

(Sample continues) (Sample continues)	**Nurses and healthcare professionals:** To be included in the study, participants had to be: • working in the ICU where the study was conducted; • have frequent interactions with family members of the ICU patients; • aged eighteen (18) years and above, and • able to read and write English. **Family members:** The inclusion criteria for family members were as follows: • The family member had to have a patient admitted in the ICU where the study was conducted. • The family member's patient had to be admitted for a minimum period of 72 hours. • The family member had to be aged 18 years or older. • The family member had to be able to read and write in English
Sampling	The sampling of nurses, healthcare professionals and family members will be discussed separately. **Sampling of nurses:** Stratified random sampling was the specific method of sampling used for nurses. Their cultural group was used for stratification, to ensure that different cultural groups were represented in the sample. Proportionate sampling was adopted and the researcher randomly selected participants from a sampling frame. In this study the researcher made use of the list of nurses working in the ICU where the study was conducted. **Sampling of healthcare professionals:** Total population sampling was the specific type of purposive sampling that was used for healthcare professionals. **Sampling of family members:** Maximum variation sampling was the specific method of purposive sampling that was used. To ensure a heterogenous sample, the researcher selected a diverse range of ages, cultural groups and gender in the sample based on the demographic profile of the patients in the ICU where the study was conducted. In associative group analysis the sample should be diverse to compare similarities and differences in experiences across different cultural groups (Kovalcikova & Lacny, 2016:83). Research participants who met the inclusion criteria were of different genders, from different ethnic backgrounds and in different age groups.

Sample Size (Sample Size continued)	According to Schutte (2016:8), in associative group analysis the same number of participants must be approached in all samples to compare findings. Sample size was therefore determined by the smallest sampled group. Healthcare professionals were the smallest group at twenty. There was a total of sixty research participants, which included twenty nurses, twenty healthcare professionals (doctors, physiotherapists, infection prevention specialists, dieticians and nurse managers) and twenty family members.
Data Collection	Data was collected by means of associative group analysis (AGA). AGA is an inferential approach, developed to study the perceptual representational system, focusing on subjective meanings and images to assess similarities and differences across cultures and between belief systems. Free word associations were used to assess perceptions around family- centred care. Free word associations were given by the research participants in response to the stimulus word, “family-centred care”.
Data Collection Process	The researcher conducted interviews with the research participants in order to collect data in answer to the research questions. The researcher conducted interviews on a one-on-one basis or in groups of two or three.
Data Analysis	Data analysis took place in four phases: **Phase 1: Ranking/scoring** The first phase of data analysis forms part of quantitative analysis. Research participants’ responses were ranked or scored by means of associative group analysis (AGA) methodology (See Annexure F1, F2 & F3). **Phase 2: Coding** The second phase of the data analysis formed part of qualitative analysis. The responses were grouped together according to similar meanings or codes (see annexure G1). Similar meanings were then divided into themes, subthemes and categories (see annexure G2) **Phase 3: Determining weight** Phase 3 formed part of the quantitative analysis and involved calculations, result presentation and comparisons. The total number of free word associations were divided into the total number of identified categories. This was done to identify the total weight of the category. Weighting was based on the ranking/scoring of the responses completed in phase 1 (see annexure G3). **Phase 4: Indicating the gap** In the final phase, the results were presented graphically by means of a semantograph or radar presentation. (Kovalcikova & Lacny, 2016:84). This allowed the researcher to visually compare the gaps in the perceptions of family-centred care amongst stakeholders in the ICU (see annexure G4).

An in-depth discussion on the research design and methods used to address the aim and objectives of the study, are presented in Chapter 3.

1.11 ETHICAL CONSIDERATIONS

Ethical approval was requested and granted by the Faculty of Health Science; University of Pretoria (see annexure A1) Permission to recruit participants was requested from, and granted by the study hospital's research committee (see annexure A2). Ethics refers to the obligations that the researcher has towards the research participants (Polit & Beck, 2017:137). The Belmont report defines three principles upon which ethical conduct is based: beneficence, respect for human dignity and justice. Certain procedures need to be complied with in order to prevent ethical violations (Grove, Burns & Gray, 2013:164; Polit & Beck, 2017:137).

1.11.1 Beneficence

The researcher conducted the study in a manner that protected the participants from discomfort and harm (Grove et al., 2013:174). The researcher believes that this research study will indirectly improve future patients' and family members' experiences, if nurses and healthcare professionals get a better understanding of family-centred care in the ICU.

The researcher anticipated the temporary discomfort of the research participants. The discomfort encountered was similar to what participants would experience in their daily lives and ceased at the termination of the study (Grove et al., 2013:174). The nature of the data collection may have inconvenienced participants. Therefore, the researcher minimised discomfort by limiting the data collection time. The researcher expected minimal psychological and economic risks from the participants. In the process of self-disclosure and introspection, the participants may have been subjected to an inherent psychological risk (Botma et al., 2010:23). The researcher was prepared to provide psychological support by referring research participants to a trauma counsellor. However, this proved not to be necessary. Economic risks refer to financial losses related to the time used by participants during data collection (Botma et al., 2010:23). For the nurses, the researcher planned the data collection during scheduled working hours. The healthcare professionals and family members were approached individually and a convenient time for data collection was arranged.

1.11.2 Respect for Human Dignity

The research participants were viewed as autonomous agents by the researcher. The research participants were free to accept or decline participation in the study. Participants who agreed to participate, could choose to decline at any time without any penalty. Participants were informed of the study in writing via an information leaflet (Annexure A). The participants were able to exercise their right to self-determination by signing informed consent (Annexure B) (Grove, Burns & Gray, 2013:164). In this study the participants were informed of the research which was being conducted as well as the potential benefits to improve practice, with specific focus on family-centred care in the ICU. The participants were informed of the aims and objectives of the research and how data collection would take place. The participants were informed that participation in the study was voluntary and would not influence their management in the ICU. The researcher conveyed the information by means of an information leaflet (Annexure A) and the contents of the information leaflet were explained to each participant. Data was collected only once the participants (nurses, healthcare professionals and family members) had volunteered to participate and had signed the informed consent document (Annexure B). Participants' right to confidentiality was respected by the researcher (Grove, Burns & Gray, 2013:169-172). Participants' personal identification was not necessary for the study. Response cards where participants wrote down free word associations were coded. Once the research participant signed informed consent, the document was stored separately from the response cards so no potential research participant could be linked to any individual participant. Data was collected by the researcher alone. Documents will be kept in a locked store-room for two years and all data will be destroyed after fifteen years.

1.11.3 Justice

The principle of justice refers to the right to privacy and the right to fair treatment (Polit & Beck, 2017:141). The researcher used purposive selection to portray the heterogeneity of the population. The researcher requested that participants be honest, because they could either share only what they wished to share, or share what they thought the researcher would want to hear. All issues relating to the confidentiality of participant information were taken into consideration. The privacy of the participants was maintained throughout the data collection process. No names or identifiable affiliations were written down on the response cards. Participants were all treated fairly and those who declined to participate were able to do so without prejudice. The researcher kept to agreements made with participants and demonstrated respect for individual values, beliefs and backgrounds (Polit & Beck, 2017:141).

1.12 LAYOUT OF CHAPTERS

This study consists of five chapters and the title and description of each chapter is briefly described in Table 1.3.

Table 1.2 Outline of the chapters

Chapter	Chapter title	Chapter description
Chapter 1	Orientation to the study	This chapter orientates the reader to the entire study. It provides a brief description of the problem, aims and objectives of the study and research design and methods used.
Chapter 2	Theoretical underpinning	Chapter 2 presents an in-depth literature review that was used by the researcher to develop the theoretical underpinning for the study.
Chapter 3	Research design and methods	This chapter discusses the research design and methodology used, including the population, data collection and analysis, rigour and ethical considerations adhered to during the study.
Chapter 4	Data analysis and interpretation of findings	Chapter 4 discusses the data analysis and interpretation of the findings, with reference to the literature reviewed that supports discussions.
Chapter 5	Conclusions, limitations and implications	This chapter concludes the study. Implications for practice, management, education and future research are discussed in addition to limitations that were encountered during the study.

1.13 SUMMARY

Chapter 1 orientated the reader to the entire study. A brief overview of the problem, aims and objectives, research design and methods of the study were provided and key terms were defined. Background information was provided in support of the formulation of the problem statement. Chapter 2 provides an in-depth literature review that supports the theoretical underpinning discussed in chapter 1.

CHAPTER 2
THEORETICAL UNDERPINNING

2.1 INTRODUCTION

Chapter 1 orientated the reader to the entire study. Chapter 2 provides and in-depth literature review that relates to the current topic, namely family-centred care in the intensive care unit. Topics covered in the review of literature include: the background to family-centred care, definition of family-centred care, the importance of family-centred care and requirements for implementing family-centred care. The literature presents findings on family-centred care from national and international studies; these findings are used to underpin the research done for this study.

2.2 FAMILY

In order to define family-centred care, it is important to understand the meaning of family and the importance of family. Seita (2014:8) states that '*family is like the air we breathe granted we fail to recognise the importance of family until its absence is felt*'.

Looking back over human history, a real family was a multigenerational tribal community where there was a joint responsibility for nurturing the young. In reality, every variation of blended caregivers qualifies as family (Seita, 2014:8). In modern research three concepts of family emerge, the first being the environmental family, in other words biological and non-biological relatives, the second being the biological relatives, referring to individuals that share genetics and lastly the caretaking family, who can be all of the above (Wiessman, 2016:927).

Family is the essential presence - the thing that never leaves a person even if one must leave it (Seita, 2014:8). Family is the single greatest social institution that influences a person's health, even more so during an ICU admission. The families take on the role as surrogate decision-makers when the patient is unable to communicate (De Beer & Brysiewicz, 2017:26). Existing definitions can be categorized in several ways. Two or more prominent concepts are the structural definitions that specify family membership according to certain characteristics such as blood relationship, legal ties or residence and functional definitions organised around core functions that family members perform, such as sharing economic resources and caring for the young, elderly, ill or disabled (Bogenschneider, Little, Rooms, Benning, Cadigan & Corbett, 2012:518)

Historically the perceptions of family were individuals who shared a biological bond with one another or, in other words, were blood relatives. The relationship may have been biological, legal or emotional.

Today, the modern view of family is whoever the patient perceives to be family; they may be related or unrelated to the patient. They are individuals who provide support and with whom the patient has a significant relationship (Davidson et al. 2017:7). In the South African context the family member in the ICU is regarded as being a person or persons who have a close, meaningful relationship with the critically ill patient. They are not necessarily blood related (De Beer & Brysiewicz, 2017:22).

For most individuals in society, primary caring relationships are learnt through the strength and support of family. A family is the child's first and principle source of strength and support (Seita, 2014:8). Families form an integral part of society and, in fostering individual well-being, well-functioning families are an integral part of ensuring optimal performance and productivity, which serves to improve individual well-being (Botha & Booysen, 2014:163).

When a member of the family is admitted to the intensive care unit, it is often unexpected. The family members then face the possibility that the loved one might die or be left with a severe disability (De Beer & Brysiewicz, 2016:44). The admission of a loved one into the intensive care unit leaves the family feeling overwhelmed and affects their ability to cope. More than half of the family members experience increased levels of post-traumatic stress symptoms around the time of a patient's admission to the ICU (Alfheim et al., 2019:9). The family members live in fear of the unknown and their family connections allow them to endure the situation (De Beer & Brysiewicz, 2017:26).

Family is important in the ICU, as they take on the role of surrogate decision-makers for the critically ill patients. Patients often want family members to be involved in decision-making about their care and most patients report that family members' perspectives are important in their care decisions (De Beer & Brysiewicz, 2017:26). Support to family members in the ICU by the healthcare team has been shown to improve patient outcomes (Davidson et al., 2017:6).

2.3 FAMILY MEMBER IN INTENSIVE CARE UNIT

"No matter how important you may think you are in 'real-life', in the environment of ICU you are 'pond life!' There is nothing you can do or say that can be of any help to the one person in the world you need to assist. It's hard being a watcher"

Family member (Christensen & Probst, 2014:64)

A critically ill patient is a person who is admitted with a potentially life threatening illness, patients are on supportive treatments and are under close, continuous monitoring to prevent life threatening complications. The environment of the ICU is highly technological, requiring healthcare workers with a broad knowledge base and a high level of decision-making skills and regard for patients and families in vulnerable circumstances. Patients require continuous, complex and detailed healthcare (De Beer & Brysiewicz, 2017:22).

The ICU environment is an unfamiliar, intimidating environment to the family in most cases. When a loved one is admitted to the ICU, the family member feels overwhelmed with different, unfamiliar sounds and an array of equipment, alarms, invasive lines and monitors adding to their already emotional state (Hlahatsi et al., 2017:48; Christensen & Probst, 2014:65). Family members are fearful to touch their family member as they are scared to set off any alarms (Christensen & Probst, 2014:68).

"We heard machines beeping, we were panicking, we thought maybe the person was dying so we had to call a nurse and ask her to check up on him because we were anxious and did not know what was going on...It would be nice if someone could tell us about all the machines and monitors"

Family member (De Beer & Brysiewicz, 2016:45)

Literature suggests that there is great concern for the psychological wellbeing of ICU family members. Long term anxiety, depression and symptoms of post traumatic distress are reported following a loved one's stay in the ICU (Shay, 2018:1). Stress is heightened as family members need to make life and death decisions on behalf of a loved one, whilst exposed to the frightening, unfamiliar ICU environment (Rippen et al., 2015:82).

The separation felt by family members when a loved one is admitted to the ICU is thought to be the leading contributor to post traumatic stress syndrome (Clark & Guzetta, 2017:97). Limiting family presence in the ICU was supposedly implemented due to the perceived potential risks, mainly around infection control, interference with patient care, increased stress for family members and patients and violation of confidentiality. There is however no conclusive evidence to validate these claims (Giannini, Garouste-Orgeas & Latour, 2014:730)

"I had to say goodbye to him as the character I had fallen in love with and lived with for 17 years"
Family member (Christensen & Probst, 2014:66)

Seventeen years ago, Hilmar Burchardi wrote in an editorial in Intensive Care Medicine that "it is time to acknowledge that the ICU must be a place where humanity has a high priority. It is time to open those ICUs which are still closed" (Burchardi, 2002:1372). Since then some changes have been seen in making the ICUs more "family friendly", but in many countries there have not been significant changes in clinical practices. In most instances, on approaching the door of an ICU, family members are still met with signage that states "Strict visiting hours. Only two family members allowed to visit at a time. No visitors under the age of 12". For a long time, ICU healthcare professionals behaved as though critical care units where designed for them rather than the patient and their families (Levy & De Backer, 2013:2224). Historically, it was standard practice to make family members wait in waiting rooms, adhering to strict visiting hours, with very little information on their loved one's condition (Clark & Guzetta, 2017:96). Unfortunately, most hospitals are still sticking to the closed unit policy. A survey done in the USA in 2008 revealed that 89,6% of ICUs still have restricted visiting times. To date no newer studies have been identified (Clark & Guzetta, 2017:96). These findings are congruent with what the researcher observed in both public and private hospitals in South Africa to date. Visiting hours are only one concept in the broader picture of caring for family members in the ICU, but literature gives a scanty, conflicting picture of the percentage of adult ICUs without restricted visiting hours. Figures range between 2 and 70% (Giannini et al., 2014:730).

An ICU admission is not an excuse to separate families. Family presence in the ICU benefits the patient, family and healthcare professionals (Levy & De Backer, 2013:2224). The family is a unit and if the health of one of its members is compromised, it affects the whole family unit (Wetzig & Mitchell, 2017:68). It does not make sense to treat the ICU patient in isolation and disregard the family members.

2.4 HISTORICAL OVERVIEW

Family-centred care was discussed as early as the 1950s as a general concept, as there was increasing awareness that separation of the child from the family brought about emotional trauma in the hospital setting (Jolley & Shields, 2009:164). Childbearing women and families in the United States of America led family-centred changes within maternity care in the 1960s and 1970s (Conway, Johnson, Edgman-Levitan, Schlucter, Ford, Sodomka & Simmons, 2006:4). The driving force behind the concept was an increasing awareness of the importance of meeting the psychosocial and developmental needs of children and the role of families in promoting the health and well-being of their children (Eichner & Johnson, 2012:396). Family-centred care became the forefront of contemporary thinking by the 1970s as it infiltrated into the healthcare system (Bogenschneider et al., 2012: 518). In the early 1980s, the US Department of Health and Human Services, The Association for the Care of Children's Health and other organisations teamed up with families in defining and providing leadership to advance the practice of family-centred care (Conway et al., 2006:4) within the paediatric setting.

In 1992, Family Voices was established in Alburqueque, USA. The group advocated children's health needs and paediatric health care (Meert, Clark & Eggly, 2010:762). At around the same time, a non-profit organisation was founded, the Institute for Family-Centred Care (FCC). This institute provides essential leadership to advance the understanding and practice of patient-and family-centred care, by promoting collaborative, empowering relationships among patients, families and healthcare professionals. The institute facilitates patient- and family-centred change in all settings where individuals and families receive care and support. The institute has recently changed its name to the Institute for Patient- and Family-Centred Care (IPFCC), (Institute for Patient and Family Centred Care, 2012). The terms family-centred care and patient- and family-centred care are used interchangeably, referring to care that is respectful and responsive to the preferences, needs and values of patients and families (Meert et al., 2013:761).

Family-centred care in the paediatric setting acknowledges that families play an important role in ensuring the health and wellbeing of the child. Healthcare practitioners acknowledge that emotional, social and developmental support are integral components of healthcare. There is respect for each child and family's strengths and cultural values. A child's hospitalisation is viewed as an opportunity to build on these strengths and support families in their caregiving and decision-making roles. Family is the child's primary source of strength and support. The perspective of the family members and the information they provide are important in clinical decision-making (Eichner & Johnson, 2012:395).

Family-centred care has since then slowly extended into other contexts including the adult intensive care unit (ICU), as the patient in ICU is often not in a position to communicate (Wetzig & Mitchell, 2017:63). In the last few decades recognising the needs of family members in the adult ICU is gaining increasing interest (Al-Mutair, Plummer, O'Brien & Clerehan, 2013:1811; Wetzig & Mitchell, 2017:63), as understanding the needs of family members can assist healthcare professionals in providing support. Family members in the ICU need support as they struggle to cope when a loved one gets admitted to the ICU (Blom, Gustavsson & Sundler, 2013:7; Christensen & Probst, 2014:69; Cypress & Frederickson, 2017:207), as admissions are often unexpected and family members are not psychologically prepared. The admission of a loved one into the ICU may result in role conflict, high levels of stress, the interruption of normal routines and potential changes in relationships among family members (Almaze & De Beer, 2017:59; Gundo, Bodole, Lengu & Maluwa, 2014:318). Family members play an important role in the outcome of the patient through the physical and psychological support they provide to the patient during and beyond admission in the ICU. Today family involvement in the ICU is becoming more common and family partnerships in healthcare are an expectation (Mitchell, Coyer, Kean, Stone, Murfield & Dwan, 2016:180; Christensen & Probst, 2017:65; Wetzig & Mitchell, 2017:63).

Family members are viewed as an extension of the patient, which forms the foundation of family-centred care (Institute for Patient and Family Centred Care, 2014; Mitchell et al., 2016:180; Wetzig & Mitchell, 2017:68). Family-centred care recognises that the patient is part of their family system and that the patient and family in care are fundamental to healthcare delivery (Institute of Family Centred Care, 2015; Wetzig & Mitchell, 2017:68). Literature examining the needs of ICU families has increased remarkably over the past forty years (Al-Mutair et al., 2013:1807; Wetzig & Mitchell, 2017:68). Using qualitative and quantitative approaches, researchers have added to the body of knowledge on the topic.

2.5 FAMILY-CENTRED CARE

Patient-centred care, patient- and family-centred care and family-centred care are frequently used interchangeably. The Institute for Patient and Family Centred Care was previously known as the Institute for Family Centred Care. The name was recently changed, which is why these terms are still used interchangeably and why different terms are found in literature (Institute for Patient and Family Centred Care, 2012). Family-centred care may take preference within the context of adult ICU care when the patient is unable to communicate and take part in the decision-making process (Mitchell, Chaboyer, Burmeister & Foster, 2009:544).

2.5.1 Patient-Centred Care

Balint, Hall and Hare (1969:249) introduced the term patient-centred medicine in 1969. The term patient-centred care was adopted by the Picker Commonwealth Program for Patient-Centred Care, and the Picker Institute, after that in 1988 (Conway et al., 2006:4). Patient-centred care is defined as care that is respectful of, and responsive to individual patient preferences, needs and values (Meert et al., 2013:761). Patient-centred care is about treating the person receiving healthcare with dignity and respect and involving them in all decisions about their health. This is also sometimes referred to as person-centered care. Patient-centred care is a partnership approach between patients and healthcare professionals (Wallstrom & Ekman, 2018:578). Person-centred care responds to each patient’s wants, needs and preferences. Abundant opportunities are given to the patient to be informed and involved in their medical decision-making. Healthcare professionals guide and support care around patients’ physical and emotional needs, improving and maintaining their quality of life. Person-centred care is individualised and has a high regard for the patient’s cultural preferences (Davidson et al., 2017:57).

2.5.2 Patient- and family-centred care

The Institute for Patient and Family Centred Care (2012) defines patient- and family-centred care (PFCC) as ‘*an approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients and families*.’ PFCC is a multi-dimensional concept, aiming to shift the focus away from healthcare professionals to thinking more about what is happening to patients. It has been recognised as one of the six core domains of high-quality healthcare (Lloyd, Elkins & Innes, 2018:55). PFCC applies to patients of all ages and may be practiced in any healthcare setting (Mitchell et al., 2009:544). This term may take preference when the patient is able to communicate and play an active role in decision-making (Davidson et al., 2017:7).

2.5.3 Family-centred care explained

Family-centred care, sometimes also referred to as patient-family-centred care, is an approach to healthcare that is respectful of, and responsive to individual families' needs and values (Davidson, Aslakson & Long, 2017:7). For the purpose of this study the term family-centred care will be used, as the focus is on the needs of family members in the ICU. Family-centred care, as with PFCC is seen as an innovative approach to the planning, delivery and evaluation of healthcare that is grounded in mutually beneficial partnerships among healthcare professionals, patients, families and providers. Family-centred care views the family as an integral part of patient care. The term 'family-centred care' is predominantly recognised in the paediatric setting, where families are most involved with their children (Kuo et al., 2012:298). The concept is relevant and extends to the adult ICU population, as the patient is unable to communicate because they are often sedated, mechanically ventilated and too ill to make decisions for themselves. Family members then become their advocates and primary decision-makers (De Beer & Brysiewicz, 2017:24). Family-centred care in the adult ICU is far more than what may be experienced in paediatric settings, which has a narrowed, focused philosophy of family-centred care, where the parents assume greater responsibility for the management and actual care of the chronically ill child. In family-centred care the relationship between the family and healthcare professional is essential, based on mutual respect, collaboration and support for the family and the patient (Mitchell et al., 2009:544).

2.5.4 Family-centred care in the Intensive Care Unit

The four principles or core concepts of family-centred care are dignity and respect; information-sharing; participation and collaboration (Brooke & Warren, 2014:397; Institute for Patient-and Family-Centred Care, 2014)

Dignity and Respect: Healthcare professionals listen to, and honour patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated in the planning and delivery of care.

Information Sharing: Healthcare professionals communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete and accurate information in order to effectively participate in care and decision-making.

Participation: Patients and families are encouraged and supported to participate in care and decision-making at the level they choose.

Collaboration: Patients, families and healthcare professionals and healthcare leaders collaborate in policy and program development, implementation and evaluation; research; facility design and professional education, as well as in the delivery of care.

Patients and family members are left feeling vulnerable whilst admitted to the ICU, as they experience feelings of helplessness, powerlessness and hopelessness. There is a feeling of insecurity and fear of the unfamiliar technology-dominated ICU environment (Christensen & Probst, 2014:67). Separating families from their loved ones leaves risk of medical error, emotional trauma, care inconsistency, lack of preparedness for transitions in care and unnecessary costs due to the disruption in their lives (Christensen & Probst, 2014:69). The Institute for Patient and Family Centered Care (2012) is campaigning to change the concept from viewing the families as visitors to the families as partners in healthcare (Latour & Coombs, 2019:1)

There has been increased interest in family-centred care, resulting in a surge of research, yet there is still not a clear understanding of family-centred care (Davidson & Strathdee, 2019:1; Davidson et al., 2017:59). However, there is agreement in terms of the principles fundamental to family-centred care (Davidson et al., 2017:5). Therefore, defining family-centred care remains a gap in existing literature.

There is increasing awareness that, to achieve the best outcomes, patient and family members must be actively involved in healthcare decisions and they must have access to information and support. Families are expected to make critical decisions regarding their loved one’s care, whilst being there to love and support them. Their ability to provide this love and support and to make decisions in times of emotional stress is hindered, especially when the patients are unable to speak for themselves (Nolen & Warren, 2014:394).

2.6 HEALTHCARE PROFESSIONALS AS STAKEHOLDERS IN FAMILY-CENTRED CARE

When a patient is admitted to the intensive care unit, they are seen by various healthcare professionals in order to ensure holistic care. Interaction with healthcare providers varies according to individual patient conditions and needs. As family-centred care is described as an approach to healthcare that is respectful and responsive to the needs and values of families, it is the responsibility of healthcare professionals to provide support to family members in the ICU (Davidson et al., 2017:7).

Family-centred care involves the patient, family members, nurses and healthcare professionals as stakeholders. Healthcare professionals include specialist physicians, dieticians and physiotherapists, to name but a few.

There is often lack of communication between healthcare professionals and family members (Ka-Ming Ho, 2016:12). Caring for family members is largely overlooked in training curriculums, with limited content on the cultural and religious considerations of the patient and family with regard to death and dying (Shariff, Olson, Salas & Cranley, 2017:26 & Ka-Ming Ho, 2016:12). Healthcare professionals may not know what to do or say, which may lead to a feeling of inadequacy and may be perceived by the family member as lack of compassion (Shariff et al., 2017:26). Healthcare professionals need to have an understanding of the impact of an ICU admission on a family member in order to better support them. Nurses and healthcare professionals need to provide open, honest and regular communication with one another and with family members (Davidson et al., 2017:10).

Effective communication between healthcare professionals and family members has been shown to improve family-centred care and decrease anxiety in the family member (Davidson et al., 2017:23).

2.7 IMPORTANCE OF FAMILY-CENTRED CARE

Research identifies that critical illness has a significant impact on the family members of the critically ill. The family members are left with the responsibility of making important decisions on their loved one’s behalf, because most patients in the ICU are too ill to participate in decision-making. (Davidson et al., 2017:5). In addition, family members carry the burden of caring for their loved one after discharge. More than 50% of survivors of critical illness have post discharge disability (Davidson et al., 2017: 5). More than half of family members experience increased levels of post-traumatic stress symptoms around the time of a patient's admission to the ICU (Alfheim et al., 2019:9). Such a family is referred to as a "Post-Intensive Care Syndrome Family" (PICS-F). Supporting families has been shown to improve patient outcomes (Davidson et al., 2017:5). Family-centred care impacts the patient, the family, nurses, healthcare professionals and the hospital.

2.7.1 The patient

Patients feel isolated from society and that which is familiar to them when they are admitted to the ICU. Family members form the link to what is familiar to the patient and this allows the patient to feel as though they are still engaged in society, bringing a sense of normalcy to an abnormal situation (Brysiewicz & Emmamally, 2017:1; Christensen & Probst, 2014:69)

Family involvement in the ICU has a positive impact on patient outcomes as they provide emotional support to the patient. Family members can assist in calming the agitated, disorientated patient, giving the patient a sense of comfort and safety (De Beer & Brysiewicz, 2017:1; Rippen et al., 2015:82). In cases where the patient is not able to communicate, family members are expected to make decisions on behalf of their loved one (Brysiewicz & De Beer, 2016:24). Some myths exist amongst nurses and healthcare professionals working in the ICU that the presence of family members is detrimental to the patient due to an infection risk, care interference and patient tiring, but there is no evidence in research to support these myths (Shay, 2018:2).

2.7.2 Nurses and healthcare professionals

With nurses and healthcare professionals already burdened with overwhelming, ever-increasing workloads, the need to focus on family-centred care is questioned. However, research has shown that including family in caring for the patient may enhance patient recovery and outcome to illness (Brysiewicz & Emmamally, 2017:1). Families play a crucial role in positive patient outcomes. Therefore, it is essential to engage with families when caring for patients in the ICU. Families should be viewed as facilitators of care rather than a burden (Brysiewicz & Emmamally, 2017:1). Family-centred care in the ICU may ease anxiety in the patient, potentially reduce the need for sedation and analgesia and thereby decrease the workload of healthcare professionals

(Brysiewicz & Emmmamally, 2017:1). Relationships with healthcare professionals are important to patients and families in the ICU (Cypress & Frederickson, 2017: 209)

When a patient is admitted to the ICU, it is important that nurses and healthcare professionals gather essential information on the history of the patient, as well as their culture and ethnic preferences. However, patients, are not always able to communicate this information. Family engagement and the cultivation of a deep-trusting relationship is necessary to gain an understanding of the patient's history, feelings, perceptions and beliefs in relation to their illness (Siffleet et al., 2015:309). Family members can offer comprehensive personal information to nurses and healthcare professionals, which may guide the management plan (Rippen et al., 2015:82). Family members develop bonds with the nurses and healthcare professionals who are caring for the patient. Nurses, healthcare professionals, patients and family members are all co-participants in healthcare (Cypress & Frederickson, 2017:209)

Bonds formed do, however, have the potential to lead to increased distress and a negative emotional response if the patient dies. A coping strategy employed by healthcare professionals is emotional disconnection, where they tend to distance themselves by placing focus on the physical aspects of care as opposed to the emotional. This emotional disconnection is a strategy of self-preservation (Shariff et al., 2017:27), but may be perceived as "cold" or "uncompassionate" by family members (Brysiewicz & Emmamally, 2017:1). Caring for families of the critically ill patient could place a personal burden on the carer. Nurses reportedly experience sadness and this may impact their ability to provide the best care, leaving them with a sense of powerlessness to help when families were pleading with them to keep the patient alive (Siffleet et al., 2015:309). Caring for families may increase the risk of clinician burnout (Gerritsen et al., 2017:552).

A common concern in the implementation of family-centred care is that the family could potentially disrupt patient care; nurses may perceive the family as taking the focus away from patient duties resulting in error (Rippen et al., 2015:82). Other concerns include breaching patient confidentiality and privacy (Meert et al., 2013:762). However, there is little evidence to confirm that family presence negatively impacts staff performance and interferes with patient care (Shay, 2018:2; Rippen et al., 2015:82). There are mixed views on family-centred care amongst nurses and healthcare professionals (Ingram, Kamat, Coopersmith & Vats, 2014:917; Satiago, Lazar, Jiang & Burns, 2014: 19). Nurses reportedly tend to be more favourable towards family-centred care than health care professionals (Zaforteza, Garcia_Mozo, Amoros, Perez, Maqueda & Delgado, 2014:84). There is still room for improvement regarding physicians making themselves available in the units during visiting hours to meet with and update significant others on the progress of their loved ones (Hlahatsi et al., 2017:51).

Ingram et al. (2014:917) reported that physicians accept the positive impact of family-centred care, but there remain logistical concerns around ward rounds being less effective, time constraints, harming patients and an increasing workload for healthcare professionals. In another contextual ICU study, most intensivists valued incorporating family members in care rounds as it helped build rapport and facilitated the communication of plans and outcomes for the patients, some intensivists were neutral and others were dissatisfied with including family members in care rounds due to time constraints (Allen et al., 2016:585).

Nurses acknowledge the need to support family in the ICU in most cases (De Beer & Brysiewicz, 2017:25; & Allen et al., 2017:585; & Cypress & Frederickson, 2017:212). However, obstacles are identified when it comes to implementation, such as lack of formal policies and written guidelines about family presence (Cypress & Frederickson, 2017:211). Conversely, it was found that alleviating the emotional stress of a family member and receiving validation from a family improves the job satisfaction and emotional wellbeing of the nurse. Effective partnerships with families in the ICU have positive outcomes for the nurse (Siffleet et al., 2015:309) and healthcare professionals (Ingram et al., 2014:917). Research demonstrates inconsistencies around family-centred care. Findings suggest knowledge gaps on the potential benefits of involving families in ICU care (Santiago et al., 2014:20).

Family members, nurses and healthcare professionals need to work together and in solidarity to achieve the best possible outcomes for the patient in critical illness (De Beer & Brysievicz, 2017:26). Healthcare professionals may be inconsistent in their perceptions of family-centred care. Finding a balance is imperative for all involved (Cypress, 2017:208).

2.7.3 Family member

Family members gain satisfaction in helping with the physical care of a patient. It grants the family member a sense of purpose and makes them feel needed and useful. Family involvement in the care of a family member is an opportunity to show compassion and caring to the family member as this articulates a sense of humanity and, in the African context, the opportunity to honour the principle of Ubuntu (De Beer & Brysiewicz, 2016:46; De Beer & Brysiewicz, 2017:23.).

Ubuntu, a concept fundamental to the African people, links to family care in the ICU. Fundamental to the African culture, primary values are articulated as intense humanness, caring, sharing, respect, compassion and associated values, thus ensuring a happy and quality community life in the spirit of family. The philosophy of Ubuntu depicts how an African is anchored within and connected to the community. In a study done by De Beer and Brysiewicz (2017:25) on the conceptualisation of family care during critical illness, family care was perceived by family members as a shared responsibility between healthcare professionals and family members. Thus, it correlates with the predominantly internationally researched concept of family-centred care.

When a family member is in contact with the patient, they are more likely to understand the seriousness of the illness. Separating the family member from the patient is a reminder of the threat to the family system through loss of their loved one (De Beer & Brysiewicz, 2016:48). Research has shown that family presence during cardio-pulmonary resuscitation and invasive procedures has therapeutic benefits for the family (Rippen et al., 2015:82). The family members are able to comprehend the seriousness of the condition of the patient and this provides reassurance that everything was done for their loved one, which facilitates the grief process (Rippen et al., 2015:82). Some literature suggests evidence around concern that family members may experience increased emotional distress with interventions (Gerritsen et al., 2017:552), and that family presence may affect the family members' lasting memories of the patient (Cypress & Frederickson, 2017:212). Family members who know what to expect, tend to be less anxious and more compliant (Hlahatsi et al., 2017:51). Access to information, knowledge about the patient's care and prognosis and orientation to the technical environment of the ICU reduces anxiety and uncertainties (De Beer & Brysiewicz, 2016:46; Gerritsen et al., 2017:551; Munyiginya & Brysiewicz, 2014:6).

An informed family member is able to support the patient better (De Beer & Brysiewicz, 2016:48), is more cooperative with healthcare professionals (Hlahatsi et al., 2017:49) and empowers them to make informed decisions (De Beer & Brysiewicz, 2017:24). Information is necessary for family members as it allows them to process the situation and gain control (De Beer & Brysiewicz, 2016:48). The involvement of the family members in the care of the patient assists with their informational needs, through its visual impact, and it fosters hope when family members witness improvements in the patient's condition. Traumatic injuries can be visually disturbing to families; involvement in care helps them overcome the initial distress (Wetzig & Mitchell, 2017:69).

Family members should be included in patient care and should be treated as an entity. Failing to do so could lead to a breakdown in communication, misunderstanding the diagnosis, issues related to gaining informed consent and dissatisfaction with the provision of healthcare (Brysiewicz & Emmamally, 2017:1). Collaboration between healthcare professionals is essential in the implementation of family-centred care. Family members experience emotional turmoil when the information they receive is not factual, or is dishonest or inconsistent. Conflicting, contradictory information from healthcare professionals leads to confusion and concern by family members. Failure to provide information has the potential to impact on the emotional and physical wellbeing of the family (De Beer & Brysiewicz, 2016:48). Healthcare professionals have a direct influence on the wellbeing of family members (Meyer et al., 2013:173; Probst et al., 2016:391). Providing information to family members allays anxiety (De Beer & Brysiewicz, 2016:48).

Supporting family members may improve patient outcomes by allowing the family to be more effective caregivers (Gerritsen et al., 2017:550). Families can successfully contribute towards caring for their ICU relative in the general ICU population. Considering ways for this to occur is recommended (Wetzig & Mitchell, 2017:69).

2.7.3.1 Needs of ICU family members

Initial emotions experienced by the ICU family member include fear, anxiety and guilt. The family members' needs are often low on the list of priorities of the healthcare professionals and are therefore neglected, as the focus tends to be on stabilising the patient who is critically ill. Meeting the needs of family members may improve the outcome for patients and relieves the stress and anxiety of the family member (Hlahatsi et al., 2017:49).

Wetzig and Mitchell (2017:67) conducted an integrative review on the needs of families of ICU trauma patients. Sixteen (16) studies were included and the following recurrent needs emerged: Information, making sense, hope, support, involvement and protection.

Information: Family members' informational needs are multi-faceted. Healthcare professionals need to deliver information that is consistent, honest and understandable, even if this information is not positive (Wetzig & Mitchell, 2017:67; De Beer & Brysiewicz, 2016:46). There is confusion and a breakdown in trust when healthcare professionals render information that is contradictory (Wetzig & Mitchell, 2017:67; Cypress & Frederickson, 2017:210).

Poor communication has been shown to be a major source of stress for the family member. The family member is nervous, anxious and frustrated with regard to the unpredictability of their family member's condition. Open communication promotes trust and confidence in healthcare professionals (Hlahatsi et al., 2017:49). Information sharing extends to information regarding visiting times, contact telephone numbers of the ICU, nature of the technical environment, the provision of literature around the patient's illness and access to hospital chaplains. Family members described how this information in writing would be beneficial (De Beer & Brysiewicz, 2016:46).

Making sense: When family members receive information from healthcare professionals, they need to be able to comprehend this information and understand how it relates to their relative (Wetzig & Mitchell, 2017:67). According to Wetzig and Mitchell (2017:67), many family members report poor comprehension of their loved one's diagnosis, prognosis and treatment; often family members relate it to trying to comprehend a whole new language. Family members need information that is easy to understand and relate to. The healthcare professionals need to relay this kind of information, bearing in mind that family members often do not have a medical background (Wetzig & Mitchell, 2017:67). Family members stress the need to be given information patiently and sensitively, especially when it comes to end-of-life decisions, poor prognosis and functional disabilities of the patient (De Beer & Brysiewicz, 2016:46).

> "*They have contacted me and told me that he is brain dead and the doctor just came and told us, you know he just told us sorry you know your child is brain dead, you know, with no compassion...*"
>
> Family member regarding her child (De Beer & Brysiewicz, 2016:46)

Nurses are often the ones that provide the most information to family members about their loved one's condition. Doctors provide information that is not always understandable to the family member and doctors are not always available. Family members like to be informed of results from diagnostic tests such as X-rays and blood tests (Hlahatsi et al., 2017: 49).

Hope: Family members need to remain hopeful regardless of their loved one's condition. Hope sustains a family member and promotes their ability to remain an advocate for the best care and best prospects of the patient. Even in the event of patient demise, a family member's hope is sustained if they are able to reflect on the fact that the best care was given and that their loved one did not experience any suffering (Wetzig & Mitchell, 2017:67; Christensen & Probst, 2014:68; De Beer & Brysiewicz, 2016:47).

Support: Although family members get support from extended family and friends, healthcare professionals are found to be the primary support during the ICU period. Family members rely on healthcare professionals for support as they are considered to be the experts. When family members do not receive adequate support from healthcare professionals, family members' satisfaction with the healthcare declines and they are left feeling apprehensive, anxious and even betrayed by the healthcare professionals (Wetzig & Mitchell, 2017:67). Support from healthcare professionals can be in the form of guidance, including how to cope with everyday responsibilities and what they are allowed to do at the bedside (Wetzig & Mitchell, 2017:67). Families described the emotional turmoil as being so great that they shielded themselves and others from their emotions, providing evidence of the importance of meeting the emotional needs of family members (Wetzig & Mitchell, 2017:67).

Spiritual support is also of significant importance to the ICU family member. In some cultures, illness is viewed as a family affair and a social engagement where family members are expected to visit their sick relative to express sympathy and wish them well. Most healthcare professionals disregard religion and spirituality as they do not feel comfortable addressing the subject. Hlahatsi et al. (2017:52) identified that spiritual needs amongst South African research participants were mostly overlooked, this being particularly important due to the cultural diversity in South Africa. It is important that healthcare professionals make a conscious effort to put own beliefs aside in order to support family members (De Beer & Brysiewicz, 2017:24).

Involvement: Family members need to be involved in the care of their relatives. Being at the patient's bedside gives family members a sense of purpose and make them feel that they are contributing to their loved one's recovery. Being involved also gives the family member an improved understanding of the complexity of the illness or injuries (Cypress & Frederickson, 2017:209). Early on in the ICU admission family members have a strong desire to be at the bedside. Being physically close to their loved one is very important, even if they are not actively participating in anything. Additionally, family members are able to witness day to day improvements in their loved one's condition, which sustains their hope (Wetzig & Mitchell, 2017:68; De Beer & Brysiewicz, 2016:46).

The presence of family members has a calming effect on the patient, as it provides much needed support and comfort and aids in their recovery (Hlahatsi et al., 2017:49; Cypress & Frederickson, 2017:211). Family members may be empowered to support their loved one if they are allowed to participate in routine nursing care at the bedside. Involving family members builds trust relationships between family members and healthcare professionals (Hlahatsi et al., 2017:49).

Protection: Family members feel as though they need to protect their loved one, but they feel powerless to do so, which adds to the emotional turmoil (Wetzig & Mitchell, 2017:68; Christensen & Probst, 2014:65). To meet the needs of the family member in ICU and limit the risk of post-intensive care syndrome, interventions should be aimed at decreasing psychological stressors for the family member. In the last decade, care of the ICU patient has shifted from a physician-centric approach to an approach that is more patient- and family-centred (Allen et al., 2017:582).

2.7.4 Hospital

The former president of the United States of America, Barack Obama, addressed the issue of family presence and visiting hours in hospitals in a memorandum to the secretary of health and human services in April 2010. The memorandum clarifies that hospitalised patients have the right to determine who may visit them, participate in their care plan and make decisions for them in medical emergencies (Obama, 2010). Change is necessary to move away from viewing family members as visitors in the ICU. Family needs to be viewed as part of the healthcare team (Cypress & Frederickson, 2017:212).

Families are recognised for the contributions they make to their members and to society. Yet families are seldom substantively incorporated into the normal course of policy and program development, implementation and evaluation (Bogenschneider et al., 2012:514). The concepts of family impact and family support remain highly abstract, so family considerations are seldom substantively incorporated into the normal course of policy and program development, implementation and evaluation. (Bogenschneider et al., 2012:515).

Interventions that focus on family-centred care, have the potential to improve health outcomes, lead to a decreased length of ICU stay, allow for wiser allocation of resources and lead to greater patient and family satisfaction (Cypress & Frederickson, 2017:211; Goldfarb et al., 2017:1754). The involvement of family members in their loved one's ICU care, sets a hospital apart as it is highlighted as meaningful. Critical care organisations label family-centred care as important in statements and guidelines (Wetzig & Mitchell, 2017:69). Healthcare advocacy groups, some government agencies and external agencies consider patient and family-centred care processes to be a core component of quality healthcare (Goldfarb et al., 2017:1754).

According to Goldfarb (2017:1754), family-centred care is cost-effective in most cases, as it decreases the use of resources and has been shown to decrease length of stay, and it reduces the number of inappropriate diagnostic tests performed and the need for referrals. Family-centred approaches need to be systematically identified, verified and incorporated into organisational philosophy, culture and practice (Bogenschneider et al., 2012:525; Cypress & Frederickson, 2017:212).

2.8 REQUIREMENTS FOR THE IMPLEMENTATION OF FAMILY-CENTRED CARE INTO PRACTICE

The implementation of interventions around family-centred care is not without its challenges. Despite the evidence and extensive research done on family-centred care, putting evidence into practice remains an ongoing challenge (Kuo et al., 2012:298; Gerritsen et al., 2017:552; Hlahatsi et al., 2017:52). Davidson et al. (2017:5) identify that structured interventions and approaches to support family members in the ICU are needed to diminish the effect of an ICU admission and to better equip family members for decision-making and caregiving roles.

2.8.1 Nurses and healthcare professionals

Lack of preparedness by healthcare professionals in caring for family members is a concern. It is imperative that healthcare professionals acknowledge their own perceptions of family-centred care (Shariff et al., 2017:21). The healthcare professionals' own personal view around family-centred care will influence their engagement with the family. If they have had a previous negative experience with an ICU family member, they will be less likely to engage with family members in future (McConnell & Moroney, 2015:995).

Cumulative and unresolved grief limits personal functioning and impacts the healthcare professional's ability to deal with future deaths and the needs of family members (Shariff et al., 2017:27). Support from management is necessary in the form of debriefs after critical incidents, as well as respect towards informal, individualised self-care strategies. Cultivating support in a unit enables healthcare professionals to continue practicing competently as valued members of the team (Shariff et al., 2017: 21).

2.8.2 Hospital

Organisational constraints, including stipulated visiting hours, restrictions on the number of family members allowed at the bedside and the pressures placed on ICU staff to prepare for admissions, are limitations that impede family-centred care. Healthcare professionals can accommodate families in their own capacity, but hospital policies and protocols need to be revised to support family members in the ICU (Shariff et al., 2017:26).

The architecture of the ICU, such as lack of space around the bedside, plays a role in the implementation of family-centred care. There is a risk that family members may injure themselves whilst trying to care for their family in the ICU. There is already an increased workload and some healthcare professionals are fearful of legal consequences related to family involvement (McConnell & Moroney, 2015:995).

2.8.3 Positive findings and gaps in literature around family-centred care

The most common interventions around family-centred care focus on family visitation (Latour & Coombs, 2019:1; Munyiginya & Brysiewicz, 2014:7) and presence on rounds (Davidson et al. 2017:23), information strategies, family involvement in care and family presence during resuscitation (Latour & Coombs, 2019:1). Effective communication, compassion and collaboration among administrative and front-line workers are strategies that could further enhance family-centred care in the ICU (Shariff et al. 2017:26).

Davidson et al. (2017:5) conducted a systematic review of the literature around family-centred care in the ICU. From this review 23 recommendations were made. However, the recommendations were weak indicating the relatively low quality of evidence for family-centred care improvement strategies. Weak recommendations identify the gap in the research.

Research in this field is ongoing as it is a complex and unique field. Continued partnerships, information and sharing in family-centred care are needed to continue developing the field of study (Latour & Coombs, 2019:2). To develop quality strategies to move family-centred care forward, it is recommended that healthcare professionals and the administrators of individual ICUs identify strategies for staging their implementation according to their unique priorities and available resources (Davidson et al., 2017:37).

Recommendations are made that mixed-method studies be carried out as they provide comprehensive data on the needs of family members of the adult ICU patient within and beyond those from single-method studies. A broad understanding is necessary to inform practice change and provide future interventions to better meet the needs of these families (Wetzig & Mitchell, 2017:69)

To promote quality of care to family members, research results need to be transferred into practice. Whilst it is internationally recognised that family-centred care is valuable and beneficial, there is concern that research results are not being transferred into practice due to their complexity. There is ongoing research on how to promote sustainable change and transform healthcare services within complex practice settings, such as the ICU. Institutional, team and individual factors influence the change process (Zaforteza et al., 2015a:78).

Factors limiting the implementation of family-centred care are: pardoning evidence related to family-centred care in the ICU, an imbalance of power-relations amongst healthcare professionals, lack of nurse participation in policy development and unit structures which promote a “closed unit” that is intimidating to family members. On the contrary factors facilitating change towards family-centred care include: joint commitment amongst healthcare professionals, leadership in daily matters and a dialogic reflective process. Shared commitment strengthens an individual's determination when faced with structural factors that resist change. Working together can bring about a change towards family-centred care (Zaforteza et al., 2015b:344).

2.9 FAMILY-CENTRED CARE IN THE SOUTH AFRICAN CONTEXT

In the South African context, research in the field of family-centred care is still in its infancy. Family-centred care is conceptualised as togetherness, partnership, respect and dignity (De Beer & Brysiewicz, 2017:20). South Africa is a diverse country with different cultures and religions. Vast cultural diversities exist amongst family members, which may differ from those of healthcare professionals who provide care (Hlahatsi et al., 2017:52). Family members tend to view critical illness from a religious or spiritual perspective, where the nurse tends to view it from a technological, illness-focused perspective (De Beer & Brysiewicz, 2016:45), which may lead to conflicting opinions and practices. It is imperative that all spiritual and cultural beliefs be respected and not overlooked (De Beer & Brysiewicz, 2017:26).

Results of a quantitative study done by Hlahatsi et al. (2017: 51) in Gauteng, showed that there is room for improvement around physician availability, updates on the patients' condition, flexibility around visiting hours, lack of privacy when discussing patient condition and meeting the spiritual needs of family members. More research needs to be done in South Africa, focusing on the needs of family members in the ICU in order to improve practice (De Beer & Brysiewicz, 2017:26).

2.10 SUMMARY

"The family is the centre of life and it is the key to eternal happiness"
L. Tom Perry

Critical care nursing is becoming increasingly challenging, patient acuity is high, technology is ever advancing, regulations and documentation constraints govern practice. To ensure best outcomes, there is increasing evidence that patients and families need to be more involved in healthcare decisions and need access to information and support (Zaforteza et al., 2015b:336; Cypress & Frederickson, 2017:201; Brysiewicz & Emamally, 2016:1).

The family member of an ICU patient is emotionally vulnerable. The technological environment, uncertainty and confusion accumulate leaving them feeling helpless, powerless and hopeless (Christensen & Probst, 2014:68). Healthcare professionals need to support relatives through this turbulent time (Christensen & Probst, 2014:69).

Up to 75% of family members suffer from post-intensive care syndrome (PICS), a debilitating combination of symptoms which result in significant cognitive, physical and mental impairment that last long after their loved one has been discharged (Shay, 2018:1). Promoting family presence, engagement and empowerment in the ICU is beneficial to the patient and family members and improves satisfaction with healthcare (Shay, 2018:1). In order to successfully implement family-centred care, individual perceptions need to be understood (De Beer & Brysiewicz, 2017:26) and family members, nurses and healthcare professionals need to work collaboratively to understand these perceptions and expectations (Bogenschneider et al., 2012:525; Zaforteza et al., 2015a:84; Institute for Patient and Family Centred Care, 2014)
.

Chapter 2 provided an in-depth literature review that supports a background to the current study. In chapter 3 the research design and methods used in the study will be discussed.

CHAPTER 3
RESEARCH DESIGN AND METHODS

3.1 INTRODUCTION

Chapter 2 provided an in-depth review of the literature which included: a historical overview, the definition of family-centred care, the importance of family-centred care and requirements for implementing family-centred care. The literature formed the theoretical underpinning for this study. Chapter 3 describes the research design and methods used to address the research objectives of the study.

3.2 AIM AND OBJECTIVES OF THE STUDY

The aim of this study was to explore and describe stakeholders' perceptions of family-centred care in the intensive care unit. To address the aim of the research the objectives were to:

- describe nurses', healthcare professionals' and family members' perceptions of family-centred care in the intensive care unit;
- explore nurses', healthcare professionals' and family members' perceptions of ideal family-centred care in the intensive care unit, and
- describe the gap between nurses', healthcare professionals' and family members' perceptions of family-centred care in the intensive care unit.

3.3 RESEARCH DESIGN

A research design is the blueprint for conducting a study. It ensures maximum control over factors that could potentially interfere with the validity of the study findings. The research design guides the planning and implementation of a study, in order to achieve accurate results (Cresswell, 2014:12; Grove et al., 2013:195). The researcher used a quali-quanti research design, also known as a mixed- methods design. Qualitative and quantitative data were collected concurrently and analysed together. The qualitative data was transformed into quantitative data (Cresswell, 2014:15; Harwell, 2011:156).

Qualitative data forms the baseline of the research design, using free word associations which were given by participants in response to the stimulus word "family-centred care". These free word associations were then coded and transformed into quantitative data and presented on semantographs. Quantitative data provides a visual representation of results to allow for a comparison of findings amongst nurses, healthcare professionals and family members.

3.4 QUALITATIVE RESEARCH DESIGN

Qualitative research designs aim at describing life experiences from the perspective of the research participant. It lends significance to the subjective human experience. Qualitative research falls within a naturalistic holistic framework and allows the researcher to explore depth, richness and complex characteristics in the lives of human beings (Creswell & Poth, 2018:42; Grove et al., 2013:57). Data collection usually requires personal contact with the participants (Creswell & Poth, 2018:43; Moule & Goodman, 2014:175) and data is in the form of words (Polit & Beck, 2017:741).

Qualitative research allows the researcher to gain insight into phenomena that are not well known, not well understood or contextual (Creswell & Poth, 2018:45; Botma et al., 2010:182). According to Malagon-Maldonado (2013:120) and Turner, Balmer and Coverdale (2013:307), qualitative research is a social investigation to understand how a group of people interpret their environment, their work or how care is perceived. The researcher made use of qualitative data collection in order to gain insight into how nurses, healthcare professionals and family members perceive family-centred care in the intensive care unit. Qualitative data forms the baseline of the research design, using free word associations which were given by participants in response to the stimulus word "family-centred care".

The strength of qualitative data is that the focus is on events as they occur naturally in order to get a grasp on what is happening in "real life". Qualitative research is useful when a researcher needs a complex, detailed understanding of an issue (Cresswell & Poth, 2018:45). The emphasis is on a specific case, a focused and bounded phenomenon embedded in its context. Local influences are not disregarded, but taken into account. There is a strong possibility of gaining a good understanding of an issue that may be difficult to define. (Cresswell & Poth, 2018:46; Miles, Humberman & Saldana, 2014:11). There is richness and holism in qualitative data, as well as significant potential for the data to provide in-depth descriptions of a phenomenon in real context (Cresswell & Poth, 2018: 44; Miles et al., 2014:11).

3.5 QUANTITATIVE RESEARCH DESIGN

Quantitative research is based on the precise and controlled collection of data along with a meticulous analysis of results (McLiesh, Rasmussen & Schultz, 2018: 39). Numerical data is used for understanding aspects of the world. The focus of the research is measurement and the results can be observed, measured or counted (McLeish et al., 2018:39). This research method describes variables, examines relationships amongst variables and determines cause and effect interactions between variables (Polit & Beck, 2017:49; De Vos, Strydom, Fouche & Delport, 2014:64; Grove et al., 2013:23).

Quantitative research operates within a logical positivism philosophy where strict rules of logic, truth, laws, axioms and predictions apply. The belief is that truth is absolute and there is a single reality that can be defined through careful measurement. The researcher remains completely objective and the researcher's personal perceptions, feelings and values cannot enter into the measurement of reality (McLeish et al., 2018:39; Grove et al., 2013:24).

Quantitative researchers believe that all human behaviour can be measured, and that human behaviour is objective, purposeful and measurable. Finding the right tool or measurement will enable the researcher to discover the truth (Grove et al., 2013: 24).

Quantitative research design in nursing research operates within a post positivist philosophy, which focuses on the discovery of reality characterised by patterns and trends that can be used to describe, explain and predict phenomena (De Vos et al., 2014:7; Grove et al., 2013:24). The belief is that truth can be discovered, but only imperfectly. The post-positivist approach also discards the idea that the researcher remains completely objective about what will be discovered, but concurs with the importance of controlling the environment and potential influences (De Vos et al., 2014:7; Grove et al., 2013: 24).

In this research the qualitative data are coded and then quantified, specific weight is attached to each free-word association and the mean weight is calculated per category. The findings are then represented in semantographs to allow for a comparison of findings (see chapter 4, section 4.4).

3.6 QUALI-QUANTI RESEARCH DESIGN

In reality, both words (qualitative) and numbers (quantitative) are needed to understand the world (De Vos et al., 2014:66; Miles et al., 2014: 42). When the two research methods are used in combination, one can add depth and deeper understanding to data (De Vos et al., 2014:66; Miles et al., 2014:43). It is also known as a mixed-method design, a type of design that offers researchers the opportunity to utilise strengths from both qualitative and quantitative research designs.

Quali-quanti research designs encompass elements of both qualitative and quantitative approaches (De Vos et al., 2014:434; Grove et al., 2013:208). Because phenomena are complex, using a quali-quanti research design allows the researcher to capture the essence of phenomena (Chiang-Hanisko, Newman, Dyess, Piyakong & Liehr, 2016:1; Grove et al., 2013:208). In nursing research mixed-method research is gaining popularity, as using a combination of qualitative and quantitative research strategies provides a scientific base for practice and provides depth to qualitative enquiry (Chiang-Hanisko et al., 2016:1; Bressen et al., 2016:2878). However, mixed-method research is still under development and limited guidance remains for nurse researchers in literature (Bressan et al., 2016: 2878).

Five approaches to quali-quanti research designs are, but are not limited to: Convergent design (Hong et al., 2018:7); sequential explanatory strategy; sequential exploratory strategy; sequential transformative strategy, and concurrent triangulation strategy (Grove et al., 2013:209). In this study the research uses a convergent design, where qualitative and quantitative components are usually, but not necessarily, concomitant (Hong et al., 2018:7; Kryzywosz-Rynkiewicz, 2013:101). The researcher examines the same phenomenon by interpreting qualitative and quantitative results. Data is brought together in the interpretation phase, or by integrating qualitative and quantitative datasets, or by transforming data into ranks or scales (Hong et al., 2018:7; Miles et al., 2014:43) which is applied in this study. The researcher uses quantitative data to understand the qualitative data (Grove et al., 2013:209). The researcher collected qualitative data in the form of “free word associations” in response to the stimulus word “family-centred care”. This data was then coded and transformed into quantitative data and the results were represented in the form of a semantograph. According to Kryzywosz-Rynkiewicz (2013:100), associative group analysis appears to be a promising method that allows for quantitative and qualitative analysis at the same time, in order to understand content amongst different groups.

Associative group analysis is done on two levels: qualitative (the semantic content), where free word associations are analysed and coded; and quantitative (quantification of meanings), where meanings are quantified and transformed into a visual representation in the form of a semantograph (Kryzwosz-Rynkiewicz, 2013:101). The free word associations are described in more depth in section 3.11.4 and examples of semantographs can be viewed in annexure G4.

3.7 RESEARCH METHODS

The research methods will be discussed in terms of the context, population, sampling and sample size, data collection, data analysis and data interpretation. Research methods are the procedures used to construct a study and to gather and analyse information related to the research question (Polit & Beck, 2012:741).

3.7.1 Context

The research was conducted in a 23 bedded ICU in a 360-bed capacity urban private hospital in Pretoria, Gauteng Province. The ICU admits critically ill patients under the following disciplines: Neurosurgery, general surgery, orthopaedic surgery, maxilla-facial surgery, internal medicine and neurology. Patients admitted to the ICU are fully dependant on nursing care. For a more detailed description of the context refer to Chapter one, section 1.10.1.

3.7.2 Population

The research population refers to the entire set of elements, individuals or objects that have similar characteristics in which a researcher is interested (De Vos et al., 2014:223; Burns & Grove, 2013:544; Polit & Beck, 2017:337). In this study the population included nurses, healthcare professionals and family members in the intensive care unit.

In this study the population was confined within a specific context. Therefore, the researcher could only select a sample from the available nurses and healthcare professionals working in the ICU where the study was conducted. The target population was nurses, healthcare professionals and family members in the intensive care unit where the study was conducted.

3.7.3 Sample and Sampling

A research sample is a subgroup of a population (individuals, elements or objects) or group that is chosen to act as representatives of the entire population (De Vos et al., 2014:223; Moule & Goodman, 2014:290; Polit & Beck, 2017:275). In this study the sample consisted of nurses, healthcare professionals and family members.

Sampling refers to the process the researcher uses to select a portion of the population that is representative of the entire population. Thus inferences can be made about the entire population (De Vos et al., 2014: 224; Polit & Beck, 2017:275).

The samples and sampling of nurses, healthcare professionals and family members will be discussed individually.

3.7.3.1 Nurses

The inclusion criteria for nurses were as follows: professional and enrolled nurses working with critically ill patients at a selected urban hospital.

Nurses who were included were:

- working in the ICU where the study was conducted for a minimum of 24 hours per week;
- aged 18 years and above, and
- able to read and write in English.

The sample size for this study consisted of a total of twenty (20) nurses.

Sampling of Nurses

Stratified random sampling was the specific method of sampling used, taking into consideration the variables of the population that were critical to achieve representativeness (De Vos et al., 2014:230; Grove et al., 2013:359). This kind of sampling is mainly used to ensure that the different groups or segments of a population acquire sufficient representation in the sample (De Vos et al., 2014:230). Cultural group was used for stratification, to ensure that different cultural groups were represented in the sample.

Advantages of random sampling are that it reduces the possibility of systematic errors, minimizes sampling biases and produces a more representative sample (Alvi, 2016:13). Disadvantages may be that the technique is time-consuming and requires increased effort. The researcher was able to minimise these disadvantages by obtaining the duty roster of the nurses and planning data collection around these days.

Proportionate sampling was adopted, which is a method of stratified random sampling where the numbers of subjects are selected in proportion to their occurrence in the population. The researcher randomly selected participants from a sampling frame, as a sampling frame is a list of every member of the population with membership defined by the sampling criteria (Grove et al., 2013:359). In this study the researcher made use of the list of nurses working in the ICU where the study was conducted.

The benefit of stratified random sampling is that the sample produced is representative of the population, as it captures the diversity in a heterogeneous population (Alvi, 2016:22; De Vos et al., 2014:230). The disadvantages of stratified random sampling are that it is time-consuming, requires a lot of effort and, if the variable for stratification is not chosen correctly, the research results will be flawed (Alvi, 2016:22). The researcher overcame these disadvantages by selecting cultural group as a variable for stratification and making use of the ICU's shift roster and a list of all nurses employed in the unit to identify the demographic profile of the unit.

The researcher selected the research participants from a sampling frame. A list of all nurses that were employed in the unit at the time of data collection was given to the researcher by the unit manager. The researcher determined the cultural group of each of the nurses, calculated the distribution of nurses per cultural group in the whole population and then determined the number of research participants needed per cultural group to ensure a correct stratification of the population (see table 1.1)

Once the distribution of nurses had been determined, the researcher assigned a number to each research participant according to their cultural group. Correlating numbers were placed in a container. The researcher then randomly drew numbers from the container and identified who the number belonged to on the list of nurses. From there the researcher identified when the nurse would be working and approached the nurses during their scheduled duty time. The researcher selected five extra numbers per cultural group of nurses, to be used if those who were selected during the first selection were not available on the day of data collection. Table 3.1 represents the total population and sample of nurses during the period of 01/03/2018-31/5/2018.

Table 3.1: Nurses - Summary of the target population and sample size

Cultural Group	African	Coloured	Indian	White	Other	Total
Population	25	3	3	5	0	**36**
Sample size	14	1	2	3	0	**20**
Percentage	70%	5%	10%	15%	0	**100%**

The table represents the variable chosen for stratification, which was cultural group. The number of participants in each stratum was based on proportionate sampling, which in turn was based on the demographic profile of the unit where the study was conducted. The number of participants in Table 1.1 represents the sample number that the researcher aimed to achieve in the study (refer to chapter 4 to see what the researcher was able to achieve). According to Schutte (2016:8), the same number of participants must be approached in all samples to compare findings. Sample size was therefore determined by the smallest sampled group. Healthcare professionals were the smallest group at twenty, which is why the sample of nurses was also kept at twenty.

3.7.3.2 Healthcare professionals

The inclusion criteria for healthcare professionals were as follows: doctors, dieticians, physiotherapists, infection prevention specialists working with critically ill patients in the ICU where the study was conducted.

<u>Sample of healthcare professionals:</u>

Healthcare professionals who were included:

- were working in the ICU where the study was conducted;
- had frequent interaction with family members of the ICU patients;
- were aged 18 years and above, and
- were able to read and write in English.

The sample size for this study consisted of a total of twenty (20) healthcare professionals. Healthcare professionals included doctors (9), dieticians (2), physiotherapists (4), infection prevention specialists (2), unit managers (2) and a nursing standards manager (1).

<u>Sampling of healthcare professionals:</u>

Due to the contextual nature of this study and small sample size, all healthcare professionals were asked to participate in the study. Total population sampling was the specific type of purposive sampling that was used for healthcare professionals.

Total sampling involves selecting the entire population that have a set of characteristics. Total sampling is commonly used when the number of cases being investigated is relatively small (Etikan, Musa & Alkassim, 2016:3). The sample selected in purposive sampling is based on a specific purpose that the researcher has in mind. Inclusion criteria for the sample is predefined and only those that meet the criteria or characteristics are included (Alvi, 2016:30; De Vos et al., 2014:232). Purposive sampling is commonly used for the identification and selection of information-rich cases (Palinkas, Horwitz, Green, Wisdom, Duan & Hoagwood, 2015:534) and is appropriate for research that intends to understand a population better (Alvi, 2016:14).

An advantage of purposive sampling is that this method of sampling requires less time and effort. The disadvantage is that sampling techniques are predisposed to coming across systematic errors and sampling biases. The sample cannot usually be defined as a good representation of the population and inferences drawn from the sample cannot be generalizable to the population (Alvi, 2016:14). The researcher was able to overcome these disadvantages of using total sampling, as the population was small and the study is contextual in nature.

3.7.3.3 Family members

The inclusion criterion for family members was as follows: Family members who had a patient admitted in the ICU where the study was conducted.

Sample of family members:

Family members included in the study:

- had a patient admitted in the ICU where the study was conducted;
- had a patient admitted for a minimum period of 72 hours in the ICU where the study was conducted;
- had to be aged 18 years or older, and
- had to be able to read and write in English.

The sample size for this study consisted of a total of twenty (20) family members.

Sampling of family members:

Maximum variation sampling was the specific method of purposive sampling that was used (Polit & Beck, 2017:493). The purpose of maximum variation sampling is documenting unique or diverse variations that have emerged in adapting to different conditions. The researcher is able to recognise significant patterns that cut across variations (Creswell & Poth, 2018:158; Palinkas et al., 2015:534). Maximum variation sampling gives the researcher an opportunity to investigate a subject from all available angles, thereby allowing for a better understanding of the phenomenon (Etikan et al., 2016:3). To ensure a heterogenous sample, the researcher selected a diverse range of ages, cultural groups and gender in the sample, based on the demographic profile of the patients in the ICU where the study was conducted. In associative group analysis the sample should be diverse to compare similarities and differences in experiences across different cultural groups (Kovalcikova & Lacny, 2016:83). The research participants who met the inclusion criteria were of different genders and from different ethnic backgrounds and age groups.

The advantage of maximum variation sampling in this study is that the researcher ensures that every subgroup of the population is included in the sample, increasing the likelihood that the research findings will reflect differences from different perspectives (Creswell & Poth, 2018:158; Alvi, 2016:32). The disadvantage is that the sample is not representative and findings can therefore not be generalised (Alvi, 2016:32). The researcher addressed this disadvantage through the contextual nature of the study. The study findings are limited to the ICU where the study was conducted.

Table 3.2 represents the total population and the sample of patients admitted from the period of 01/03/2018-31/5/2018.

Table 3.2: Family members - Summary of the target population and sample size

Cultural Group	**African**	**Coloured**	**Indian**	**White**	**Other**	**TOTAL**
Population	36	7	2	135	0	**180**
Sample	6	5	2	7	0	**20**
Percentage	30%	25%	10%	35%	0	**100%**

The researcher selected the sample of family members based on the demographics of the patients admitted in the ICU over the mentioned time period. The sample number in Table 1.2 represents the sample that the researcher aimed to achieve in the study (refer to chapter 4 to see what the researcher was able to achieve).

3.7.4 Data collection

The researcher collected data by means of associative group analyses (AGA). AGA is an inferential approach, developed to study the perceptual-representational system, focusing on subjective meanings and images to assess similarities and differences across cultures and between belief systems. AGA uses the stimulus word as the unit of analysis and key unit in the perceptual-representational system and analyses free verbal associations, determining the vertical and horizontal structure of the belief system (Szalay & Brent, 1967:164; Kelly, 1985:36; Kovalcikova & Lacny, 2016:83). Through associative group analyses, the researcher gained an understanding of the nurses', healthcare professionals' and family members' perceptions of family-centred care within the context of the ICU.

Free word associations were used to assess perceptions around family-centred care. Free word associations were given by research participants in response to a stimulus word. The vocabulary used in the free associations is assumed to reflect the person's dispositions. In this study the stimulus word was *family-centred care*. The vocabulary used in the free word associations is assumed to reflect the person's outlook or perceptions (Kovalcikova & Lacny, 2016:83). Based on an analysis of the findings, the researcher was able to identify the perceptions of nurses, healthcare professionals and family members with regard to their current view of family-centred care in the ICU and what their perception of ideal family-centred care is.

3.7.5 Data collection process

According to Polit and Beck (2017:213) data collection is the process of gathering information in order to address the research problem. The researcher conducted interviews with research participants in order to collect data to answer the research questions. The researcher conducted interviews on a one-on-one basis or in groups of two or three. When interviews were conducted in groups, nurses, healthcare professionals and family members were interviewed separately, groups were not mixed. Nurses, family members and a few of the healthcare professionals were interviewed in a small room near the waiting area of the ICU, room had couches for participants to sit, door could be closed to ensure privacy. Healthcare professionals who were not interviewed in the small room were interviewed either in their personal office or at a coffee shop on the hospital premises. An interview is a common method of gaining information from research participants in qualitative and descriptive studies. An interview allows for the researcher to have increased control of the content of the interview to obtain essential information. The researcher designs the question before the interview and the interviewer asks the question exactly as it has been designed. The question is asked in the exact same way to all research participants. If participants do not understand the question, the interviewer may only repeat the question once (Grove et al., 2013:422)

The researcher first conducted a pilot study to test the research methods, made necessary amendments and then proceeded with the formal data collection process.

3.7.5.1 Pilot interview

Prior to the parent study, the researcher conducted a pilot interview. According to Polit and Beck (2017:213), a pilot study is a small-scale version or trial run designed to test the research methods that the researcher intends to use for a large scale, more rigorous study, which is sometimes referred to as the parent study. The purpose of a pilot study is not to answer the research question, but rather to identify and absolve potential flaws in the study (Polit & Beck, 2017:213; De Vos et al., 2014:237). A pilot interview is useful for the inexperienced researcher to practice interview techniques and determine the appropriateness of the interview questions, in order to seek information in the context of the study in preparation for the major study (Majid, Othman, Mohamed, Lim & Yusof, 2017:1077). The researcher conducted a pilot interview in order to determine whether the research participants would understand the concept “family-centred care” and would understand what was expected of them with regard to writing down their free word associations.

The researcher conducted the pilot interview with six participants. These participants included four registered nurses and two family members in an ICU separate to the one where the parent study was conducted. The researcher explained to the participants that it was a pilot interview, which meant that the purpose was to test understanding and that the results would not be reported (De Vos et al., 2014:237).

Two of the six participants where given the information leaflet to read through, to determine understanding. Two typing errors were found in the information leaflet and consent form. Corrections were made for the final study. Participants gave feedback that the information leaflet was easy to understand and easy to read, so no clarification of content was needed. Two registered nurses and one family member were given a biographical questionnaire to fill in in the pilot interview. All demonstrated a clear understanding of the questionnaire, so no further clarification or corrections needed to be made. No changes were made to the demographic data.

The researcher conducted one-on-one interviews with the participants for the pilot interview (see annexure E1 for interview guide). Each participant received a response card which contained 15 open lines to write down responses (see annexure E3). Each Participant was given a code which was written in the top left-hand corner. The participants were asked to write down free word associations about family-centred care with regard to the following question: “Write down what comes to mind first when you think of family-centred care in the ICU.” They were given one minute to write down these free word associations (Kelly, 1985:37). Once the participants were done answering the first question they were asked to write down free associations with regard to the ideal family-centred care environment in the ICU by means of the following question: “Write down what comes to mind first when you think of the ideal family-centred care environment.’ Once again they were given one minute to write down their free-word associations. To ensure accuracy the researcher did not provide any examples. The cards were then collected for interpretation.

Upon analysis of the data, two of the participants had written in paragraph format and given broad descriptions of family-centred care, not necessarily related to the ICU in which they were currently working. As a result, the answers for questions 1 and 2 appeared very similar. On further discussion it turned out that the participants felt that family-centred care was definitely lacking in their ICU and that there is room for improvement.

The researcher made the following amendments to the data collection sheets: To avoid answers being written in paragraph format, the researcher changed the response card to a point format which limited space per line (see annexure E4). To ensure that the participants answered the questions in the context of their own ICU and by using words only, the researcher rephrased the first question as follows (see annexure E2): “Write down what comes to mind first when you think of family-centred care in GICU.”

Once amendments were made, the researcher asked two more family members to take part in the pilot interview in order to test the amendments. The family members answered using words according to the free word association methodology. The disadvantage of this, however, was that the researcher could not assume what the research participant meant with certain words. Once free word associations had been written down, the researcher had a look at what the participant had written and then asked the participant to clarify any misunderstandings to ensure accurate data interpretation. The researcher was aware that the participants might still use phrases or sentences instead of words. However, an advantage of the phrases was that it assisted the researcher in the data analysis, as it provided more clarity compared to words alone. The researcher coded all data collected to establish themes, subthemes and categories from the data.

3.7.5.2 Collecting the data

The researcher informed the participants about the study prior to data collection. The aim and importance of the study was explained. Once the participants volunteered to participate, the researcher gave them a patient information leaflet (see annexure C) and organised a date and time that would suit them for data collection. Prior to data collection, participants were given the opportunity to ask questions.

The researcher was familiar with the nurses and healthcare professionals working in the ICU. She had worked in the unit as a Clinical Training Specialist from August 2015 until June 2018. During data collection the researcher first stated the purpose of the research study, explaining the process and how long it would take. Written consent was obtained from all the research participants (see annexure C). The researcher collected demographic data to enable her to identify the characteristics of the participants. Each participant was given a code according to population group, with nurses being coded as N, healthcare professionals as OHCP and family members as FM. The researcher allocated numbers to the participants per population group. Thus, the first participant from the nurse population was coded as N1. The researcher recorded the code to ensure accurate data capturing. Each research participant was given a response card with eight (8) open lines. The identification code was recorded at the top of every card (see annexure E4). Thereafter participants were asked to write down their free associations about family-centred care with regard to the following question: Write down what comes to mind first when you think of the family-centred care in the ICU. Participants were given one minute to write down free word associations.

Once the participants were done the researcher collected the cards and then handed out a second card with eight (8) open lines. Once again the code was recorded at the top of every card. Then the next question was asked. The participants were asked to write down their free associations in relation to the ideal family-centred care environment in the ICU in terms of the following question: Write down what comes to mind first when you think of the ideal family-centred care environment. The participants were once again given one minute to write down their free word associations in relation to the question. They were instructed to write down only words, not sentences, for both questions. To ensure accuracy, the researcher did not provide any examples. The cards were then collected by the researcher and placed in a sealed envelope for data analysis at a later stage (Kovalcikova & Lacny, 2016:83). The data collection took approximately 15 minutes per participant.

The exact processes of data collection from nurses, healthcare professionals and family members will be discussed separately.

Data collection from nurses: The nurses were informed of the research one month prior to data collection, during the monthly ICU ward meeting with the consent of the hospital management and unit manager of the ICU where the study was conducted. The researcher herself informed the research participants of the research study. Data collection from the nurses took place during their scheduled on-duty time, without disrupting their responsibilities or causing any disruption in patient care. The data was collected from the nurses in groups of two or three by the researcher herself. The participants were not allowed to discuss their thoughts, as this may have influenced their individual responses.

Data collection from healthcare professionals: The researcher arranged a time to meet with the doctors, physiotherapists, dieticians and infection prevention specialists on an individual basis. Data collection took place on an individual basis, not in a group format, as it was difficult to arrange a time and place that suited all the healthcare professionals equally. The time and place were determined by the research participant, either on the hospital premises or at any other convenient place such as a nearby coffee shop.

Data collection from family members: Family members were approached on an individual basis, prior to visiting hours. Data collection took place at their convenience. Due to the increased stress and anxiety experienced by family members, the researcher was conscientious in approaching individual family members. Increased stress and anxiety are associated with a shorter length of ICU stay, as family members have not had time to calm their emotional turmoil (Belayachi et al., 2014:115; Turner-Cobb et al., 2016: 20). Therefore, the researcher did not approach family members of patients admitted for less than a 72-hour time period. The researcher also did not approach family members who appeared to be distressed, anxious or emotional. The researcher did not identify any signs of distress, anxiety or emotional turmoil during data collection. However, if she had, the process would have been stopped and the researcher would have referred the family member/s to a trauma counselor who was affiliated with the hospital where the study was conducted.

3.7.6 Data analysis

Data analysis took place in four phases:

Phase 1: Ranking/scoring

Phase 1 forms part of quantitative analysis. After data collection, the cards were organised and prepared for data analysis. Each participant in the group was given a code and the code was recorded in the top left corner of the response cards. Participant's demographic data was collected prior to data collection, using a separate form (see annexure D1 & D2) that included the following characteristics: participant's cultural group, gender, age and period working in the ICU, for the nurses and healthcare professionals, or admission days of patient for the family member/s. The researcher assigned a rank weighting to each response (Kovalcikova & Lacny, 2016:83). The associative group analysis technique suggests that the word association which is written first, is more relevant to the participant. A weighted ranking is assigned according to the relevance of an association. If, for ***example***, the participant wrote down 12 responses scoring was assigned as follows: 6, 5, 4, 3, 3, 3, 3, 2, 2, 1, 1, 1 (see annexures F1, F2 and F3). If participants wrote down fewer responses, for example 3, the scoring was assigned as follows: 6, 5, 4 (Kovalcikova & Lacny, 2016:83). The weighting was determined by means of the empirical testing of a differential stability of rank placement in a test and retest method. The weight rank provided group specific priorities of meaning (Kovalcikova & Lacny, 2016:83).

Table 3.3 shows a summary of how free associations provided by research participants are ranked or scored if participants wrote down 12 free associations or responses.

Table 3.3: Quantitative analysis: scoring of free associations

Responses provided by research participants	Score/Rank weight allocated per response
Response 1	Rank weight : 6
Response 2	Rank weight : 5
Response 3	Rank weight : 4
Response 4,5,6,7	Rank weight : 3
Response 8 & 9	Rank weight : 2
Response 10, 11, 12	Rank weight : 1

Phase 2: Coding

The second phase of data analysis formed part of qualitative analysis. Research participants' responses were grouped together. This took place shortly after scoring (see annexure G1). Once the process of scoring was completed, the researcher categorised each free word association according to similar meanings or codes (Kovalcikova & Lacny, 2016:83). Similar meanings were divided into themes, subthemes and categories (see annexure G2) (Maree, 2016:119). To ensure inter-coding reliability the researcher asked her research supervisors, who are familiar with the process, to re-code the data (Maree, 2016:6).

Phase 3: Determining weight

Phase 3 formed part of quantitative analysis and involved calculations, result presentation and comparisons. The total number of free word associations was divided into the total number of identified categories. This was done to identify the total weight of the category (Kovalcikova & Lacny, 2016:83). This allowed for the comparison of data regarding perceptions of family-centred care amongst stakeholders in the ICU (see annexure G3). The weighting of categories was based on the ranking/scoring of the responses completed in phase 1.

Phase 4: Indicating the gap

In the final phase, the results were presented graphically by means of a semantograph or radar presentation (Kovalcikova & Lacny, 2016:84). A semanotgraph was presented per population group to allow the researcher to visually compare the perceptions of family-centred care amongst stakeholders in the ICU. The semantograph gave a graphic representation of the gaps that exist between current perceptions of family-centred care and ideal family-centred care. The researcher herself designed the semantograph using Microsoft Exel, 2010. The researcher also gave a graphic representation of research results in tabular format to allow for a clearer interpretation of percentage values per category (see annexure G4).

3.7.7 Data interpretation

Once the data was analyzed, the researcher attempted to answer the research questions: How do nurses, healthcare professionals and family members in the intensive care unit perceive family-centred care? How do nurses, healthcare professionals and family members perceive ideal family-centred care in the intensive care unit? What are the gaps between nurses', healthcare professionals' and family members' perceptions of family-centred care in the intensive care unit? Once the data was interpreted, the researcher suggested implications for practice, education, management and future research. The findings will be presented to the ICU where the study was conducted in an attempt to improve family-centred care.

3.8 RIGOUR

This study used a quali-quantitative design. Therefore, strategies to ensure rigour for both qualitative and quantitative designs were ensured and these will be discussed below.

3.8.1 Rigour in qualitative research

Rigour in qualitative research refers to striving for excellence in research using discipline, scrupulous adherence to detail and strict accuracy (Grove et al., 2013: 708). Control decreases the chance of error in quantitative research and, therefore, increases the probability that study findings are a true reflection of reality. The researcher imposed rules to increase control in the study (Grove et al., 2013:36). The researcher strived for rigour and control in the research study by using a viable research method and ensuring that the data was collected with accuracy and that she did not influence participants' responses in any way.

The degree of rigour in qualitative research is established by five standards, namely: credibility, transferability, dependability, confirmability and authenticity (Cresswell & Poth, 2018:256; Maree, 2016:123).

Credibility ensures that the research is conducted according to set standards and that it is a true reflection of the data and context (Cresswell & Poth, 2018:258; Polit & Beck, 2017:559; Maree, 2016:123). The researcher used a research design, data gathering method, data collection process and data analysis method that are a well-recognised and a standard way of conducting research.

Transferability is the likelihood that findings could be replicated in another context where circumstances are similar (Maree, 2016:124; Botma et al., 2010:233; Polit & Beck, 2017:560). In the study the researcher provided a thick, rich and thorough description of the research design, context, participants, data collection and analysis methods (Maree, 2016:124; Polit & Beck, 2017:526), so that readers could determine whether their circumstances were similar and whether the findings were replicable in their context (Maree, 2016; Botma et al., 2010:233; Polit & Beck, 2017:560).

Dependability refers to the reliability of the data (Polit & Beck, 2017:559). If the research were to be conducted by another researcher under the same conditions, research findings should be the same. The researcher enhanced dependability by validating findings by means of the literature, presenting detailed descriptions of the context, research process and findings and referring to peer examinations, as discussed earlier. The researcher made use of a second coder to analyse the data (Maree, 2016:124; Botma et al., 2010: 234) and research supervisors assisted the researcher with data analysis to enhance dependability (Maree, 2016:119).

Confirmability comprises specific processes of data collection, data analysis and the presentation of data that are specific to the research design that was used. Thus, other researchers should be able to come to the same conclusion if they were to replicate the study in a similar context (Botma et al., 2010:234; Polit & Beck, 2017:560). Confirmability is the degree of neutrality or the extent to which the research findings were shaped by the research participants and not by the researcher's bias, motivation or interest (Maree, 2016:125).

Authenticity refers to the researcher's ability to illustrate the true experiences and feelings of the participants (Cresswell & Poth, 2018: 258; Polit & Beck, 2017:560; Botma et al., 2010:235). The researcher ensured the authenticity of the data collected from nurses, healthcare professionals and family members by accurately interpreting data and not allowing own bias to influence the interpretation of the results.

3.8.2 Rigour in quantitative research

Degree of control in quantitative research is established by four standards namely: internal validity, external validity, reliability and objectivity.

Internal validity is the truth value in the research findings for the subjects or informants and the context in which the study was conducted (Cresswell & Poth, 2018:258; Cohen, Manion & Morrison, 2011:183; Krefting, 1991:215). Internal validity aims to demonstrate that the research findings can be sustained by the data, in other words the research findings must accurately describe the phenomena being researched (Cohen et al., 2011:183). In quantitative studies, truth is assessed by how well threats to the internal validity of a study have been managed, as well as the validity of the instruments as a measure of the phenomenon under study (Burns et al., 2013:393; Krefting, 1991:215). Various assessments of the construct and content validity of AGA indicate that it is a viable measure of meaning and its related evaluative elements. With regard to construct validity, this is the extent to which the particular instrument or measure used for data collection conforms to the theoretical context in which it is located (Cohen et al., 2011:188). Construct validity in AGA relates directly to the perceptual-representational theory of belief systems and is consistent with other theories (Kelly, 1985:37).

Regarding content validity, this refers to how accurately and comprehensively an instrument or measure covers the domain or items that it proposes to cover (Cohen et al., 2011:188). AGA has been compared to five other widely accepted measures of meaning: similarity scaling or judgement methods; substitution; grouping or classification; judgement of relationship, and the semantic differential (Kelly, 1985:37). Inter-correlations of all six measures revealed high correlations between AGA and those of all measures except for those of the semantic differential. Further analysis revealed that the semantic differential and other measures, including AGA, yielded similar results to attitude measures (Kelly, 1985:37). Face validity verifies that the research measure looked like or gave the appearance of measuring the content desired for the study (Grove et al., 2013:694). Face validity in AGA results has been confirmed in previous studies (Kelly, 1985:37).

External validity is the ability to generalise from the study sample to the larger population, in other words the degree to which the findings can be applied to other contexts and settings or other groups. In quantitative research, external validity depends on how well threats to the study have been managed (De Vos et al., 2014:152; Polit & Beck, 2017:560; Krefting, 1991:216). In order to enhance external validity, the researcher ensured that the research participants were representative of the population to which she wished to generalise the results (Polit & Beck, 2017:560).

Reliability refers to the consistency of the data. If the research study was replicated using the same subjects in a similar context, the findings should be consistent (Maree, 2016:238; Cohen et al., 2011:199). In quantitative research, reliability is the criterion concerned with the stability, consistency and equivalence in the study. Replication of the testing procedures should not alter the findings (Cohen et al., 2011:200; Kefting, 1991:216). The concept of reliability is, however, based on the assumption that only one single reality exists. It conforms to a largely positivist worldview (Cohen et al., 2011:200, Kefting, 1991:216). If one assumes multiple realities, the notion of reliability is no longer applicable (Kefting, 1991:216).

Objectivity refers to freedom from bias in the research participants and results. Objectivity is the degree to which the findings are a function of the informants and conditions of the research and not of other biases, motivations and perspectives. The researcher should have minimal influence over the subjects' responses. The objective researcher is seen as scientifically distant; one who does not influence and is not influenced by the study (Kefting, 1991:217). The researcher ensured objectivity by asking the research question in the same manner to all participants. The researcher did not interact with the research participants while they were responding. The researcher also ensured that, while the interviews were being conducted with two or three participants, the participants did not interact with one another. This was done to ensure that the responses from the research participants were their own.

3.9 SUMMARY

This chapter discussed the research design and methods used in detail, including population sample, data collection and ethical considerations. Chapter 4 discusses the data analysis process.

CHAPTER 4
RESULTS AND DISCUSSION

4.1 INTRODUCTION

Chapter 3 described the research design and research methodology used in the study. Chapter 4 discusses the data analysis, the interpretation and the results. The findings of the study are addressed with reference to the literature reviewed. The aim of the study was to explore and describe stakeholders' perceptions of family-centred care in the intensive care unit.

The research results will be discussed in terms of the demographic information; orientation and presentation of results which will detail how the responses from research participants were ranked and weighted. A summary of the overarching themes, subthemes and categories that emerged from the data will follow. The research results will then be discussed in terms of the nurses', healthcare professionals' and family members' perceptions of family-centred care in the ICU; nurses', healthcare professionals' and family members' perceptions of ideal family-centred care in the ICU and the gaps that were identified between nurses', healthcare professionals' and family members' perceptions of family-centred care in the intensive care unit.

4.2 DEMOGRAPHIC INFORMATION

The researcher interviewed the research participants, either in small groups of no more than three at a time or on a one-on-one basis. Participants included nurses, healthcare professionals and family members in an intensive care unit in Pretoria, Gauteng. One doctor declined to participate due to time constraints and the researcher approached a member of the management team to replace the doctor. Five family members were invited to participate, but declined. No reason was given and the researcher did not probe them any further. No nurses declined participation. A total of sixty (60) participants who met the inclusion criteria (see Chapter 3, section 3.7.2) took part in the study. Table 4.1-4.3 summarises the demographic details of the research participants.

Table 4.1 provides a summary of the nurses' demographic information.

Table 4.1: Nurses: demographic information

Nurses:		Total Sample: 20 participants		
Gender:	Male	Female		
	1	19		
Age:	Range in years	Mean Age		
	27-45 years	36,8 years		
Cultural Group:	African	Coloured	Indian	White
	14 (70%)	1 (5%)	3 (15%)	2 (10%)
Years of Experience in ICU	Range in years	Mean		
	2-13 years	6,09 years		
Post Grad Qualification	Yes	No		
	11	9		

Of the twenty research participants who took part in the study, there were nineteen females and one male participant. The mean age of the participants was 36,8 years with an average of 6,09 years' experience working in the intensive care unit. Eleven of the twenty participants had post-basic qualifications. Out of the twenty participants, there were fourteen African participants, which equated to 70% of the sample, one coloured participant, which equated to 5% of the sample, three Indian participants, which equated to 15% of the sample and two white participants, which equated to 10% of the sample.

Table 4.2 provides a summary of the healthcare professionals' demographic information.

Table 4.2: Healthcare professionals: demographic information

Healthcare professionals		Total Sample: 20 participants		
Gender:	Male	Female		
	9	11		
Age:	Range in years	Mean Age		
	27-56 years	41,5 years		
Cultural Group:	African	Coloured	Indian	White
	7 (35%)	0 (0%)	1 (5%)	12 (60%)
Years of Experience in ICU	Range in years	Mean		
	2-31 years	13,7 years		
Post Grad Qualification	Yes	No		
	18	2		

Of the twenty research participants who took part in the study, there were eleven females and nine male participants. The mean age of the participants was 41,5 years with an average of 13,7 years' experience working in the intensive care unit. Eighteen of the twenty participants had post-basic qualifications. Out of the twenty participants there were seven African participants, which equated to 35% of the sample, one Indian participant, which equated to 5% of the sample and twelve white participants, which equated to 60% of the sample. Of the healthcare professionals there were eight doctors, five physiotherapists, two dieticians, one renal dialysis nurse, two infection prevention specialists and two participants from hospital management.

Table 4.3 provides a summary of the family members' demographic information

Table 4.3: Family members: demographic information

Family members:	Total Sample: 20 participants			
Gender:	Male	Female		
	7	13		
Age:	Range in years	Mean Age		
	21-62 years	43,15 years		
Cultural Group:	African	Coloured	Indian	White
	6 (30%)	2 (10%)	0 (0%)	12 (60%)
Number of days family member was admitted in the ICU	Range in days	Mean		
	3-42 days	17.45 days		

Of the twenty research participants who took part in the study, there were thirteen female and seven male participants. The mean age of the participants was 43,15 years. The average admission days that their family member was admitted in ICU was 17,45 days. Out of the twenty participants there were six African participants, which equated to 30% of the sample, two coloured participants, which equated to 10% of the sample and twelve white participants, which equated to 60% of the sample.

4.3 Orientation and presentation of results

The results will be presented according to the themes, subthemes and categories that emerged from the data. The researcher will first present the themes, subthemes and categories that emerged from the data in table form. Thereafter, the researcher will present the weighting of the themes, subthemes and categories. Each theme, subtheme and category will then be discussed separately with reference to family-centred care in the current and ideal ICU environment. Weighting in percentage form will be presented per theme, subtheme and category. The researcher will present examples of the responses given by the research participants in table form. The final part of the discussion of the results will be to indicate the gaps that were identified.

Two questions were asked to all research participants:

Question 1: Write down what comes to mind first when you think of the family-centred care in the ICU.

Question 2: Write down what comes to mind first when you think of the ideal family-centred care environment.

Phase 1 of the data interpretation involved the ranking/scoring of the responses given by the research participants. Each response was given a rank weighting, see chapter 3, table 3.3 for a summary of how participant's responses were ranked/scored in phase 1 and annexure F1, F2 and F3 for the ranking/scoring of responses. Table 4.4 represents themes, subthemes and categories that emerged from the data after coding (phase 2):

Table 4.4 Themes, subthemes and categories

Theme	Subtheme	Category
1.Communication	Orientation	Rules
		Environment
	Information	
	Multi-disciplinary communication	
2.Environment	Physical Environment	
	Care Environment	Nursing competency
		Workplace culture
	Patient Environment	Electronics/ Entertainment
	Family Environment	
3.Continuum of feelings	Current feelings	
4.Reflections	Current perceptions	
	Nurse dependant	
	Expectations	
	Family involvement	
4.Spiritual Care		

The five main themes that emerged from the data was communication, environment, continuum of feelings, reflections and spiritual care. Communication was further divided into orientation and information. Orientation was further categorised into rules and environment. Environment was further divided into physical environment, care environment, patient environment and family environment. Care environment was further categorised into nursing competency and workplace culture. Patient environment was further categorised into electronics/entertainment. Continuum of feelings was further divided into current feelings. Reflections was further divided into current perceptions, nurse dependant expectations and family involvement. Spiritual care had no subthemes or categories. Each theme will be discussed under section 4.3 and 4.4.

Phase 3 involved the weighting of categories based on the score/rank that was allocated in phase 1 (see annexure G3 to view the overall scores and weighting of categories). These figures were transformed into a percentage value, which will be presented and discussed in section 4.3 and 4.4
The overall weighting of responses given by nurses was 460 in relation to current family-centred care and 470 in relation to ideal family-centred care. The total weighting of responses given by healthcare professionals was 458 in relation to current family-centred care and 449 responses in relation to ideal family-centred care. The overall weighting of responses given by family members was 496 in relation to current family-centred care and 443 responses in relation to ideal family-centred care.

Table 4.5 provides a summary of the overall weighting provided for each theme in relation to the perception of family-centred care as it is currently. Weighting was determined based on calculations done to free associations as described in phase 1. A percentage value was calculated to weight responses as described in phase 3. The data revealed that 39% of responses related to communication, 34% of the responses related to the ICU environment, 9% of the responses related to the continuum of feelings, 17% of the responses related to reflections and 0.4% related to spiritual care.

Table 4.5: Themes and total weighting of responses related to family-centred care in the *current* ICU environment

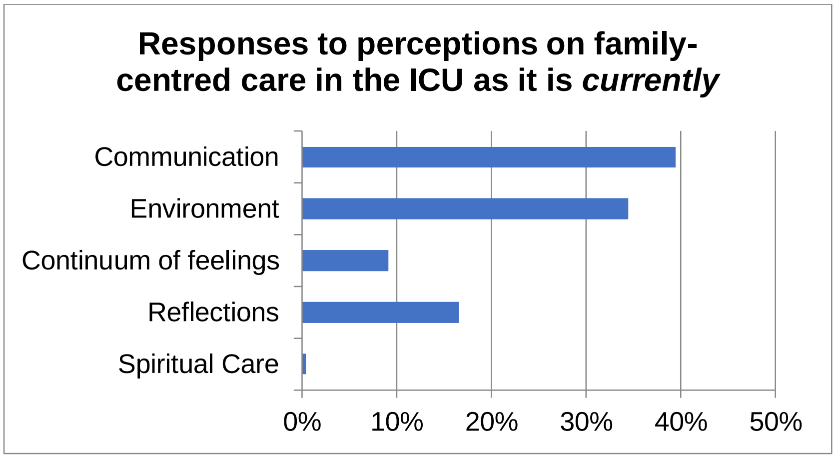
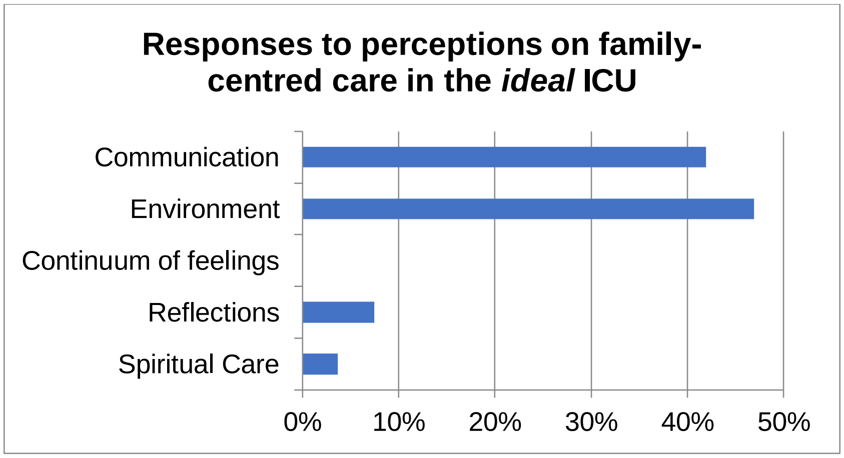


Table 4.6 provides a summary of the overall weighting provided for each theme in relation to the perception of family-centred care as it is in the ideal ICU. The data revealed that 42% of the responses related to communication, 47% of the responses related to the ICU environment, 0% of the responses related to the continuum of feelings, 7% of the responses related to reflections and 4% related to spiritual care.

Table 4.6: Themes and total weighting of responses related to family-centred care in the *ideal* ICU environment



Colour codes will be used to distinguish between the quotations from the participants to support the data. The colour coding will indicate whether the quotation/s came from a nurse, healthcare professional or a family member. Blue represents nurses, green represents healthcare professionals and purple represents family members. Abbreviations were used in the images, with N representing nurses, HCP representing healthcare professionals and FM representing family members (see table 4.7).

Table 4.7 Depiction of colours and abbreviations used

Colour	Category of research participant
Blue	**Nurse (N)**
Green	**Healthcare professional (HCP)**
Purple	**Family member (FM)**

4.4 THEMES, SUBTHEMES AND CATEGORIES

The findings will be discussed in terms of the themes, subthemes and categories that were identified during data analysis. The data will be represented in the form of a bar graph for a visual representation of weighting per theme, subtheme and category. Examples of the free word associations used by the research participants are represented in table form. The research participants wrote down free word associations related to "family-centred care". Most research participants responded by writing sentences or phrases rather than words. "Free word associations" will be referred to as "free associations" After presenting examples of free associations in table form, a discussion of the analysis and interpretation of findings, with reference to the relevant literature, will follow.

The chapter concludes with semantographs (phase 4) representing the following findings:

- Gaps that exist amongst nurses, healthcare professionals and family members in comparing current versus ideal family-centred care.
- Gaps that exist amongst nurses, healthcare professionals and family members regarding the most prominent themes.

The prominent themes include:

  - Communication;
  - environment, and
  - spiritual care

4.4.1 Theme 1: Communication

Communication was a consistent theme that emerged from all research participants when they described their current perceptions of family-centred care.

Communication*: current perceptions*

Figure 4.1 represents the percentage of research participants who wrote down free associations that were related to communication; 35% of nurses, 52% of healthcare professionals and 32% of family members wrote down responses associated with communication as it is *currently* in the ICU.

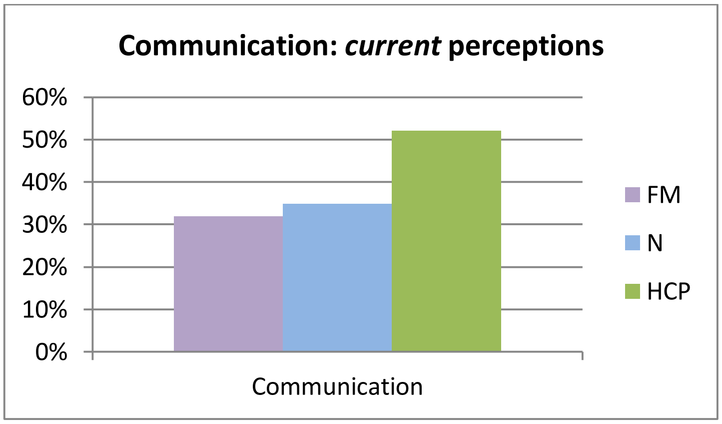


Figure 4.1: Communication: *current perceptions*

Communication is defined as a transaction and message creation. The transmission of a message may be verbal or written information from a sender to a receiver and it follows a specific process: sender-message-receiver (Siemsen, Madsen, Pedersen, Michaelsen, Pedersen & Andersen, 2012:439). The process occurs in a context of physical space, cultural and social values and psychological conditions (Kourkouta & Papathanasiou, 2014:65). Communication is never one-directional, but an interaction where the sender of the message becomes the receiver and vice versa. Failure to recognise this two-way communication often leads to negative conclusions and attitudes (Kourkouta & Papthanasiou, 2014:65). Communication includes both verbal and non-verbal communication. Non-verbal communication is articulated through the use of facial expressions, gestures, posture and physical barriers such as distance from the speaker. There needs to be a link between verbal and non-verbal communication (Kourkouta & Papathanasiou, 2014:66).

Sometimes the message that is sent is not what is received. The decoding of messages is based on individual factors and subjective perceptions. Messages are not interpreted according to what the sender has said, but rather according to the receiver's own code (Kourkouta & Papathanasiou, 2014:66). When a healthcare professional talks to a family member using technical terms and medical terminology, the message may be misinterpreted due to lack of understanding (Kourkouta & Papathanasiou, 2014:66). According to Sari, Prabandari and Claramita (2016:58), the communication skills of healthcare professionals is a fundamental quality of professionalism, regardless of the level of training.

Communication is central to human interaction. Without communication people cannot relate to those around them, make their needs and concerns known or make sense of what is happening to them (Casey & Wallis, 2011:35). It is essential that healthcare professionals communicate with family members using terminology that is clear to them. Family members need to understand what is happening to their family member in order to process and make sense of what is happening. When a family member has processed and correctly understands the situation, they are able to cope better (Furquan & Zakaria, 2017:365).

One of the most common sources of dissatisfaction for families in the healthcare setting is poor or bad communication with the healthcare professionals (Bueno, Alonso-Ovies, Haras, La Calle, Lallemand, 2017:338). Patients and family members rate communication with healthcare professionals as one of their most important needs (Furqan & Zakaria, 2017:365). This is consistent with the findings in this study. Nurses, healthcare professionals and family members all rated communication as important in family-centred care, as it is *currently* in the ICU and as it should be in the *ideal* setting.

Communication*: ideal perceptions*

Fifty percent (50%) of nurses, 56% of healthcare professionals and 49% of family members, wrote down free associations that related to communication in the *ideal* environment. Figure 4.2 represents the percentage of research participants who wrote down free associations that were related to communication in the *ideal* environment.

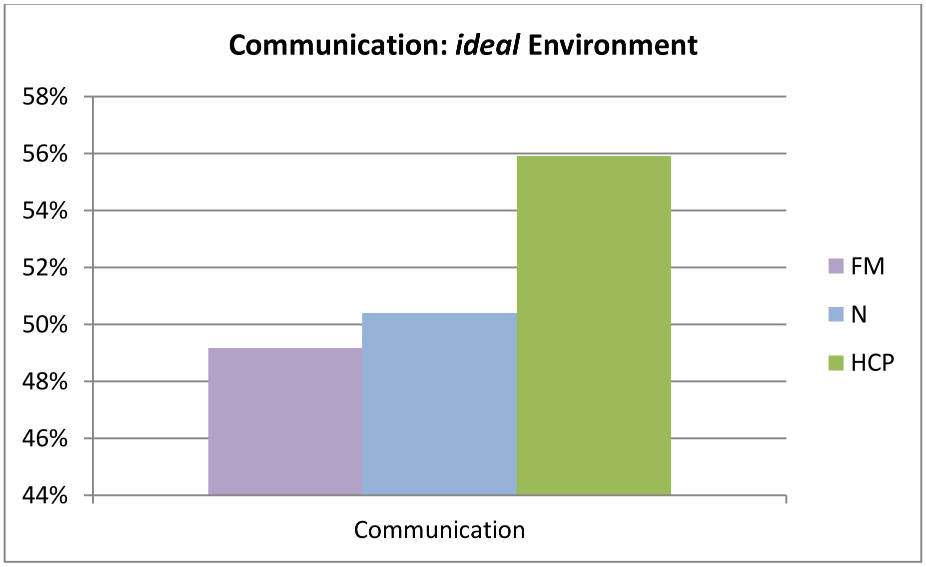


Figure 4.2: Communication: *ideal environment*

Not only is it important for healthcare professionals to communicate effectively with the family, but they should also communicate effectively with each other to ensure continuity, safety and quality of healthcare for all (Langley, Kisorio & Schmollgruber, 2015:39; Casey & Wallis, 2011:35). Poor communication amongst members of the multi-disciplinary team is a common problem (Langley, Kisorio & Schmollgruber, 2015:39). A breakdown in communication amongst team members may lead to fundamental differences in a perception of the patient's condition, which then leads to feelings of moral distress (Langley, Kisorio & Schmollgruber, 2015:39). Communication breakdown amongst members of the multi-disciplinary team leads to feelings of lack of trust, absence of collegiality, restricted institutional and mutual support and the continued submission of nurses in the ICU (Langley, Kisorio & Schmollgruber, 2015:41).

Literature supports that effective communication is an important component of family-centred care (Furqan & Zakaria, 2017:365). This study reiterates the importance of communication in family-centred care amongst all stakeholders in the ICU.

Subthemes related to communication

Three subthemes were identified in communication, namely orientation, information and communication amongst the multi-disciplinary team. These subthemes and their related categories will be discussed under section 4.3.1.1. - 4.3.1.4. Figure 4.3 represents the subthemes that were identified based on free associations related to orientation, information and communication amongst the multi-disciplinary team as it is *currently* in the ICU. Percentages will be discussed under each section.

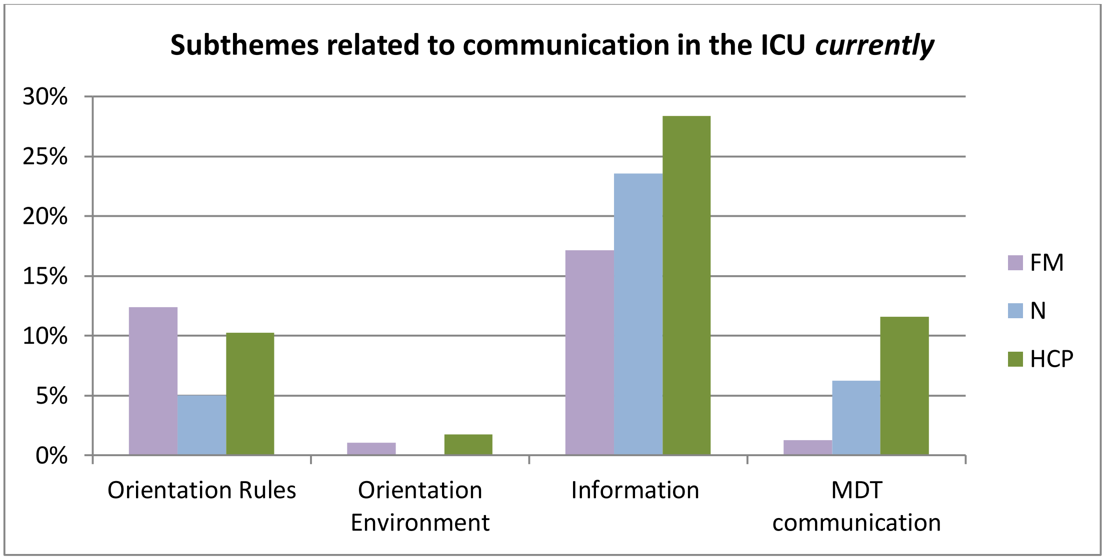


Figure 4.3: Communication subthemes: *current perceptions*

Figure 4.4 represents the subthemes that were identified based on free associations related to orientation, information and communication amongst the multi-disciplinary team in the *ideal* ICU. Percentages will be discussed under each section.

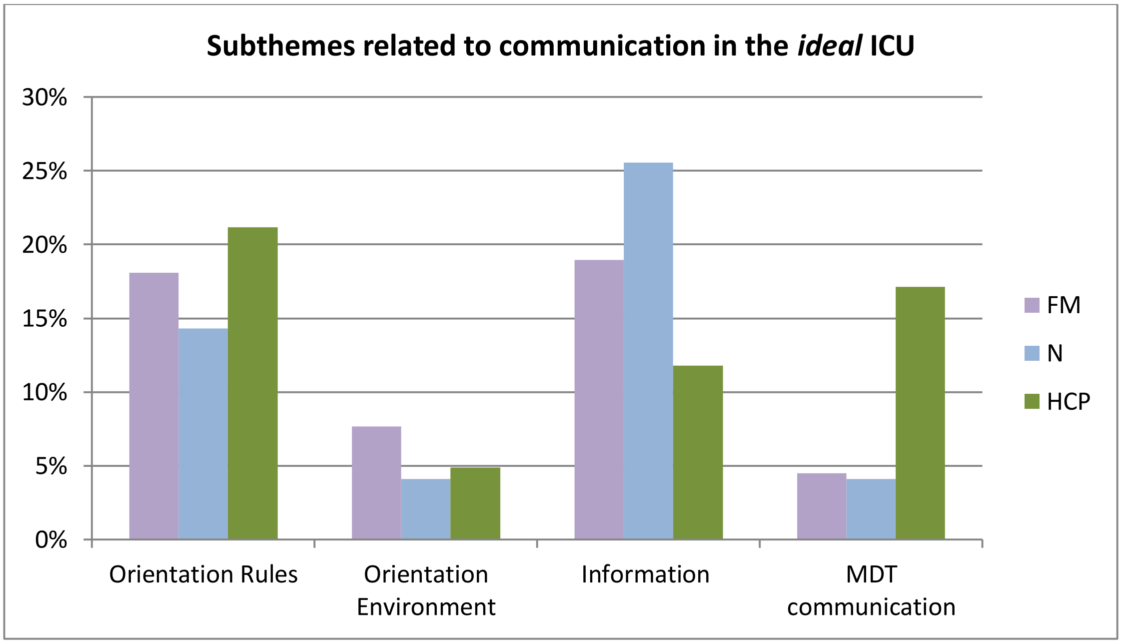


Figure 4.4: Communication subthemes: *ideal perceptions*

4.4.1.1 Subtheme 1: Orientation

All categories of research participants made comments related to orientation to the ICU environment in their responses. Two categories were identified related to orientation, namely rules and environment.

- **Rules**

Free associations related to rules in the ICU were consistent amongst all stakeholders for both *current* and *ideal* perceptions of the ICU environment. Rules included commentary around visiting hours, number of visitors allowed per patient, children as visitors in the ICU and rules around infection control. Table 4.8 provides examples of free associations that were written down by research participants relating to *current* rules in the ICU; 5% of nurses, 10% of healthcare professionals and 12% of family members wrote down associations relating to rules in the ICU.

Table 4.8: Rules: *current perceptions*

Nurses (5%)
"Sometime don't understand visiting time policy" –Nurse participant 5 *"Misunderstandings regarding rules" – Nurse participant 10* *"Visiting time is a big challenge"- Nurse participant 20*
Healthcare professionals (10%)
"Visiting hours unduly strict" – Healthcare professional participant 5 *"No visiting on first day" – Healthcare professional participant 16* *"Visiting hours-Adherence" – Healthcare professional participant 19*
Family members (12%)
"Says strictly no under 12s, yet children went in" – Family member participant 20 *"Allowed to come outside visiting time" – Family member participant 17* *"Strict rules" – Family member participant 16*

Table 4.9 provides examples of free associations that were written down by research participants that related to rules in the *ideal* ICU; 14% of nurses, 21% of healthcare professionals and 18% of family members wrote down associations related to rules in the *ideal* ICU.

Table 4.9: Rules: *ideal perceptions*

Nurses (14%)
"*Open visiting times" – Nurse participant 05* *"Allow them to be with the patient as much as they want and to excuse us when nurses need to be busy with the patient"- Nurse participant 19* *"I have to follow the rules in the hospital: control the visiting time (if patient's not unstable)" – Nurse participant 20*
Healthcare professionals (21%)
"Flexible visiting hours" – Healthcare professional participant 5 *"Strictly two visitors per patient" – Healthcare professional participant 09* *"Limited people at bedside/in the ICU" – Healthcare professional participant 13*
Family members (18%)
"Open visiting time within reason" – Family member participant 16 *"Longer visiting hours-especially if there are only 2 slots/day" – Family member participant 15* *"Be able to be with family, especially on admission" – Family member participant 13*

Healthcare professionals tend to view the ICU as a place with rigid rules, which allows them to keep control of family members who in some instances are viewed as a disturbance (Zaforteza et al., 2014:82; Levy & De Backer, 2013:2223). Healthcare professionals tend to take ownership of the workspace and therefore establish what is normal for the unit in terms of behaviours, use of space, good practice and measures of control (Zaforteza et al., 2014:82; Levy & De Backer, 2013:2223). This was in keeping with the current study. Most nurses and healthcare professionals stated that visiting hours should be flexible within reason, but should be kept in place.

Visiting hours, number of visitors by the bedside and whether or not children should be allowed to visit a family member in the ICU, tend to be based on personal beliefs and views rather than evidence-based practice (Zaforteza et al., 2014:81). Some healthcare professionals believe that family presence may cause emotional upset for the family member or that family presence may hinder patient care (Clark & Guzetta, 2017:97, Levy & De Backer, 2013:2223; Gondwe et al., 2011:99), yet research has refuted these traditional concerns (Shay, 2018:2; Clark & Guzetta, 2017:97; Giannini et al., 2014:730). Family presence allows the family member to see that everything is being done for the patient, it removes doubt around the patient's situation and reduces their anxiety and fear around what is being done to their loved one (Shay, 2018:1; Clark & Guzetta, 2017:97). In this study family members were not opposed to the rules in most cases. They merely wanted flexibility, information and consistency around the rules.

Family members view restrictive visiting hours as them being denied access to visiting their loved one (Hlahatsi et al., 2017: 49). Family members stress the need for flexible visiting times in the ICU. Family members would like the option of being able to visit at any time to have proximity to the patient and find visiting times impractical sometimes (Hlahatsi et al., 2017:51; Clark & Guzzeta, 2017:96; Davidson et al., 2016:107; Munyiginya & Brysiewicz, 2014:7).

Nurses tend to be flexible about visiting hours in situations that are under their control. However, hospital policies and protocols need to be reassessed to ensure that family members are supported (Lloyd et al., 2018:60; Hlahatsi et al., 2017:51; Shariff et al., 2017:26; McConnell & Moroney, 2015:996; Santiago et al., 2014:20). Findings in this study concur with current literature. Nurses and healthcare professionals agreed that there should be flexibility around visiting hours and family members used free associations in relation to flexibility around visiting hours when it came to the ideal family-centred care environment. Restricting visiting hours has an impact on the health and well-being of the patient and family member. The presence of a family member has a calming effect on the patient and gives the family member an opportunity to provide support and comfort to their loved one, which may help decrease length of ICU stay (Hlahatsi et al., 2017:49; Goldfarb et al., 2017:1751; Giannini et al., 2014:271).

Family members suggested that information on the rules of the ICU, including visiting hours, should be available in writing (De Beer & Brysiewicz, 2016:46). Nurses should provide information on what the family can expect within the ICU environment. This may be in the form of information letters with contact details of the unit, handed to the family in the first few hours of a patient's admission into the ICU (Hlahatsi et al., 2017:51; Davidson et al., 2017:106).

Initially, opening the ICU to family members may cause distress to the healthcare professionals. However, in the long run it was found that policy change brings about benefits for the ICU staff through improved communication with family members leading to increased trust. This shows that flexible visiting hours can benefit the patients, families and healthcare professionals (Giannini et al., 2014:732; Levy & De Backer, 2014:2224). By allowing family members flexible visiting times, the ICU can become a welcoming place which respects the needs of patients and families and where humanity receives priority (Giannini et al., 2014:732).

- **Environment**

Family members and healthcare professionals reviewed orientation specific to the ICU environment in the current setting and ideal setting. Nurses did not mention orientation to the ICU environment as current practice, but did perceive it as relevant in the ideal family-centred care environment. Table 4.10 provides examples of free associations that were written down by research participants that related orientation to the ICU environment as it is *currently*; 0% of nurses, 2% of healthcare professionals and 1% of family members wrote down free associations related to orientation in the ICU.

Table 4.10: Orientation: *current perceptions*

Nurses (0%)
No comments made by nurses
Healthcare professionals (2%)
"The environment is daunting to family until they are explained to" – Healthcare professional participant 5
Family members (1%)
"*No explanation of equipment/medicine/processes" – Family member participant 15* *"Orientation to the ICU environment" – Family member participant 17*

Table 4.11 provides examples of free associations that were written down by research participants related to orientation in the *ideal* ICU environment; 4% of nurses, 5% of healthcare professionals and 8% of family members wrote down free associations related to orientation in the ICU.

Table 4.11: Orientation: *ideal perceptions*

Nurses (4%)
"Orientate the family member especial the one's that they've never been in ICU" – Nurse participant 07 *"Better environment by introduction of the unit" – Nurse participant 08*
Healthcare professionals (5%)
"Orientation to the ICU for likely elective cases" – Healthcare professional participant 5 *"Education around ICU and environment" – Healthcare professional participant 09* *"Orientation of family member to environment" – Healthcare professional participant 12*
Family members (8%)
"Reception/orientation area" – Family member participant 12 *"Clear indication as to what to expect before seeing your family member" – Family member participant 20*

In the ICU care is given to critically ill patients who are frequently in need of constant supervision. The patients are surrounded by high-technology equipment intended to treat, support and monitor vital signs. The management of technical equipment, such as ventilators, infusion pumps, monitors and dialysis makes healthcare in the intensive care setting more complex (Alasto, Salminen, Lakanmaa & Leino-Kilpi, 2017:81; Bagherian, Sabzevari, Mirzaei & Ravari, 2016:20; Tunlind, Garnstrom & Engstrom, 2015:116).

There are arguments that technology in some ways collides with nursing science and prevents the holistic care of the patients. Technology sometimes overshadows the basic needs and technical work is prioritised above nursing (Bagherian et al., 2016:21; Tunlind et al., 2015:117), which breaks down trust relationships (Tunlind et al., 2015:116).

Caring for the patient in this technological environment must be seen as multi-faceted when it comes to how it affects the ICU nurses' experience. Advanced care would not function without technology, nor would care take place without skilled interaction and the maintenance of basic nursing skills. Technology can be seen as a tool and barrier to patient-centred care (Alastalo et al., 2017:81; Bagherian et al., 2016:20; Tunlind et al., 2015:122).

For the family member this environment is awe-inspiring, yet evokes feelings of intimidation, fright and the perception of inhumaneness and control (De Beer & Brysiewicz, 2016:45; Christensen & Probst, 2014:67). For the nurse this environment becomes second nature. Some nursing behaviour may even become machinelike and their focus shifts to the machinery rather than the patient (Tunlind et al., 2015:116; Christensen & Probst, 2014:67). For the family member the ICU environment is alien and noisy (Christensen & Pobst, 2014:68). The ICU alarms can be a constant source of irritation for staff working in the ICU; however, these same alarms instil fear in the family member. Family members may even be afraid to interact with the patient for fear that they will set off an alarm (Christensen & Probst, 2014:68). Findings from this study show that nurses and healthcare professionals do not place much emphasis on orientation to the ICU environment in the current setting. Nurses made no mention of it (0%) and only 1% of healthcare professionals wrote down free word associations. There was slightly more reference to orientation to the ICU environment in the ideal setting amongst nurses (4%) and healthcare professionals (5%). Family members placed slightly more emphasis on orientation to the ICU environment in the ideal setting (8%) and 1% wrote down free word associations with reference to the current ICU setting.

The ICU environment is very challenging and is described as a harsh environment of machines, monitors and constantly beeping alarms, which leads to feelings of inadequacy in the family member (De Beer & Brysiewicz, 2016:45 Christensen & Probst, 2014:68). Therefore, family members emphasise the need for orientation to the technical context of the ICU (Wetzig & Mitchell, 2017:67; Cypress & Fredrickson, 2017: 209; De Beer & Brysiewicz 2016:45; Davidson et al. 2016:104 & Munyiginya & Brysiewicz 2014:7). Family members should be orientated to the ICU on the first day of admission (Hlahatsi et al., 2017:49).

4.4.1.2 Subtheme 2: Information

Information emerged amongst all stakeholders as part of *current* family-centred care perceptions and *ideal* perceptions.

Information: *current perceptions*

When looking at the responses to current family-centred care practices, there were conflicting views around the information received. Some family members, nurses and healthcare professionals felt that families were kept updated and well-informed. Others had an opposite viewpoint, where they felt that communication was lacking and that family members were not kept informed. Table 4.12 provides examples of free associations that were written down by research participants that related to information in the ICU as it is *currently*; 24% of nurses, 28% of healthcare professionals and 17% of family members wrote down free associations related to information in the ICU.

Table 4.12: Information: *current perceptions*

Nurses (24%)
“Family they always get progress report from the nurses and doctors about their members” - Nurse participant 07 *“Give them daily progression about the patient” – Nurse participant 12* *“Give information with patient condition” – Nurse participant 12* *“Explain the progress of the loved one” – Nurse participant 13* *“Information about feedback from doctors” – Nurse participant 14* *“Decreased information from doctors” – Nurse participant 01* *“Bad communication between family, nurse, unit manager” – Nurse participant 06* *“Poor communication with doctors”- Nurse participant 10* *“Nurses not allowed to give detailed information about condition”- Nurse participant 10*

Healthcare professionals (28%)
“Correct info given to family” – Healthcare professional participant 03
“Information to families” – Healthcare professional participant 03
“Family mostly well-informed about condition and progress” – Healthcare professional participant 05
“Kept informed all the time” Healthcare professional participant 07
“Nurses feel intimidated, they therefore don’t want to talk to family members” – Healthcare professional participant 01
Family members (17%)
“Nurses explain the condition of the patient” – Family member participant 08
“Being updated” Family member participant 06
“Need to be kept updated and informed to know if my mom is ok” – Family member participant 13
“Uninformed” – Family member participant 12
“Not informed” – Family member participant 10

Information: ideal perceptions

Table 4.13 provides examples of free associations that were written down by research participants that related to information in the *ideal* ICU; 26% of nurses, 12% of healthcare professionals and 19% of family members wrote down free associations related to information in the ICU.

Table 4.13: Information: *ideal perceptions*

Nurses (26%)
“Timely information from beginning” – Nurse participant 01
“Doctors to communicate with patient’s immediate family daily on patient’s condition” – Nurse participant 04
“Have one session with Dr once a week for long term patients” Nurse participant 06
“Clarity on things they don’t understand”- Nurse participant 08
“Give them more information about the patient” – Nurse participant 14
“Communication with doctor and nurses” – Nurse participant 15
Healthcare professionals (12%)
“Appointments with Dr’s daily to brief family” – Healthcare professional participant 01
“Nursing professionals being available to help me understand issues around patient” Healthcare professional participant 02
“Information access” – Healthcare professional participant 04

“Information brochure” – Healthcare professional participant 04 *“Information leaflets” – Healthcare professional participant 05* *“Regular appointments with doctors” – Healthcare professional participant 05* *“Nurse communicates with family” ─ Healthcare professional participant 06*
Family members (19%)
“Someone (doctor/nurse/counsellor) available in waiting area for any questions, support, information” – Family member participant 20 *“Feedback from staff” ─ Family member participant 18* *“Like a private nurse who gives the family updates every 4 hours” – Family member participant 15* *“Regular communication from nurse and doctors” – Family member participant 14* *“A staff member to update family 100% of the time” – Family member participant 11* *“Communication - Genuine, interested, sufficient time, empathy” – Family member participant 10* *“Kept up to date” – Family member participant 10* *“Nurses give information” ─ Family member participant 02* *“The communication between the family members and nurses must improve regarding patient’s health” – Family member participant 01*

Information is one of the most essential needs of the family member in the ICU (Buena et al., 2018:338; Wetzig & Mitchel, 2017:67; De Beer & Brysiewicz, 2016:45B; Munyiginya & Brysiewicz, 2014:7). Information that is accessible, acceptable and accurate and that meets a person’s needs should be shared actively and consistently (Buena et al., 2018:338; Casey & Wallis, 2011:35).

The ICU offers a unique set of challenges to information flow: there are multiple members of the multi-disciplinary team involved, incongruent rounding times, changing shift leaders and prompt changes in the patient’s clinical condition (Buena et al., 2018:342; Allen et al., 2017:582). The timing of ward rounds often occurs before visiting hours, which hinders effective communication with the family member/s. The bedside nurse is often placed in the position to transfer all information (Allen et al., 2017:582; Shariff et al., 2017:21). These challenges are in keeping with the findings in the current study, where there are conflicting views with regard to current communication in the ICU. Regardless of whether the views were positive or negative, the findings emphasise the importance of clear, consistent, honest information in the ICU.

Buena et al. (2018:342) identified that families and healthcare professionals have different perceptions around information needs. It is important for healthcare professionals to be aware of these differences.

Questions that are most important to family members have to do with the patient's prognosis and the severity of the condition (Buena et al., 2018:343). Family members don't necessarily place emphasis on whether it is the nurse or the doctor who provides information. Emphasis is, however, placed on the need for consistent information that is factual and honest (Buena et al., 2018:3043; Cypress & Fredrickson, 2017:210; De Beer & Brysiewicz, 2016:48). Findings in this study concur that access to information by the family member is important in family-centred care. Nurses and doctors need to be available to provide information and this information should be consistent and not conflicting.

Gaining information and understanding around a patient's condition allows the family member/s to regain balance, which sustains their energy and hope. With honest comprehensive information, the family member/s are able to find meaning and rebuild their lives under new conditions (Buena et al., 2018:35; Cypress, 2017:211). Information on a patient's condition, whether improving, stable or declining, is of vital importance to the family (Buena et al., 2018: 343; Cypress & Frederickson, 2017:214; De Beer and Brysiewicz, 2016:46).

Providing clear, accurate, honest, understandable information will facilitate high quality and ethical, shared decision-making (Mackie, Mitchell & Marshal, 2018:132; Furqan & Zakaria, 2017:366). As the ICU patient is often unable to communicate due to critical illness, the family member takes on the role of surrogate decision-maker.

One of the four core concepts of family-centred care is information sharing. Healthcare professionals should share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families should receive timely, complete and accurate information in order to effectively participate in the care and decision-making (Institute for Patient and Family-centered care, 2017).

4.4.1.3 Subtheme 3: Multidisciplinary team communication

Multi-disciplinary team communication emerged as relevant for nurses, healthcare professionals and family members in both the *current* and *ideal* family-centred care environments. Table 4.14 provides examples of free associations that were written down by research participants that related to communication amongst the multidisciplinary team in the ICU as it is *currently*; 6% of nurses, 12% of healthcare professionals and 4% of family members wrote down free associations related to multidisciplinary team communication in the ICU as it is *currently*.

Table 4.14: Multi-disciplinary team communication: *current perceptions*

Nurses (6%)
“Decreased information shared from doctors” – Nurse participant 01 *“Nurse does not have information from doctor” – Nurse participant 05* *“Doctor comes but never says anything” – Nurse participant 06*
Healthcare professionals (12%)
"Lack of communication between MDT” – Healthcare professional participant 09 *“Poor communication between MDT” — Healthcare professional participant 10* *“Good team approach in the ICU” – Healthcare professional participant 12*
Family members (1%)
“Consistency of feedback from doctors and nurses” – Family member participant 18

Table 4.15 provides examples of free associations that were written down by research participants that related to communication amongst the multidisciplinary team in the *ideal* ICU; 4% of nurses, 17% of healthcare professionals and 4% of family members wrote down free associations related to multidisciplinary team communication in the ICU.

Table 4.15: Multidisciplinary team communication: *ideal perceptions*

Nurses (4%)
“Doctors to communicate daily with patient’s immediate family on patient’s condition” – Nurse participant 04 *“Doctors to have time to explain to the family” – Nurse participant 05* *“Doctor to interact more with family” — Nurse participant 10*
Healthcare professionals (17%)
“Creating a platform for equal communication. Dr and pt, nurse and pt, Dr and nurse-Nurse and family, Dr and family-patient and family via appointments, improving listening skills, empowering all parties” – Healthcare professional participant 01 *“Specific time with family” – Healthcare professional participant 06* *“All MDT members involved in a team meeting” – Healthcare professional participant 08* *“MDT ward rounds so everyone is on par” – Healthcare professional participant 10*

Family members (4%)
“Team meetings with all involved in patient care” – Family member participant 17 *“Doctors need to communicate with the nurses - nurses need to be able to explain medicine/equipment/processes to family” – Family member participant 15*

Provision of information to the family that is consistent is a common theme identified in the literature (Buena et al., 2018:3043; Cypress & Fredrickson, 2017:210; De Beer & Brysiewicz, 2016:48). Some families reported inconsistencies in the information provided by various members of the healthcare team regarding patients’ prognosis or predicted outcomes and they expressed a need for unvarying information (Wetzig & Mitchell, 2017:67; De Beer & Brysiewicz, 2016:46). The current study found that inconsistencies were described by healthcare professionals and family members, indicating a lack of communication amongst the members of the multi-disciplinary team.

Consistency in information gives the family the reassurance that healthcare professionals communicate with one another and that all members of the healthcare team are aware of what is going on. Communication amongst the family members, patient and healthcare professionals is crucial to foster good decision-making and the co-ordination of care (Cypress & Frederickson, 2017:210).

The family member of the ICU patient often takes on the role of surrogate decision-maker, for shared decision-making, which is achieved through partnership amongst the ICU multidisciplinary team, patients and their family members. Good communication is vital. Shared decision-making requires regular meetings between the ICU team and the family (Mackie et al., 2018:132; Furqan & Zakaria, 2017:366).

Zaforteza et al. (2014:82) identifies how nurses are often not included in information sharing and how the multi-disciplinary team does not always establish space for shared communication. Nurses are often unaware of what the physician has told the family, who sometimes receive more information about the patient than what is known to the nurse (Zaforteza et al., 2014:82). In this study nurses emphasised that doctors often did not communicate with them or with the family members. In some instances family members and nurses stated that doctors were not always available, difficult to get hold of or unapproachable.

The hierarchy within the multi-disciplinary team reveals another barrier to communication. Physicians tend to make final decisions and are resistant to change. Nurses may have ideas or suggestions around patient care. However, they do not approach the physician as they feel that the physician might be unlikely to change his routine, or their suggestion may be ignored (Langley et al., 2015:39; Zaforteza et al., 2014:84). An imbalance in power relations may threaten patient safety, while working together in a team approach improves care processes and patient outcomes (Zaforteza et al., 2014:84).

Some approaches to improve communication amongst the multi-disciplinary team and family members have been identified, two of which include multi-disciplinary ward rounds and family meetings. Structured multi-disciplinary ward rounds are a conversation between the doctor, other members of the healthcare team, nurse, patient and family member/s. These conversations should be held at the patient's bedside in an attempt to involve all members in the treatment care plan (Lloyd et al., 2018:61). Family meetings are meetings that are held with the family members, doctors, nurses and healthcare professionals involved in the care of the patient. Family meetings are complex multidisciplinary processes to increase effectiveness of communication, which enables family members to make important medical decisions on behalf of the patient (Furqan & Zakaria, 2017:365; Hlahatsi et al., 2017:51).

Multi-disciplinary ward rounds and family meetings have improved communication between healthcare professionals, patients and family members (Lloyd et al., 2018:60; Furqan & Zakaria, 2017:365). They have also been shown to have other added benefits such as decreased length of ICU stay without an increase in mortality and a reduction in the use of critical care (Furqan & Zakaria, 2017: 366). Family members displayed fewer symptoms of post traumatic distress, anxiety and depression (Furqan & Zakaria, 2017:366) and had a stronger sense of trust in the team after these communication strategies (Davidson et al., 2017:106; Cypress & Frederickson, 2017:213; Ingram et al., 2014:917). Healthcare professionals and nurses wrote down free word associations in relation to multi-disciplinary ward rounds as part of the ideal family-centred care setting. This is in keeping with the literature.

Nurses found that they spent less time having to re-explain plans and clarify information to family members. In addition, family members and nurses benefit from the teaching that occurs during rounds and the participants' perception of a healthcare team was positive (Ingram et al., 2014:917).
As ideal as multi-disciplinary team communication sounds, it is not without its challenges. Organising meetings with families is difficult due to a number of barriers, including organisational priorities, time constraints, financial constraints and lack of training (Lloyd et al., 2018:57; Furqan & Zakaria, 2017:366; Ingram et al., 2014:917). Doctors emphasised time constraints in dealing with family members, as well as lack of adequate facilities to properly communicate with family members.

Family members should be allowed space and time to address their concerns and to ask the multi-disciplinary team members questions (Hlahatsi et al., 2017:51). Information sharing amongst the multidisciplinary team and the family is essential for communication and decision-making around suitable goals of care for the patient, as the patients may be unable to communicate their own wishes. Family meetings provide objective information and allow multi-disciplinary team members to share opinions and reach consensus on what would benefit the ICU patient and family members most (Hlathatsi et al., 2017:51).

4.4.2 Theme 2: Environment

The second theme that was identified was that of environment. The ICU environment was a theme that was consistent amongst all stakeholders in this research study, when asked to describe their *current* perceptions of family-centred care.

Figure 4.5 represents the percentage of research participants who wrote down free associations that were related to the ICU environment; 38% of nurses, 26% of healthcare professionals and 40% family members wrote down free associations related to the *current* ICU environment.

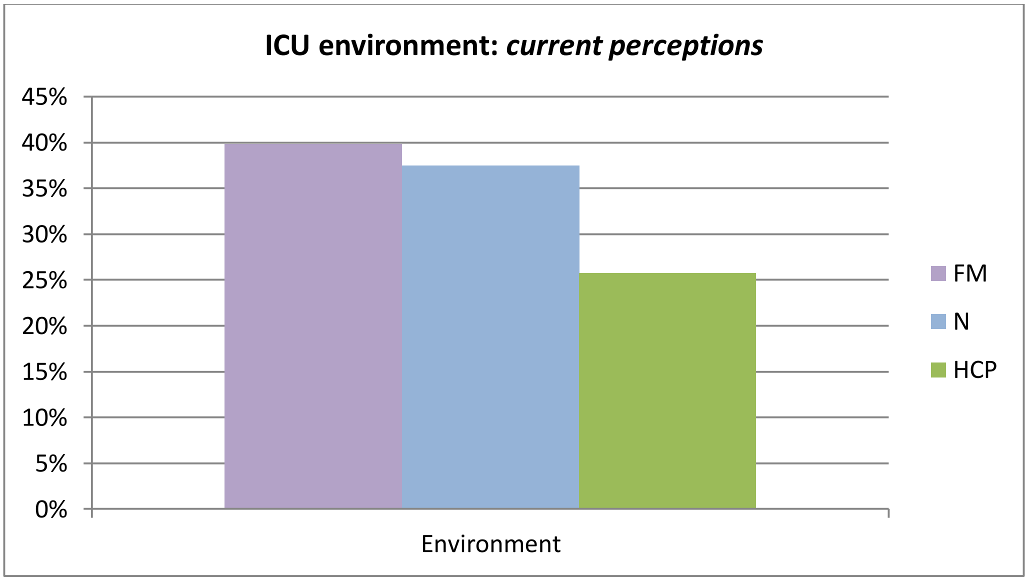


Figure 4.5: ICU environment: *current perceptions*

Figure 4.6 represents the percentage of research participants who wrote down free associations that were related to the *ideal* ICU environment; 49% of nurses, 38% of healthcare professionals and 40% of family members wrote down free associations related to the ICU environment when asked to describe *ideal* family-centred care.

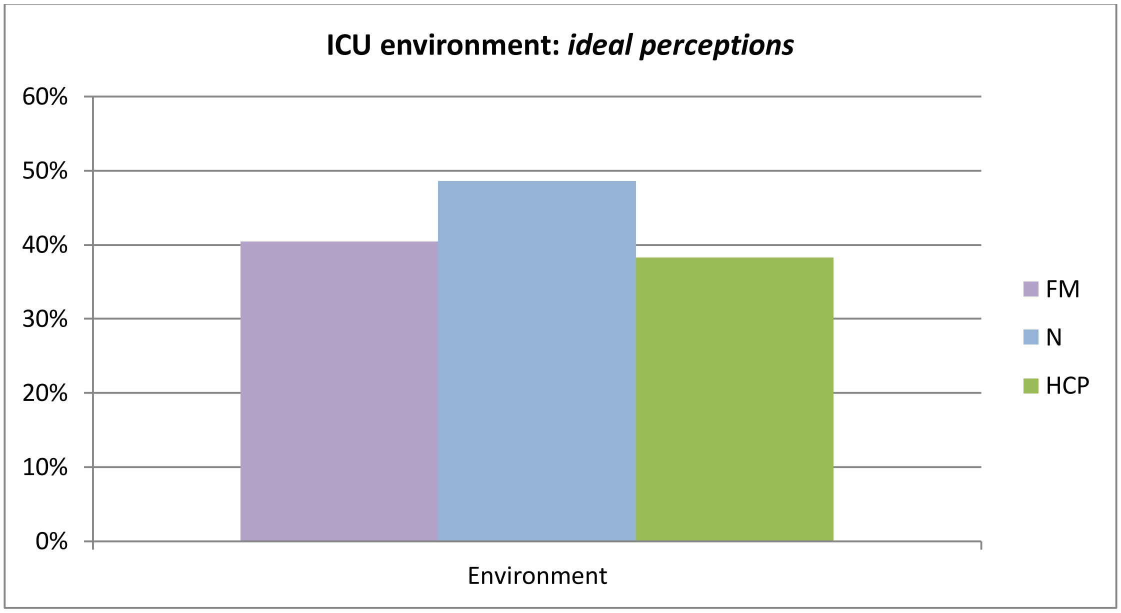


Figure 4.6: ICU environment: *ideal perceptions*

Major barriers to accommodating families in the ICU are the availability of resources and the physical structure or layout of the ICU. These barriers include lack of space, no place for family to sleep and no way to accommodate family members who have come from far (Hetland et al., 2018:73; McConnel & Moroney, 2015:995). Space constraints limit the number of individuals who can be present around the bedside, not only for visits, but for bedside rounds as well (Hetland et al., 2018:73; Santiago et al., 2014:20; Rippen et al., 2015:83).

Facility design has been shown to play a role in healing, for patients, families and staff alike, by reducing infections and medical errors, decreasing stress and improving privacy (Rippen et al., 2015:83; Zimering, Ulrich, Zhu, DuBose, Seo, Choi & Joseph, 2008:63). A growing volume of literature is suggesting that a carefully designed and well-built environment will increase family presence and satisfaction, involvement with care and other desired outcomes of family-centred care (Rippen et al., 2015:83; Zimering et al., 2008:91; Olausson, Ekebergh & Osterberg, 2014:131; Jongerden, Slooter, Peelen, Wessels, Ram, Kesecioglu & Van Dijk, 2013:1632; Choi & Bosch, 2012:68).

Visiting rooms, although close to the ICU, are too small in many instances and/or do not have enough chairs to accommodate all the visitors (Hlahatsi et al., 2017:50). Lack of privacy for the family members is another concern in the ICU; there is a lack of adequate facilities where healthcare professionals can discuss private, confidential information with the family members.

Family members also might not have a private space to go to when they are sad or emotional (Hetland et al., 2018:73; Hlahatsi et al., 2017:51).

Caring for family members in the ICU is complex and paradoxical at times (Rippen et al., 2015:93). Although, the design of the ICU may play a role in facilitating family-centred care, it can by no means be viewed in isolation (Rippen et al., 2015:94). The ICU environment goes beyond the physical layout of the ICU; the space must be supported by the workplace culture. The physical ICU and the workplace culture need to be congruent in order to successfully inspire family-centred behaviours in an environment that is supportive of patients, family members, nurses and healthcare professionals (Rippen et al., 2015:95).

Four subthemes were identified in the ICU environment namely, physical environment, care environment, patient environment and family environment. Care environment was further divided into two categories, namely nursing competency and workplace culture. These subthemes and related categories will be discussed further under sections 4.3.2.1-4.3.2.4.

Subthemes related to the ICU environment

Figure 4.7 represents the subthemes that were identified based on free associations related to the *current* ICU environment regarding the physical environment, the care environment, the patient environment and the family environment. Percentages will be discussed under each section.

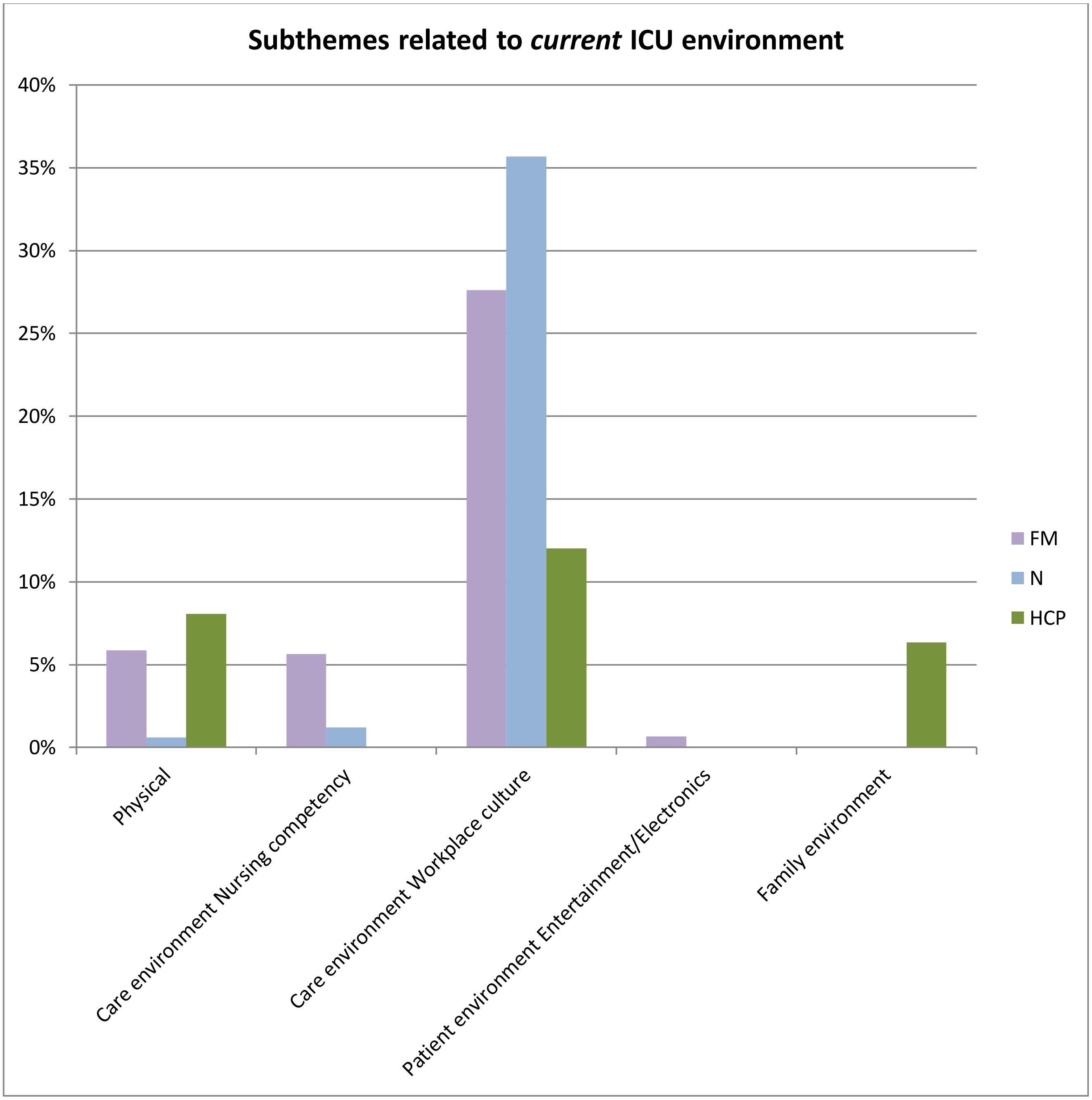


Figure 4.7: Subthemes, ICU environment: *current perceptions*

Figure 4.8 represents the subthemes that were identified based on free associations related to the physical environment, the care environment, the patient environment and the family environment in the *ideal* ICU. Percentages will be discussed under each section.

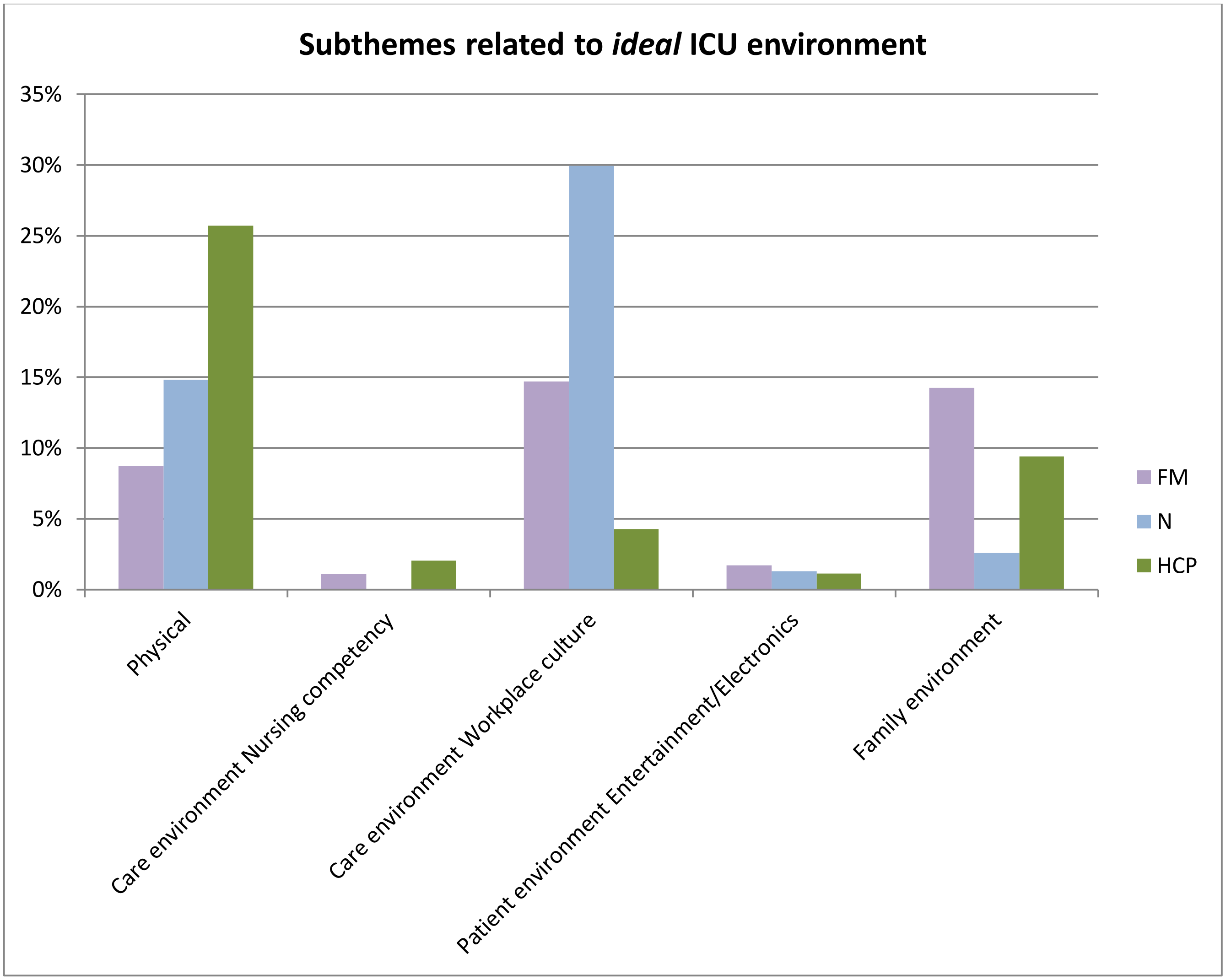


Figure 4.8: Subthemes, ICU environment: *ideal perceptions*

4.4.2.1 Subtheme 1: Physical environment

Free word associations related to the physical environment of the ICU emerged amongst all categories of research participants, when asked to describe their *current* perceptions of family-centred care in the ICU. Physical environment included commentary around the physical layout of the ICU, noise levels and lighting.

Table 4.16 provides examples of free associations that were written down by research participants that related to the physical environment in the ICU as it is *currently*; 1% of nurses, 8% healthcare professionals and 6% of family members wrote down free associations related to the physical environment.

Table 4.16: Physical environment: *current perceptions*

Nurses (1%)
"Quietness of the ICU" – *Nurse participant* 14
Healthcare professionals (8%)
"Cold environment" – *Healthcare professional participant* 03 "*Isolation rooms are cold and unfriendly"* – *Healthcare professional participant* 13 "*Poor positioning of beds, should face window for patient to see more light"* – *Healthcare professional participant* 13 "*Lack of privacy"* – *Healthcare professional participant* 14
Family members (6%)
"*Cold environment" – Family member participant 11* *"Noisy environment" – Family member participant 12* *"Super clean environment" – Family member participant 14*

Table 4.17 provides examples of free associations that were written down by research participants that related to the physical environment in the *ideal* ICU; 15% of nurses, 26% of healthcare professionals and 9% of family members wrote down free associations related to the physical environment of the ICU when asked to describe family-centred care in the *ideal* setting.

Table 4.17: Physical environment: *ideal perceptions*

Nurses (15%)
"Noise level" – Nurse participant 11 *"Clean environment" – Nurse participant 11* *"Cleanliness of the unit" – Nurse participant 12* *"Silence" – Nurse participant 13* *"Quietness in the unit/therapeutic environment" – Nurse participant 15*
Healthcare professionals (26%)
"*Environment/Place to be clean at all times" – Healthcare professional participant 02* *"Breakdown circle layout" – Healthcare professional participant 03* *"Size-space around bed" – Healthcare professional participant 06* *"Sunshine/natural lighting in the ICU" – Healthcare professional participant 08* *"Look out the window (Bed positioning)" – Healthcare professional participant 13*

Family members (9%)
"*Traumatised family-privacy" – Family member participant 04*
"Privacy" – Family member participant 06
"Privacy for patient and family" – Family member participant 07
"Looks close to current design, a bit more private" – Family member participant 14

The speciality of intensive care medicine stemmed as a consequence of the poliomyelitis epidemic in the 1950's where a vast number of patients needed mechanical ventilation. Since then the ICU environment and the technology available to care for a critically ill patient has become more sophisticated and complex. The importance of intensive care units today cannot be disputed (Wenham & Pittard, 2009:178). Despite the value of the ICU, it can be an unpleasant environment to the vulnerable critically ill patient. Not only does the patient need to cope with the physical stress of illness, pain, sedation, interventions and mechanical ventilation, but also the psychological and psychosocial stressors. Additional factors that contribute to a syndrome referred to as ICU psychosis or delirium, are environmental factors which include noise, ambient light, restriction of mobility and social isolation (Gimenez et al., 2017:236; Wenham & Pittard, 2009:178).

Increased noise leads to sleep disturbance and increases pain and discomfort. This may reduce healing and increase length of stay in the ICU. Noise in the ICU is generated by monitoring systems, staff conversations, equipment alarms, noise generating beds, television, telephones ringing and carts rolling on linoleum floors (Mattiussi, Danielis, Venuti, Vidoni, Palese, 2019:10; Davidson et al., 2017:35; White & Zomorodi, 2016:19; Davidson, Powers, Hedayat, Tieszen, Kon, Shepard & Barr, 2007:21). Healthcare professionals need to recognise noise and the impact that noise levels have on patients in order to change behaviour and work towards a quieter ICU environment (Johansson, Knutsson, Bergbom & Lindahl, 2016:7; White & Zomorodi, 2016:20). According to Davidson et al. (2017:34) evidence is limited on how noise levels impact family-centred care and the overall quality of evidence on noise reduction strategies is low. However, some family members have mentioned high noise levels in the ICU due to staff members talking loudly to one another, as well as treatments and alarms. Others experience the ICU as a quiet environment (Agard, Hofhuis, Koopmans, Gerritsen, Spronk, Engelberg, Curtis, Zijlstra & Jensen, 2019:36).

The human sleep-wake cycle is largely linked to the environment, the light-dark cycle being the most powerful linking factor (Gimenez et al., 2017:236; Wehnam & Pittard, 2009:179). In the ICU, patients are exposed to unnatural light sources affecting their ability to differentiate between day and night which can contribute to disorientation (Wehnam & Pittard, 2009:180) and disturbance affecting the patients biological sleep clock (White & Zomorodi, 2016:19; Wehnam & Pittard, 2009:180; Davidson et al., 2007:22). The application of lighting strategies that support the health and well-being of patients for less sleep disruption is warranted (Gemenez et al., 2017:10). Dimmable, flexible, multidirectional lighting should be used. A patient reading light is desirable and as far as possible, ICUs should use as much natural lighting as possible. Natural light may reduce disorientation and views to the outside can be a positive distraction for patients, reducing stress (Wehnam & Pittard, 2009: 182).

The cleanliness of the ICU was also brought up when referring to the physical environment of the ICU. The cleanliness of the physical environment not only refers to the visible cleanliness of surfaces and the environment, but also ensures that the risk of infections associated with healthcare is reduced for patients and family members. With the increasing incidence of bacterial multidrug resistance, the environmental cleanliness in the ICU is of vital importance (Hopman, Donskey, Boszczowski & Alfa, 2018:1200; Mohamed, Sturm, Kight & Moodley, 2018:88). Patients in the ICU are particularly vulnerable to healthcare associated infections, where 50% of them can acquire an infection during their admission (Mohamed et al., 2018:88). In the last two decades there has been an increase in the reported outbreaks of healthcare infections leading to increased morbidity and mortality (Mohamed et al., 2018:88). Regular cleaning of high touch surfaces and adherence to infection control principles, reduce the risk of healthcare associated infections (Hopman, 2018:1198; Mohamed et al., 2018:91). Family members are reassured when their loved ones are left in a clean environment.

Going beyond noise, lighting and cleanliness, the physical layout of the ICU is another factor to consider, as it has been found to hold the potential to either help or hinder family-centred care (McConnel & Moroney, 2015:995; Rippen et al., 2015:93). Space around the ICU bed and the size of the rooms make it difficult to include family members in patient care, fostering the separation of families in the ICU rather than integration (McConnel & Moroney, 2015:995; Rippen et al., 2015:93). Space constraints lead to fear that family members may injure themselves when assisting in patient care (McConnel & Moroney, 2015:995).

Space was a common theme that emerged in research findings, in keeping with literature where lack of space available for private conversations with patients and family members was described (Lloyd et al., 2018:57). An effort should be made to allocate a room or office and conference rooms to provide privacy for the healthcare professional and family members. Family members should be given a room to deal with the sad news they receive, where they can discuss the implications with no fear of strangers listening and judging them on their decisions and family history (Hlathatsi et al., 2017:51).

Privacy in the room, room size and the bathroom led to improved patient satisfaction, with limited evidence of an impact on the family. There is no evidence to determine the relative risks, feasibility, or increased workload on staff brought about by additional space for family members around the bedside. Lack of evidence makes it difficult to justify the costs that would be incurred in providing this extra space (Davidson et al., 2017:35).

Evidence suggests that there may be a link between physical environment and patient outcomes, for example colour, lighting, ventilation systems and floor coverings have all been found to have a link to patient outcomes (Jongerden et al., 2013:1629). With visitation policies becoming more flexible, the environment of care has a growing impact on families as well (McConnel & Moroney, 2015:995; Rippen et al., 2015:93; Davidson et al., 2007:20; Gimenez et al., 2017:236; Wehnam & Pittard, 2009:179).

4.4.2.2 Subtheme 2: Care Environment

Free associations related to the care environment of the ICU emerged amongst all categories of research participants when asked to describe the *current* perceptions of family-centred care in the ICU. The care environment included commentary around compassion, empathy, support, competency of staff and nurse presence at the bedside.

Caring is perceived as human behaviour that includes cognitive, affective, psychomotor and administrative skills within which professional caring is expressed. Caring is an essential resource in the technology dominated ICU environment. The concept of caring in the ICU is central to the social interaction between the nurse, the patient and his or her family members (Wilkin, 2003:1178).

In the ICU the patient is often not able to communicate, patient advocacy lies with the nurse where the assumptions and meanings given to the patient's experience are those of the nurse and not the patient (Wilkin, 2003:1178). Knowledge and competence are the two major concepts in Guat's (1986) theory of caring. Her philosophy presents caring as a process of therapeutic intervention through helping and enabling. Caring for the ICU patient is an activity that focuses on the whole person and is more than the sum of their needs and demands (Wilkin, 2003:1178).

Hansen, Rosenkranz, Mularski and Leo (2016:446) identified that family members' perspectives of care in the ICU can be divided into three main categories, namely: competent care, communication and environment. Emotional and interrelational aspects of care are integral to family satisfaction with the care provided. Emotional and interrelational aspects of care can be described in terms of the relationship or rapport that healthcare professionals establish with their patients and the patients' family members.

In this study the care environment was further divided into nursing competency and workplace culture. These categories will be discussed in further detail under section 4.3.2.2.1-4.3.2.2.2.

- **Nursing competency**

Free associations related to nursing competency in the ICU emerged from nurses and family members when asked to describe *current* perceptions of family-centred care in the ICU.

Table 4.18 provides examples of free associations that were written down by research participants that related to how nurse competency in the ICU is *currently* perceived; 1% of nurses, 0% of healthcare professionals and 6% of family members wrote down free associations related to the competency of nurses in the ICU.

Table 4.18: Nurse competency: *current perceptions*

Nurses (1%)
"*Be competent always for them" – Nurse participant 12* *"Self-confidence, never show them you are scared or don't know" – Nurse participant 18*
Healthcare professionals (0%)
No comments made by healthcare professionals
Family members (6%)
"*Unable to care for elderly" – Family member participant 04* *"Incompetent nursing staff but dependant on nurse" – Family member participant 13* *"Not very helpful for his particular condition" – Family member participant 19*

Table 4.19 provides examples of free associations that were written down by research participants that related to how nurse competency in the *ideal* ICU is perceived; 0% of nurses, 2% of healthcare professionals and 1% of family members wrote down free associations related to the competency of nurses when asked to describe family-centred care in the *ideal* setting.

Table 4.19: Nurse competency: *ideal perceptions*

Nurses (0%)
No comments made by nurses
Healthcare professionals (2%)
“*Qualified staff”- Healthcare professional participant 02* *“Competent staff” – Healthcare professional participant 17*
Family members (1%)
“*Competency of staff” – Family member participant 04* *“Specific training on how to deal with family which is an important part of the healing process for all”* – *Family member participant 10*

According to Fakuda (2018:1), nursing competency is the core abilities that are needed in order to fulfil one’s role as a nurse. Competence is an ability acquired through experience and learning and has the following two features: 1) Potential abilities that may work successfully under certain circumstances, and 2) motivation to show one’s usefulness in applying those abilities. Fakuda (2018:1) goes on to describe that competency also has a behavioural component that is based on an individual’s interests and experiences as influenced by their motivation and attitude. Competence (ability) is a premise for developing competency (behavioural characteristics).

When nurses display competency in professional skills, family members are left with feelings of security, safety and peace of mind for their loved one in the ICU. Family members are able to relax and trust that their loved one will be taken care of well (Agard et al., 2018:35). Competent care encompasses the perceived quality of care (Hansen et al., 2016:449).

Family members value one-on-one nurse-patient ratios, as it gives them a sense of assurance that their loved ones are safe and that the healthcare professionals can be trusted to care for the patient when the family is not present (Hansen et al., 2016:449). Staff shortages are a concern in today’s hospital settings, as many institutions implement minimum staffing and rely on casual staff to cover the unit (Lloyd et al., 2018:55; Langley et al., 2015:38). In many instances, due to financial constraints, the concept of “skills mix” is utilised, where the number of professional nurses is limited and ICUs are staffed with sub-professional nurses, also known as staff nurses or enrolled nurses. Professional nurses or shift leaders are then expected to take responsibility for the staff nurses. This increases the workload of the professional nurse and leads to moral distress (Langley et al., 2015:38).

When the concept of skills mixing and casual staffing is utilised, staff competency may become challenging in the ICU as skills may be limited. Casual staff do not always have the same level of context-specific experiential knowledge as permanent staff (Lloyd et al., 2018:55).

- **Workplace culture**

Free associations related to workplace culture emerged amongst all categories of research participants for both *current* and *ideal* perceptions of family-centred care in the ICU environment.

Table 4.20 provides examples of free associations that were written down by research participants that related to workplace culture as it is *currently*; 36% of nurses, 12% of healthcare professionals and 28% of family members wrote down free associations related to workplace culture when asked to describe *current* perceptions of family-centred care in the ICU.

Table 4.20: Workplace culture: *current perceptions*

Nurses (36%)
“*Support of families*”- *Nurse participant 0*1
“*Cold towards the nurse*”- *Nurse participant 0*3
“*Family does not trust us as nurses*” – *Nurse participant 0*5
“*Provide emotional support to families*” – *Nurse participant* 10
Healthcare professionals (12%)
“Mandatory for nurse to be at bedside during visiting hours” – Healthcare professional participant 05
“Greet family” – Healthcare professional participant 09
“Emotional support to family members” – Healthcare professional participant 14
Family members (28%)
“RN’s not at the bedside” – Family member participant 03
“Friendliness of staff is on point” – Family member participant 05
“Welcoming and friendly” – Family member participant 13

Table 4.21 provides examples of free associations that were written down by research participants that related to workplace culture in the *ideal* ICU; 30% of nurses, 4% of healthcare professionals and 15% of family members wrote down free associations related to workplace culture when asked to describe family-centred care in the *ideal* setting.

Table 4.21: Workplace culture: *ideal perceptions*

Nurses (30%)
"Family respecting nursing staff" – Nurse participant 01 *"Keep relationships professional" – Nurse participant 02* *"Introduce yourself to the family" – Nurse participant 13*
Healthcare professionals (4%)
"Welcoming environment by nurses, especially the one responsible for my family care" – Healthcare professional participant 02 *"More visibility of staff" – Healthcare professional participant 10* *"Welcoming staff" – Healthcare professional participant 19*
Family members (15%)
"Empathy towards family member" – Family member participant 13 *"Friendly nurses"- Family member participant 15* *"Patient care comes first" Family member participant 17*

Workplace culture simply put is "the way things are done around here." It is an organisation's shared norms, beliefs and behavioural expectations that determine behaviour and communicate what is valued in an organisation (Hemmelgarn, Glisson & James, 2006:75). The workplace culture forms the basis for social interactions amongst co-workers, in other words how to behave within the organisation, and creates a social milieu that forms the tone, content and objectives of the work that is accomplished within the organisation (Hemmelgarn et al., 2006:75).

The relationship between the work environment and the employees establishes a perception of workplace culture, much like the way in which our personality enables us to be perceived as individuals. In healthcare, workplace culture qualifies people's work and care for their patients by reflecting a microsystem level of culture in which most of the care is delivered and experienced. Workplace culture impacts how people work, as well as the way in which patients are cared for (Manley, 2008:83).

Elements of an effective workplace culture in healthcare were described by Manley (2008:83) as a workplace that develops staff engagement, job satisfaction and empowerment. Essential to a culture of safety for both staff and patients were: shared governance, role clarification, transformational leadership, open communication, teamwork, safety, person-centeredness, support and challenge, lifelong learning and the involvement and participation of stakeholders in the workplace.

Staff, visitors and patients are able to feel and observe what goes on in an organisation. The soft elements of a workplace, better described as how people interact with one another, influences job satisfaction and workplace engagement. A positive workplace culture is one where there are shared values, beliefs and attitudes; a caring, progressive, positive, team-orientated environment, where decision-making is a shared process, and where there is interdisciplinary respect and collaboration (Catling, Reid & Hunter, 2016:138). An undesirable workplace culture leads to negative outcomes in care and is visible in situations where there are severe workforce shortages, a lack of compassion and quality care and a failure to take patient, family member and staff complaints seriously (Catling et al., 2016:138).

A positive workplace culture, as seen in staff satisfaction and good working relationships between and within teams, is important to achieve family-centred care (Lloyd et al., 2018:59). On the contrary, where there is a poor workplace culture reflected in poor staff attitudes, with staff who are sometimes unsupportive, and inflexible decision-making, with little motivation for change and lack of engagement in quality improvement, these can be a barrier to family-centred care (Lloyd et al., 2018:58). Interpersonal skills made a huge difference to the family member and the patient. Interpersonal skills were described in terms of compassion, respect, caring, emotional support, empathy, commitment, interest, the amount of attention received by the patient and the family, being taken seriously, receiving support and receiving dignified and respectful patient care by trustworthy and dedicated healthcare professionals (Agard et al., 2018: 35).

4.4.2.3 Subtheme 3: Patient Environment

Free associations related to patient environment in the ICU only emerged amongst family members when asked to describe their *current* perceptions of family-centred care in the ICU. When asked to describe the *ideal* family-centred care environment, free associations relating to the patient environment emerged amongst all categories. Patient environment included commentary around entertainment for patients, the use of electronic devices to communicate with family members and measures to provide space and time orientation to the patient. Table 4.22 provides examples of free associations that were written down by research participants relating to the patient environment as it is *currently*; 0% of nurses, 0% of healthcare professionals and 1% of family members wrote down free associations related to the patient environment when asked to describe *current* perceptions of family-centred care in the ICU.

Table 4.22: Patient environment: *current perceptions*

Nurses (0%)
No comments were made by nurses
Healthcare professionals (0%)
No comments were made by healthcare professionals
Family members (1%)
"Patient not allowed to have entertainment (scared of theft)" – Family member participant 14

Table 4.23 provides examples of free associations that were written down by research participants relating to patient environment in the *ideal* ICU; 1% of nurses, 1% of healthcare professionals and 2% of family members wrote down free associations related to patient environment when asked to describe family-centred care in the *ideal* setting.

Table 4.23: Patient environment: *ideal perceptions*

Nurses (1%)
"Comfort of the patient" – Nurse participant 11 *"Bed and table next to the patient" – Nurse participant 11*
Healthcare professionals (1%)
"Radio for the patient" – Healthcare professional participant 13 *"Cellphone available-facetime especially for faraway family member - Healthcare professional participant 16*
Family members (2%)
"TV that works for the patient" – Family member participant 03 *"More electronics for the patient-tv" – Family member participant 15*

The patient environment was mentioned in the context of having a radio, television, cell-phone and electronic devices for the patient's entertainment and for a connection to their homes and that which is familiar. Nurses expressed the need for a bed and table next to the patient for family members, ensuring patient comfort in the context of family-centred care.

Positive distractions in the ICU are described as environmental features or conditions that have been found by research to reduce stress effectively for patients and their families. These can include music, laughter-inducing entertainment, companion animals, certain kinds off art and nature (Ames, Shuford, Yang, Moriyama, Frey, Wilson, Sundaramurthi, Gori, Mannes, Ranucci, Koziol & Wallen, 2017:1;

Davidson, 2007:23). Limited literature was found on electronic devices, cellphones and televisions for the ICU patient. However, music has been shown to reduce stress and make the ICU environment more conducive to healing (Ames et al., 2017:1).

4.4.2.4 Subtheme 4: Family Environment

Free associations related to the family environment emerged amongst healthcare professionals when asked to describe *current* perceptions of family-centred care. Family environment included commentary around the waiting area, comfortable seating, coffee facilities and adequate rest areas for family members. When asked to describe family-centred care in the *ideal* environment, all categories of research participants wrote down free associations related to the family environment.

Table 4.22 provides examples of free associations that were written down by research participants that related to the family environment as it is *currently* in the ICU; 0% of nurses, 6% of healthcare professionals and 0% of family members wrote down free associations related to the family environment when asked to describe the *current* family-centred care in the ICU.

Table 4.24: ICU environment: *current perceptions*

Nurses (0%)
No comments were made by nurses
Healthcare professionals (6%)
"Waiting are cold and unfriendly" – Healthcare professional participant 13 *"Not enough space to sit in waiting area"- Healthcare professional participant 14* *"Poor facilities for visitors (Bathroom not available)"- Healthcare professional participant 16*
Family members (0%)
No comments were made by family members

Table 4.25 provides examples of free associations that were written down by research participants that related to the family environment in the *ideal* ICU; 1% of nurses, 9% of healthcare professionals and 14% of family members wrote down free associations related to the family environment when asked to describe family-centred care in the *ideal* ICU.

Table 4.25: Family environment: *ideal perceptions*

Nurses (1%)
“Proper waiting area and refreshments” – Nurse participant 05
“Rest rooms” – Nurse participant 09
Healthcare professionals (9%)
“Sit and relax facility for family” – Healthcare professional participant 7
“More space for visitors in waiting room”- Healthcare professional participant 14
“Allow one person at the bed to be comfortable on a chair – Healthcare professional participant 18
Family members (14%)
“Lounger next to the bed - more comfortable” – Family member participant 03
“Not enough chairs in waiting area” – Family member participant 04
“Comfortable chairs next to the bed” – Family member participant 07
“A place to sit - next to patient” – Family member participant 11

Family members are expected to wait for extended periods in a designated waiting area before visiting time. Waiting areas are described as too small, uninviting and being difficult for family members sharing the waiting room with worried or mourning families (Agard et al., 2018:36, Lloyd et al, 2018:55; Nolen & Warren, 2014:400). To try to make things a little more comforting for the family members, comfort needs should be addressed (Davidson et al., 2017:37; Munyiginya & Brysiewicz, 2014:7; Nolen & Warren, 2014:400).

The comfort needs of family members are comfortable chairs at the bedside and in the waiting area, space for those coming from far and sleeping facilities to get some much-needed rest (Davidson et al., 2017:37; Munyiginya & Brysiewicz, 2014:7; Nolen & Warren, 2014:400). In addition, some family members expressed the desire for access to facilities where they could buy food and drink or make a cup of coffee (Agard et al., 2018:36). Families in the ICU suffer significant sleep deprivation and related morbidity. Rest increases daily sleep duration, reduces fatigue, reduces errors and reduces pain. The provision of comfortable facilities that allow for adequate rest may reduce morbidity among family members, though no studies to date have been conducted to evaluate the effect of providing sleep facilities on family health (Davidson et al., 2017:37).

4.4.3 Theme 3: Continuum of feelings

The continuum of feelings was a theme that emerged amongst all populations in this research study when asked to describe the *current* perceptions of family-centred care. No reference was made related to the *ideal* ICU environment.

Figure 4.9 represents the percentage of research participants who wrote down free associations that were related to the continuum of feelings; 16% of nurses, 0% of healthcare professionals and 11% of family members wrote down free associations related to the continuum of feelings when asked to describe family-centred care as it is *currently.*

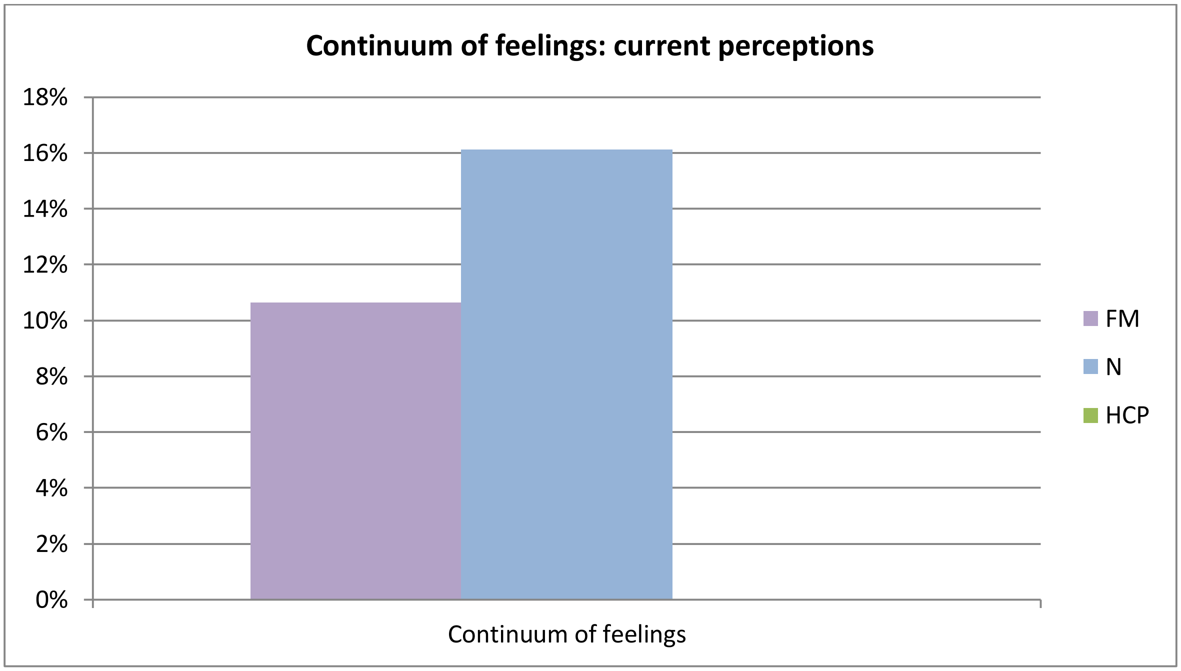


Figure 4.9: Continuum of feelings: *current perceptions*

Table 4.26 provides examples of free associations that were written down by research participants that related to the continuum of feelings in the ICU as it is *currently* perceived; 16% of nurses, 0% of healthcare professionals and 11% of family members wrote down free associations related to the family environment when asked to describe family-centred care in the *ideal* ICU. The continuum of feelings included commentary around the emotions, anxiety and turmoil that is experienced by a family member in the ICU.

Table 4.26: Continuum of feelings: *current perceptions*

Nurses (16%)
"Sadness" – Nurse participant 01 *"Fear by the family" – Nurse participant 16* *"Grieving stage is challenging because of anger" – N17*
Healthcare professionals (0%)
No comments were made by healthcare professionals
Family members (11%)
"Anxious" – Family member participant 02 *"Traumatic" – Family member participant 11* *"Uncertainty" – Family member participant 14*

No free associations related to the continuum of feelings were mentioned when participants were asked to describe the *ideal* ICU. It is well-documented that family members experience emotional turmoil when their loved one is admitted to the ICU (Alfheim et al., 2019:5; Hetland et al., 2018:72; Hlahatsi et al., 2017:48). Separation of patients from their family members is thought to be the leading contributor to post-traumatic distress syndrome (Clark & Guzzetta, 2017:97; Christensen & Probst, 2014:69). Family members often express feelings of fear, anxiety, helplessness, hopelessness and guilt (Hlathatsi et al, 2017:49; Christensen & Probst, 2014:68). The needs of family members may be overlooked by healthcare professionals as the focus is on the critically ill patient (Hlahatsi et al., 2017:49; Christensen & Probst, 2014:68).

Healthcare professionals need to learn to engage in a more meaningful way with family members. Healthcare professionals who are disconnected, who fail to acknowledge the families' presence and who maintain a task-focused or cold and clinical approach, create barriers to helping family members regain their control and may heighten their emotional vulnerability (Wong et al., 2017:99).

4.4.4 Theme 4: Reflections

Reflections was a theme that emerged amongst all categories of research participants in this study when asked to describe the *current* and the *ideal* perceptions of family-centred care.

Figure 4.10 represents the percentage of research participants who wrote down free associations that were related to reflections in the *current* ICU; 11% of nurses, 22% of healthcare professionals and 16% of family members wrote down free associations related to reflections on family-centred care in the *current* setting.

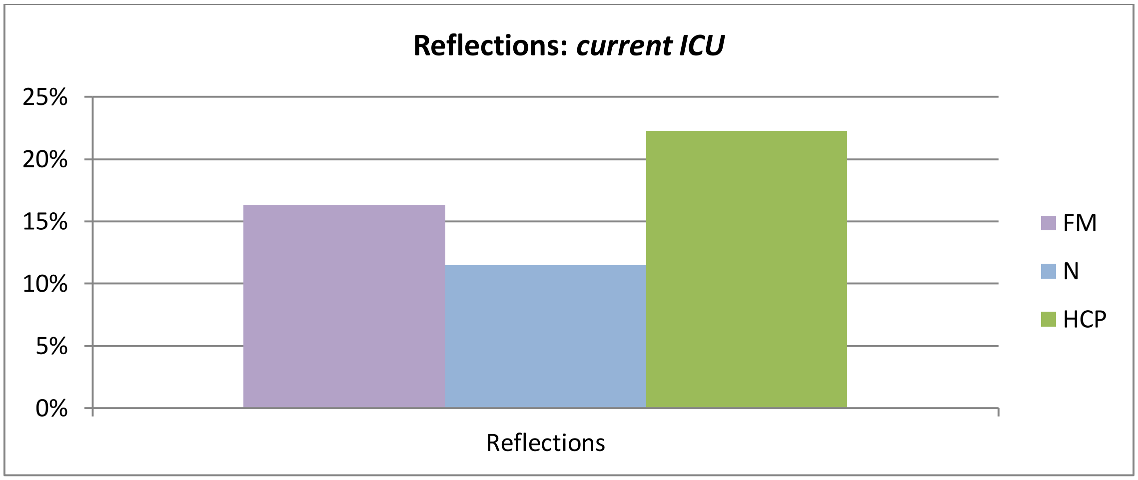


Figure 4.10 Reflections: *Current perceptions*

Figure 4.11 represents the percentage of research participants who wrote down free associations that were related to reflections in the *ideal* ICU; 14% of nurses, 6% of healthcare professionals and 2% of family members wrote down free associations related to reflections of family-centred care in the *ideal* ICU.

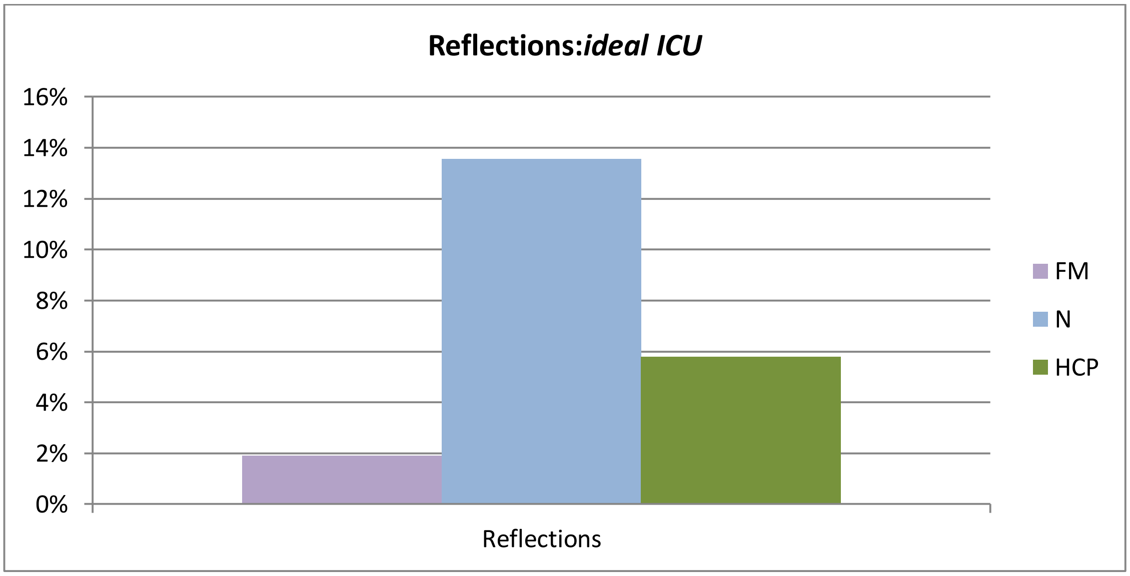


Figure 4.11: Reflections: *ideal perceptions*

Reflection in healthcare means becoming aware of our actions. It is often a team approach, where time is taken to look back and reflect on what happened, what led up to a certain event, how individuals responded, how people felt and what can be learnt from the situation. Reflection usually takes place after an event and is a constructive and valuable way of developing clinical practice, enhancing patient care and helping staff to come to terms with stressful events (Fowler, 2016:604).

During this study many free associations were related to reflections on family-centred care by the research participant. Four subthemes were identified on reflections namely, current perceptions, nurse dependency, family expectations and family involvement. These subthemes will be discussed further under section 4.3.4.1-4.3.4.4.

Subthemes: Reflections on family-centred care

Figure 4.12 represents the subthemes that were identified based on free associations related to the *current* reflections on family-centred care. Subthemes included current perceptions, nurse dependency, family expectations and family involvement.

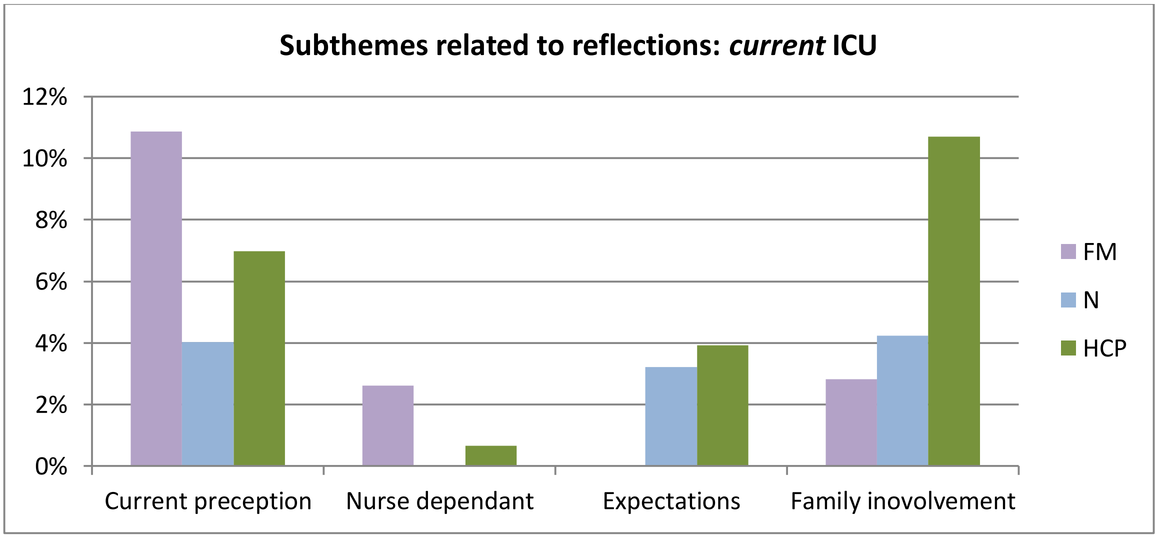


Figure 4.12: Subthemes: Reflections on family-centred care: *Current perceptions*

Figure 4.13. represents the subthemes that were identified based on free associations related to *current* perceptions, nurse dependency, expectations and family involvement in the *ideal* ICU. Percentages will be discussed under each section.

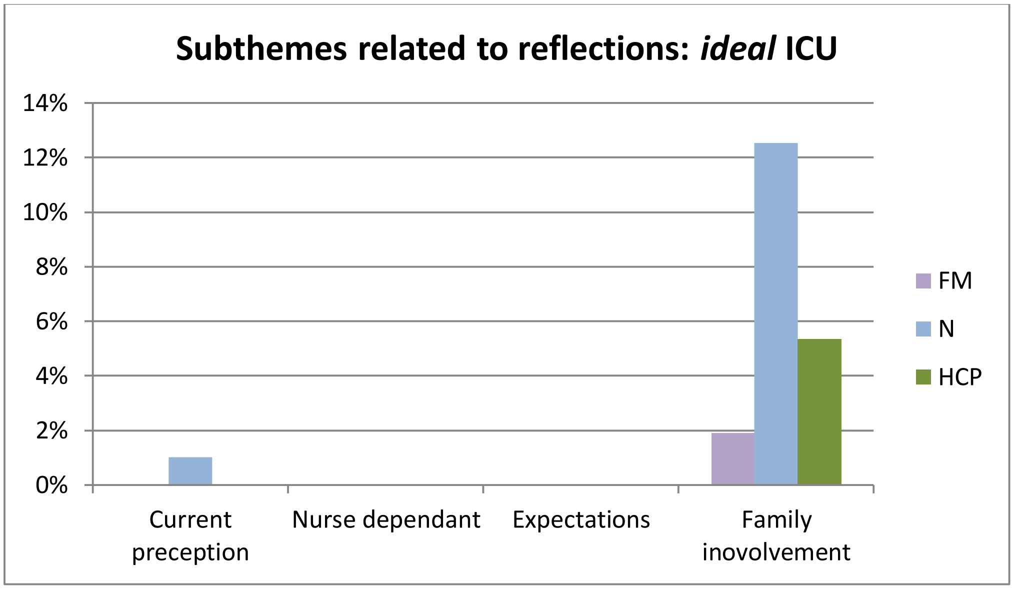


Figure 4.13 Subthemes: Reflections on family-centred care: *ideal perceptions*

4.4.4.1 Subtheme 1: Current perceptions of family-centred care

Free associations related to *current* perceptions emerged amongst all categories of research participants when asked to describe *current* perceptions of family-centred care. *Current* perceptions included commentary around the *current* state of family-centred care in the ICU. When asked to describe family-centred care in the *ideal* environment, only nurses wrote down free word associations related to the *ideal* perceptions of family-centred care.

Table 4.27 provides examples of free associations that were written down by research participants that related to *current* perceptions of the ICU; 4% of nurses, 7% of healthcare professionals and 11% of family members wrote down free associations related to how family-centred care is *currently* perceived.

Table 4.27: Family-centred care: *current perceptions*

Nurses (4%)
"Pressure from families" – Nurse participant 01 *"Of high priority, considered of high value"- Nurse participant 02* *"Patience -They are just too much to handle sometimes"- Nurse participant 18*

Healthcare professionals (7%)
"Not always possible in ICU" – Healthcare professional participant 06 *"Don't usually interact" – Healthcare professional participant 10* *"Good" – Healthcare professional participant 11*
Family members (11%)
"Does not exist" – Family member participant 03 *"Completely neglected" – Family member participant 10* *"Intruding" – Family member participant 12*

Table 4.28 provides examples of free associations that were written down by research participants that related to perceptions of the *ideal* ICU; 1% of nurses, 0% of healthcare professionals and 0% of family members wrote down free associations related to perceptions when describing the *ideal* ICU.

Table 4.28: Family-centred care: *ideal perceptions*

Nurses (1%)
"Of high importance" – Nurse participant 02
Healthcare professionals (0%)
No comments made by healthcare professionals
Family members (0%)
No comments made by family members

Perceptions refer to an individual's or group's unique way of viewing a phenomenon. It involves the processing of stimuli and the incorporation of memories and experiences in the process of understanding (McDonald, 2012:8). Some research participants wrote down free word associations linked to family-centred care as it is *currently*. Some commentary was negative and some positive.

4.4.4.2 Subtheme 2: Nurse dependent

Free associations indicating that family-centred care is nurse dependent emerged amongst healthcare professionals and family members when asked to describe *current* perceptions of family-centred care. Nurse dependency involved commentary around how family-centred care is dependent on the nurse who is taking care of the patient. When asked to describe family-centred care in the *ideal* environment, no free word associations indicating that it is nurse dependent were written down.

Table 4.29 provides examples of free associations that were written down by research participants that related to family-centred care being nurse dependent in the *current* ICU; 0% of nurses, 1% of healthcare professionals and 3% of family members wrote down free associations related to how family-centred care is nurse dependent in the *current* ICU.

Table 4.29: Nurse dependent: *current perceptions*

Nurses (0%)
No comments made by nurses
Healthcare professionals (1%)
"Nurse dependent, some are great, some not so much" – Healthcare professional participant 08
Family members (3%)
"I was treated differently by some" – Family member participant 06 *"Depends on nurse" – Family member participant 16* *"Depends on nurse and doctors on that day" – Family member participant 18*

Some nurses take on a paternalistic role with regard to ICU patient care; ICU nurses view patient care as part of their professional role and responsibility. A nurse's personal values appear to be fundamental to whether he/she chooses to involve the family member in patient care (McConnel & Moroney, 2015:996). Some nurses feel that asking a family member to be involved in care may be perceived as them trying to transfer their responsibilities onto the family member. The length of the ICU experience also tends to impact whether or a not a nurse feels comfortable involving relatives. Nurses with experience felt more confident performing tasks with the family member assisting, compared to those with less experience (McConnel & Moroney, 2015:995).

The successful implementation of an intervention to promote family involvement in patient care is influenced by the behaviour of the nurse (Mackie et al., 2018:138; Berube, Gelinas, Bernard, Gagne, Laizner & Lefebvre, 2014:222; Boltz, Resnick, Chippendale & Galvin, 2014:2405). Nurses are more involved in patient care than any healthcare professional and play a central role in advocating for patients and families. Nurses are in an ideal position to facilitate the adoption of family-centred care principles (Mackie et al., 2018:138; Khalaila, 2014:37). However, evidence suggests that nurses fail to take family needs into consideration, under- estimating them and falling short of meeting such needs (Mackie et al., 2018:138; Khalaila 2014:38; Zomorodi & Foley, 2009:1751).

Issues may arise when nurses perceive families to be demanding, troublesome or difficult to communicate with and then they engage in behaviours that limit involvement (Mackie et al., 2018:138). Therefore, the attitudes and beliefs of nurses may both help and hinder the enactment of family-centred care principles. Interventions aimed at promoting family in care should consider including strategies that challenge nurses who hold negative beliefs, attitudes and perceptions regarding family involvement in care (Mackie et al., 2018:138). Given the variation of individual beliefs, it is essential that ICU nurses understand the impact that their values have on family-centred care (McConnel & Moroney, 2015:996).

4.4.4.3 Subtheme 3: Expectations

Free associations related to expectations emerged amongst nurses and healthcare professionals when asked to describe *current* perceptions of family-centred care. Expectations included commentary around unrealistic expectations that family members may have. When asked to describe family-centred care in the *ideal* environment, no free associations related to expectations were written down.

Table 4.30 provides examples of free associations that were written down by research participants that related to expectations of family members as *currently* perceived; 3% of nurses, 4% of healthcare professionals and 0% of family members wrote down free associations related to how expectations of family members are *currently* perceived.

Table 4.30: Expectations: *current perceptions*

Nurses (3%)
“Unrealistic demands by family members” – Nurse participant 01 *“It’s challenging because they expect miracles (Lead to false hopes)”- Nurse participant 17* *“Expect - they expect more from us”- Nurse participant 19*
Healthcare professionals (4%)
“Family expectations (unrealistic) - Healthcare professional participant 06 *“Disbelief/doubt (unrealistic expectations) - Healthcare professional participant 07* *“Limited info gives false picture - unrealistic perception of illness” – Healthcare professional participant 08* *“False hope to family member by RN” – Healthcare professional participant 17*
Family members (0%)
No comments were made by family members

An expectation is defined as “the feeling or belief that something will or should happen” (Cambridge dictionary online). Some nurses and healthcare professionals reflected on how family members tend to have unrealistic expectations when it comes to their loved one’s illness and prognosis. According to Langley et al. (2015:37), communication with family members could potentially evoke feelings of moral distress due to unrealistic expectations. The doctor tells the family something they do not want to hear. the family member then approaches the nurse hoping that she has something different to say. They hold onto an unfailing sense of hope (Langley et al., 2015:38).

Beckstrand, Mallory, Macintosh, Luthy and Faan (2018:225) state that family members who are in denial and have unrealistic expectations can be a challenge in the ICU, but this is often a coping mechanism adopted by the family members. Healthcare professionals need to recognise this and expect it when interacting with family members in the ICU.

4.4.4.4 Subtheme 4: Family involvement

Free associations related to family involvement emerged amongst all categories of research participants when asked to describe *current* and *ideal* perceptions of family-centred care. Family involvement included commentary around the family member taking part in patient care and decision-making.

Table 4.31 provides examples of free associations that were written down by research participants that related to family involvement in the *current* ICU; 4% of nurses, 11% of healthcare professionals and 3% of family members wrote down free words associated with family involvement when asked to describe how family-centred care is *currently* perceived.

Table 4.31: Family involvement: *current perceptions*

Nurses (4%)
"Good involvement" – *Nurse participant* 02 "They are even welcome to spend more time and be involved in their families treatment" – *Nurse participant* 07 "Obtaining family history - helps to know patient better" – *Nurse participant* 15
Healthcare professionals (11%)
"Nursing care assistance" – Healthcare professional participant 03 *"Family involvement in care of patient" – Healthcare professional participant 07* *"Come during visiting hours when family is able to participate" – Healthcare professional participant 12*

Family members (3%)
"Not able to help care"- Family member participant 04
"No participation required/encouraged"- Family member participant 10
"I give info to the patient"- Family member participant 17

Table 4.32 provides examples of free associations that were written down by research participants that related to family involvement in the *ideal* ICU; 13% of nurses, 5% of healthcare professionals and 2% of family members wrote down free associations related to family involvement when asked to describe family-centred care in the *ideal* setting.

Table 4.32: Family involvement: *ideal perceptions*

Nurses (13%)
"To allow immediate family to be involved in patient's care"- Nurse participant 04
"Family involvement with nursing care" – Nurse participant 05
"Family participation in nursing care"- Nurse participant 10
Healthcare professionals (5%)
"Family involvement in ICU patient care"- Healthcare professional participant 08
"Family involvement in ICU"- Healthcare professional participant 10
"Family involvement when patient is extubated"- Healthcare professional participant 12
Family members (2%)
"Involved in nursing care"- Family member participant 03
"Get family members more involved in care"- Family member participant 04
"Ask more info on family history and type of person wife is"- Family member participant 17

By allowing family members to participate in routine nursing care at the bedside, they may feel empowered to further support their loved one. The involvement of significant others may provide the healthcare professionals with the opportunity to build a relationship with them and enhance the care given to the critically ill patient and family as a whole. Close family members get strength and support from other family members. The satisfaction of significant others will result in a better experience for the whole family and will encourage them to be supportive towards their loved one in the critically ill state (Hlahatsi et al., 2017: 49).

Family involvement in patient care has the potential to remove the doubts that family may have around the patient's situation (Clark & Guzzetta, 2017:97; Wetzig & Mitchell, 2017:68). Family involvement allows them to see that everything possible is being done, which may reduce their anxiety and fear about the patient's situation. The separation of patients from family members is thought to be the leading contributor of post traumatic distress syndrome (Clark & Guzzetta, 2017:97).

Family presence at the bedside in a critical care environment promotes emotional support to both the patients and their families (Cypress & Frederickson, 2017:207; Wetzig & Mitchell, 2017:68). Even if families are not actively involved in patient care, they still want to be present at the bedside and spend as much time as they can with their loved one. This is particularly true in the first phase of their loved one's illness or during the first few days after admission (Wetzig & Mitchell, 2017:68).

Touch has been seen as a way to maintain human and physical connection, whereas talking, verbal encouragement and coaching by family members helps the patient to achieve anxiety reduction, or effective breathing patterns. Verbal encouragement with caring touch is helpful during critical care situations such as CPR, weaning from a mechanical ventilation or simply during visiting hours (Cypress & Frederickson, 2017:207).

Nurses are open to family members being involved in patient care in most instances. However, there are physical, emotional and cognitive limitations that act as barriers to family involvement. Nurses tend to be concerned that family members' involvement in patient care may increase their stress and anxiety, and they may experience a sense of failure if their loved one's condition does not improve (Hetland et al., 2018:72; McConnel & Moroney, 2015:995). Some nurses also express concern around being judged by family members, and fears around safety and legal repercussions and issues involving patient privacy (Hetland et al., 2018:72; McConnell & Moroney, 2015:994).

It is important to engage with individual family members to determine the extent to which they would like to be involved (McConnell & Moroney, 2015:995). Positive relationships amongst family members, nurses, healthcare professionals and patients allow for healing and growth and promote family resilience (Cypress & Frederickson, 2017:214).

4.4.5 Theme 5: Spiritual Care

Free associations related to spiritual care emerged amongst family members when asked to describe *current* perceptions of family-centred care. Spiritual care included commentary around meeting spiritual needs, prayer and pastoral care in the ICU.

Figure 4.14 represents the percentage of research participants who wrote down free associations that were related to spiritual care in the *current* ICU: 0% of nurses, 0% of healthcare professionals and 1% of family members wrote down free associations related to spiritual care when asked to describe *current* perceptions of family-centred care.

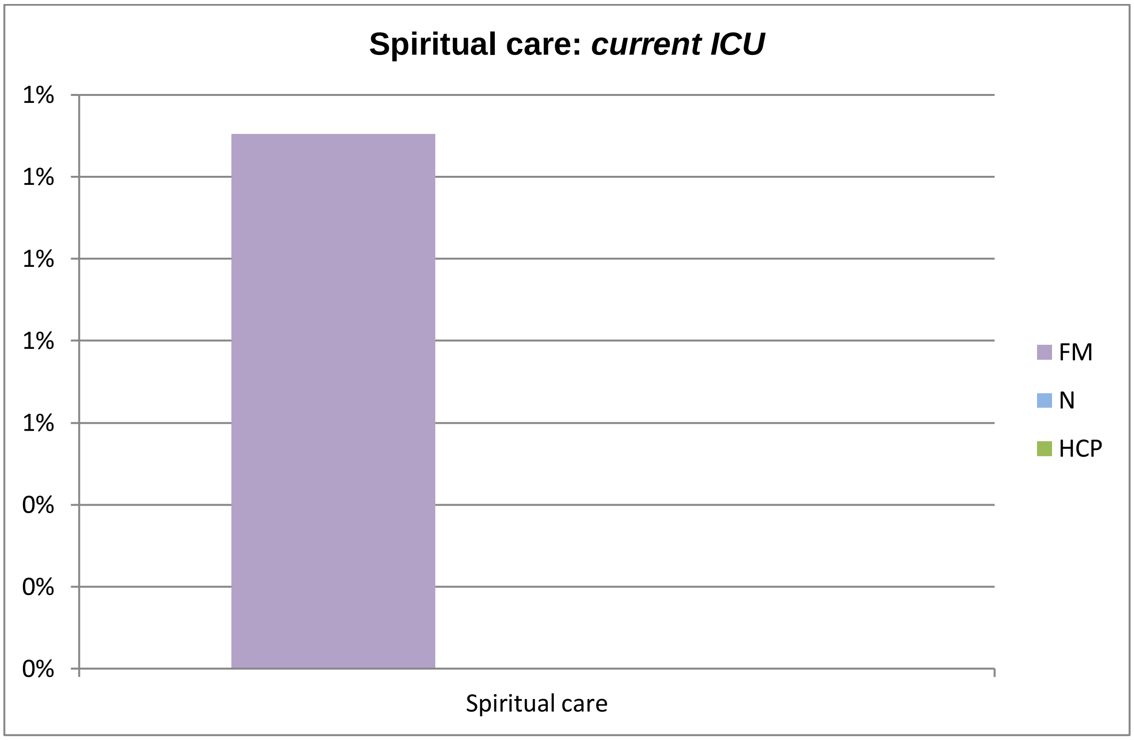


Figure 4.14 Spiritual care: *current perceptions*

Figure 4.15 represents the percentage of research participants who wrote down free associations that were related to spiritual care in the *ideal* ICU; 1% of nurses, 0% of healthcare professionals and 9% of family members wrote down free associations related to spiritual care when asked to describe perceptions of family-centred care in the *ideal* ICU.

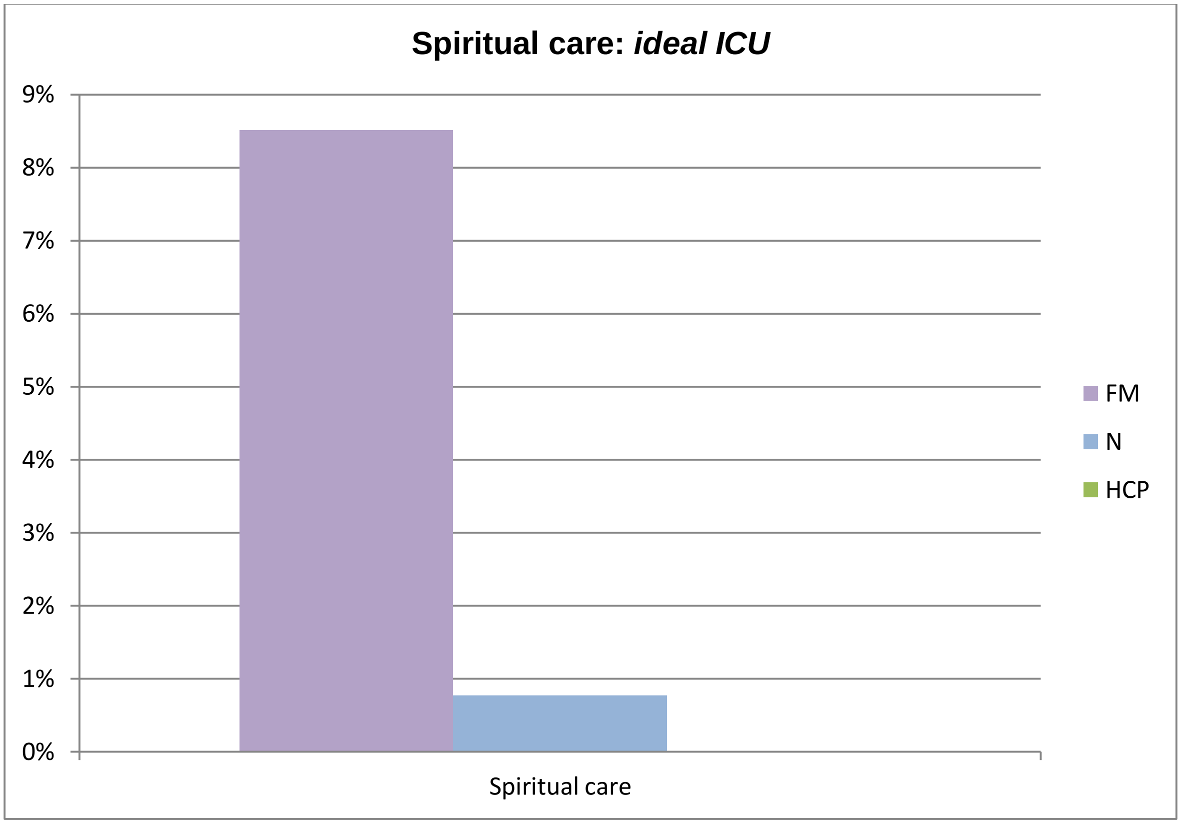


Figure 4.15: Spiritual care: *ideal perceptions*

Table 4.33 provides examples of free associations that were written down by research participants that related to spiritual care in the ICU when asked to describe *current* perceptions of family-centred care in the ICU.

Table 4.33: Spiritual care: *current perceptions*

Nurses (0%)
No comments were made by nurses
Healthcare professionals (0%)
No comments were made by healthcare professionals
Family members (1%)
"Freedom - able to pray"- Family member participant 07

Table 4.34 provides examples of free associations that were written down by research participants that related to spiritual care when asked to describe family-centred care in the *ideal* ICU.

Table 4.34: Spiritual care: *ideal perceptions*

Nurses (1%)
"I will need to be allowed to practice my religion"- Nurse participant 17
Healthcare professionals (0%)
No comments made by healthcare professionals
Family members (9%)
"Including the pastors to come"- Family member participant 05 *"Include the pastors to pray also"- Family member participant 06* *"Spiritual leader presence"- Family member participant 07*

Ruder (2008:159) defines spirituality as "a person's search for, or expression of his or her connection to a greater and meaningful context." Spirituality is defined by Steinhauser, Voils, Clipp, Bosworth, Christakis and Tulsky (2006:101) as "the search for attention to the ultimate meaning and purpose in life, often involving a relationship with the transcendent" and focused on the construct of "being at peace."

Spirituality is a natural part of human existence and the meaning of spirituality may differ from one individual to the next (Noome, Kolmer, Van Leeuwen, Dijkstra & Vloet, 2017:570; Ruder, 2008:159) Most healthcare professionals do consider the patient's spirituality when taking down their history and some even feel quite competent in doing so (Hlahatsi et al., 2017:48; Noome et al., 2017:570). Despite acknowledging a patient's spirituality, they do not often perform spiritual care (Noome et al., 2017:570), they do not feel comfortable praying with their patients and they would only pray if asked to do so. Even when they are prepared to pray, they do so with some sort of discomfort (Hlahatsi et al., 2017:49). In most settings, hospital chaplains are the professionals who provide spiritual care, but this is very rarely offered to family members in the ICU (Noome et al., 2017:570). The spiritual needs of patients and/or their family members are left to their own spiritual leader or pastor (Willemse, Smeets, Van Leeuwen, Janssen & Foudraine, 2018:584).

Before spiritual care can be offered to a family member, healthcare professionals need to be aware of their own beliefs and avoid judgement and prejudice. Understanding your own values can help improve decision-making and care (Noome et al., 2017:575).

South Africa is a diverse country with different cultures and religions. Hlahatsi et al., (2017:52) identified that the spiritual needs of family members are often overlooked. Noome et al., (2017:570) and Nolen and Warren (2014:405) concurred that addressing the spiritual needs of family members is an area in the ICU that is often overlooked.

There is limited literature on the exact role of the ICU nurse in spiritual care. ICU nurses should give attention through listening, supporting and exploring. Support from an ICU nurse is about identifying the needs and wants of patients and family by having introductory conversations around spiritual care. After engaging with family members with regard to their spiritual care needs, the ICU nurse could possibly involve chaplains for further support (Noome et al., 2017:570).

4.5 PERCEPTIONS OF FAMILY-CENTRED CARE: THE GAPS THAT EXIST

The final research objective was to explore the gaps that exist between nurses, healthcare professionals and family members regarding how they perceive family-centred care in the ICU.

These gaps will be discussed in terms of the *current* versus the *ideal* ICU as follows:

- Gaps that exist amongst nurses, healthcare professionals and family members in comparing *current* versus *ideal* family-centred care.
- Gaps that exist amongst nurses, healthcare professionals and family members regarding the most prominent themes.

Prominent themes include:

  - communication;
  - the environment, and
  - spiritual care.

***Current* versus *ideal* family-centred care: Nurses**

When identifying the gaps that exist in the *current* versus *ideal* ICU as perceived by nurses, there was a 16% variance in communication, meaning that communication was viewed as more important when describing family-centred care in the *ideal* ICU than how it is *currently*. There was an 11% variance in environment, meaning that environment was viewed as more important in the *ideal* ICU than the *current* one. There was a 2% variance in reflections. Where more emphasis was placed on reflections when describing family-centred care as it is *currently*, less emphasis was placed on reflections when asked to describe *ideal* family-centred care. There was a 1% variance in spiritual care, meaning that slightly more emphasis was placed on spiritual care when describing family-centred care in the *ideal* ICU. There was a 16% variance in continuum of feelings, which was only mentioned with free associations related to *current* family-centred care. The greatest gap that exists between the *current* and *ideal* was communication in the ICU, followed by the ICU environment. Although there was a 16% variation with regard to the continuum of feelings, this component was not mentioned in the *ideal* setting as participants' responses were linked to their current feelings and emotions. Figure 4.16 is a semantograph of the *current* ICU versus the *ideal* ICU as perceived by nurses.

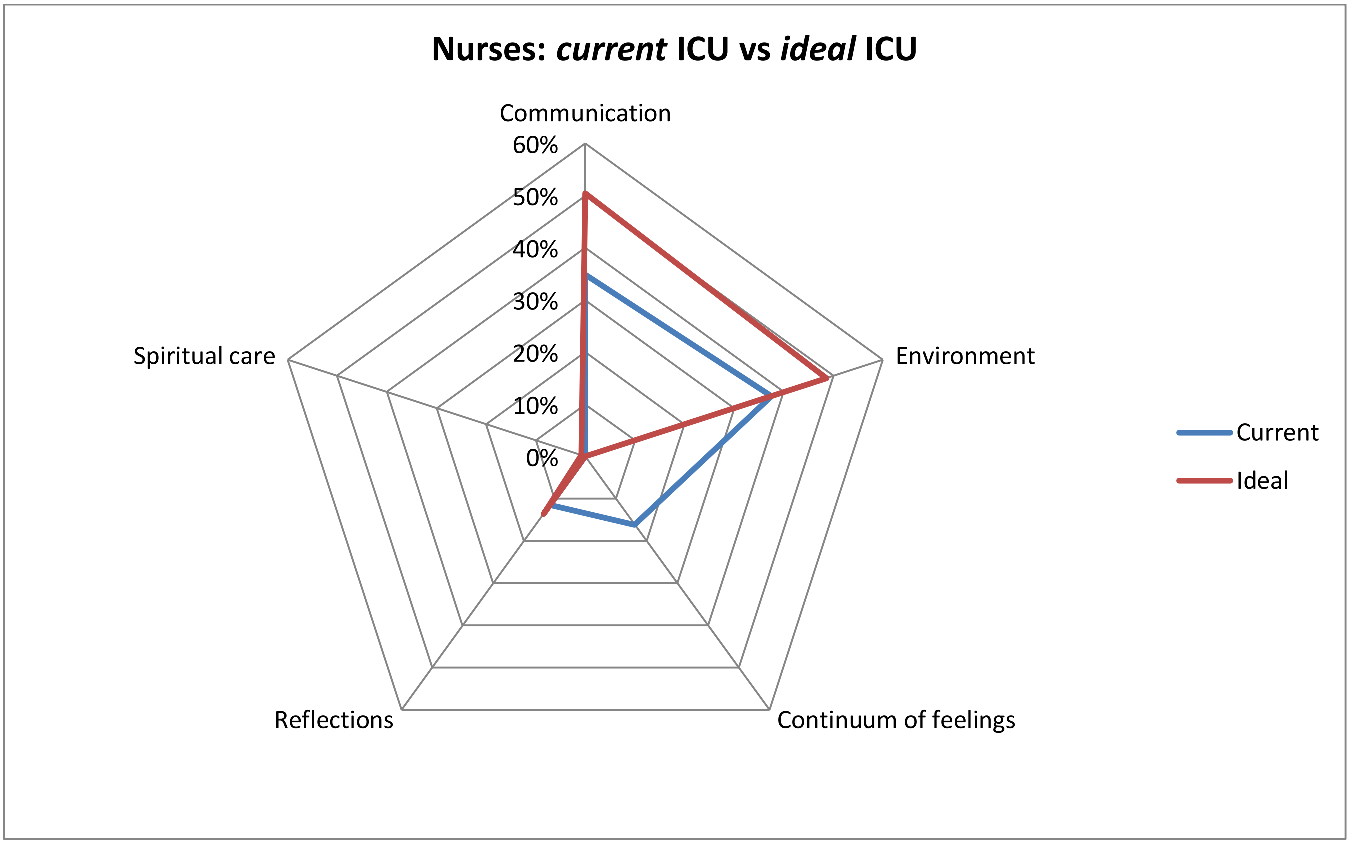


Figure 4.16: Semantograph of the current ICU vs. the ideal ICU: Nurses

Current **versus** ***ideal*** **family-centred care: healthcare professionals**

When identifying the gaps that exist in the current versus the ideal ICU as perceived by healthcare professionals, there was a 4% variance in communication, meaning that greater emphasis was placed on communication when asked to describe family-centred care in the *ideal* environment. There was a 13% variance in environment, meaning that greater emphasis was placed on the environment when describing *ideal* family-centred care. There was a 0% variance in spiritual care, meaning that healthcare professionals did not regard spiritual care as important when asked to describe the *current* and *ideal* family-centred care in the ICU. There was a 0% variance in continuum of feelings as no healthcare professional mentioned continuum of feelings in their free associations. There was a 16% variance in reflection, where more emphasis was placed on reflections when describing family-centred care as it is *currently* and less emphasis was placed on reflections when asked to describe *ideal* family-centred care. The greatest gap that exists between the *current* and *ideal* setting was reflection, followed by environment and then communication. Figure 4.17 is a semantograph of the *current* ICU versus the *ideal* ICU as perceived by healthcare professionals

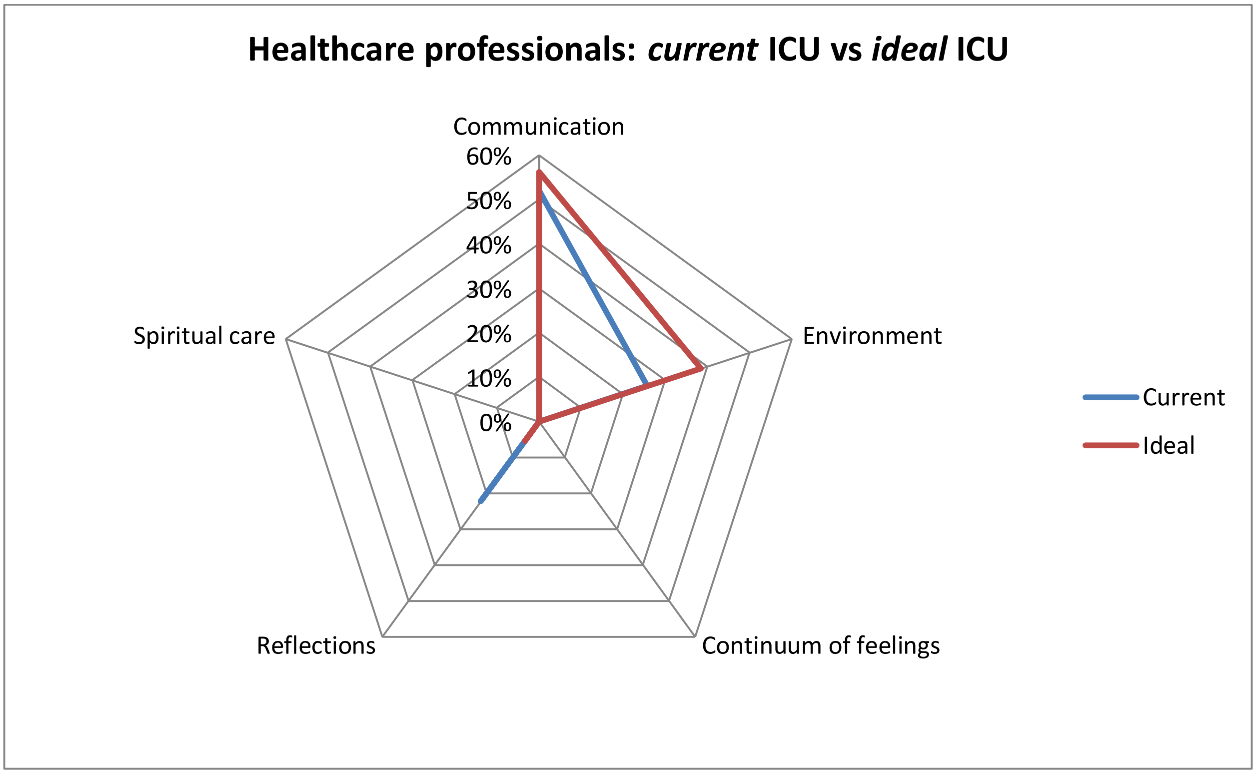


Figure 4.17: Semantograph of *current* ICU vs. the *ideal* ICU: healthcare professionals

Current versus *ideal* family-centred care: family members

When identifying the gaps that exist in the *current* versus the *ideal* ICU as perceived by family members, there was a 17% variance in communication, meaning that greater emphasis was placed on communication when asked to describe family-centred care in the *ideal* setting. There was a 1% variance in environment, meaning that slightly more emphasis was placed on environment when asked to describe family-centred care in the *ideal* setting. There was a 7% variance in spiritual care, meaning that more emphasis was placed on spiritual care when asked to describe family-centred care in the *ideal* ICU. There was a 14% variance in reflection where more emphasis was placed on reflections when describing family-centred care as it is *currently*, while less emphasis was placed on reflections when asked to describe *ideal* family-centred care There was an 11% variance in continuum of feelings, which was only mentioned with free associations related to *current* family-centred care. The greatest gap that exists between the *current* and *ideal* setting was communication followed by reflections and spiritual care. Although there was an 11% variation with regard to continuum of feelings, this component was not mentioned in the *ideal* setting and the participants' responses were linked to their *current* feelings and emotions.

Figure 4.18 is a semantograph of the *current* ICU versus the *ideal* ICU as perceived by family members.

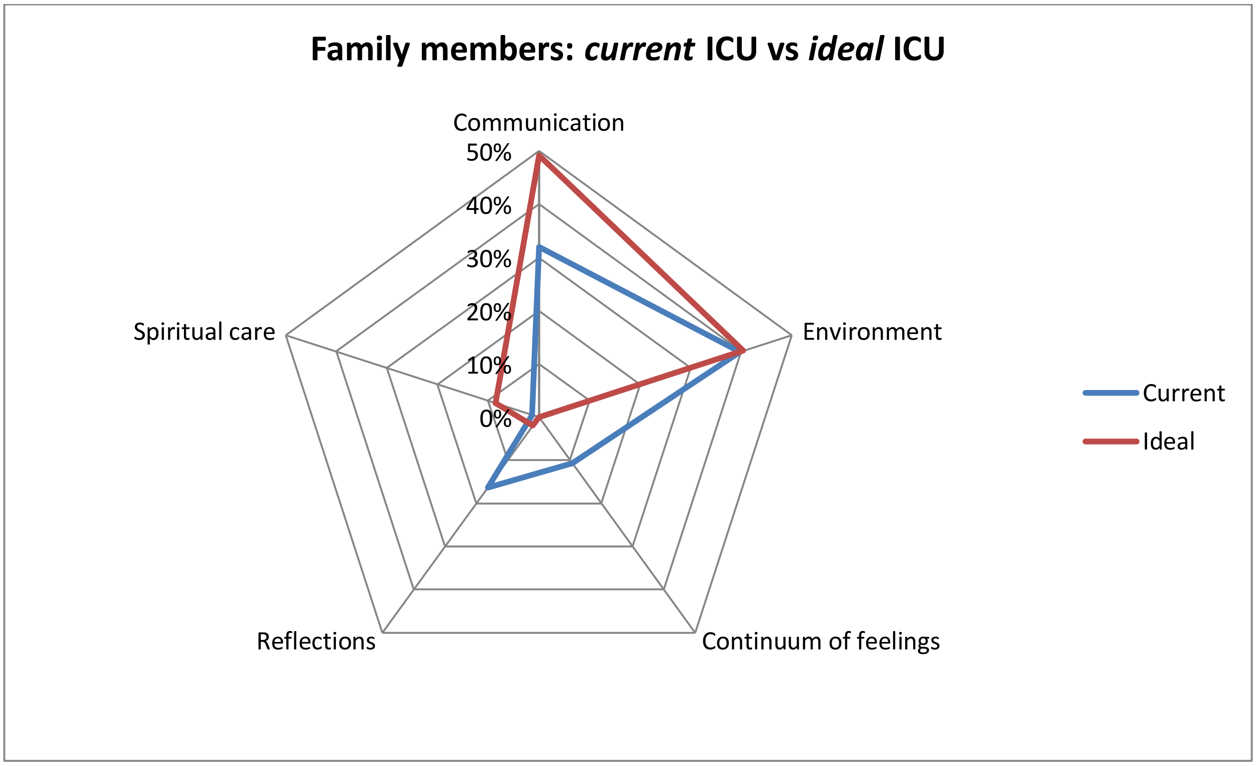


Figure 4.18: Semantograph of *current* ICU vs. the *ideal* ICU: family members

Looking at the *current* vs*. ideal* perceptions of family-centred care as perceived by nurses, healthcare professionals and family members, the most significant gaps that exist are communication, environment and spiritual care. Reflections came through strongly as well; however, more in the context of *current* family-centred care than *ideal* family-centred care. In order to identify the differences that exist between nurses, healthcare professionals and family members, one can compare how each participant group perceives communication, environment and spiritual care in the *current* and *ideal* environment. Gaps that exist amongst nurses, healthcare professionals and family members regarding the most prominent themes, which were communication, environment and spiritual care, will now be presented.

Communication: gaps that exist

Communication was divided into three subthemes, namely orientation (to rules and the environment), information and multi-disciplinary team communication. Figure 4.19 is a semantograph of how the *current* ICU environment is perceived by stakeholders in the ICU.

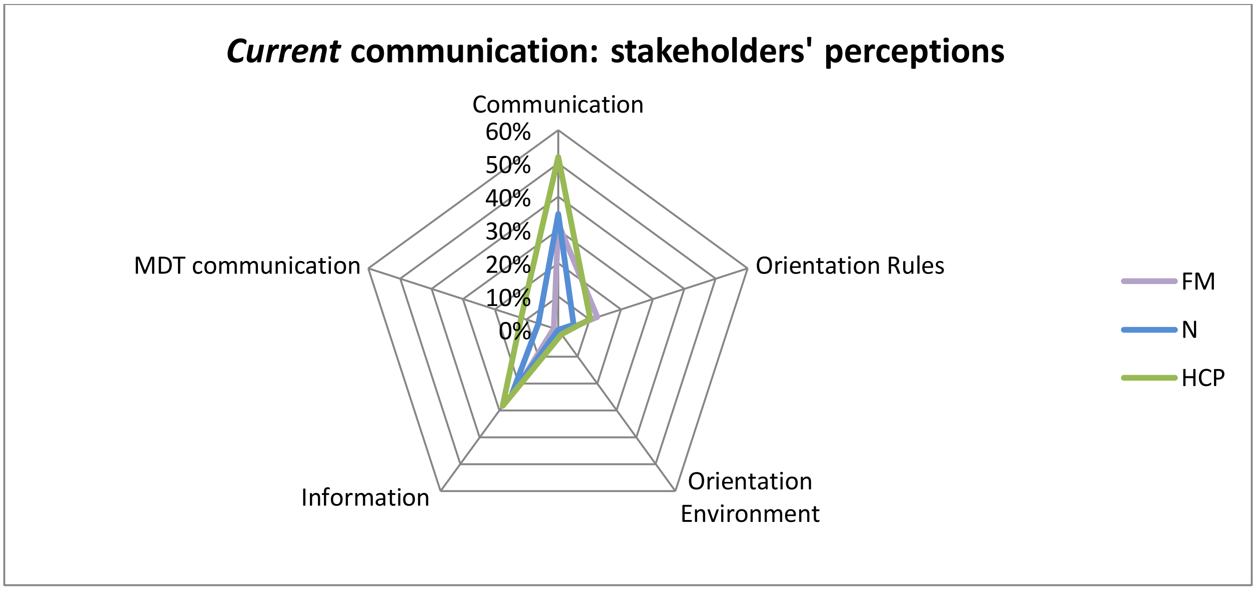


Figure 4.19 Communication: stakeholders perceptions of the *current* ICU environment

Figure 4.20 is a semantograph of how the *ideal* ICU environment is perceived by stakeholders in the ICU.

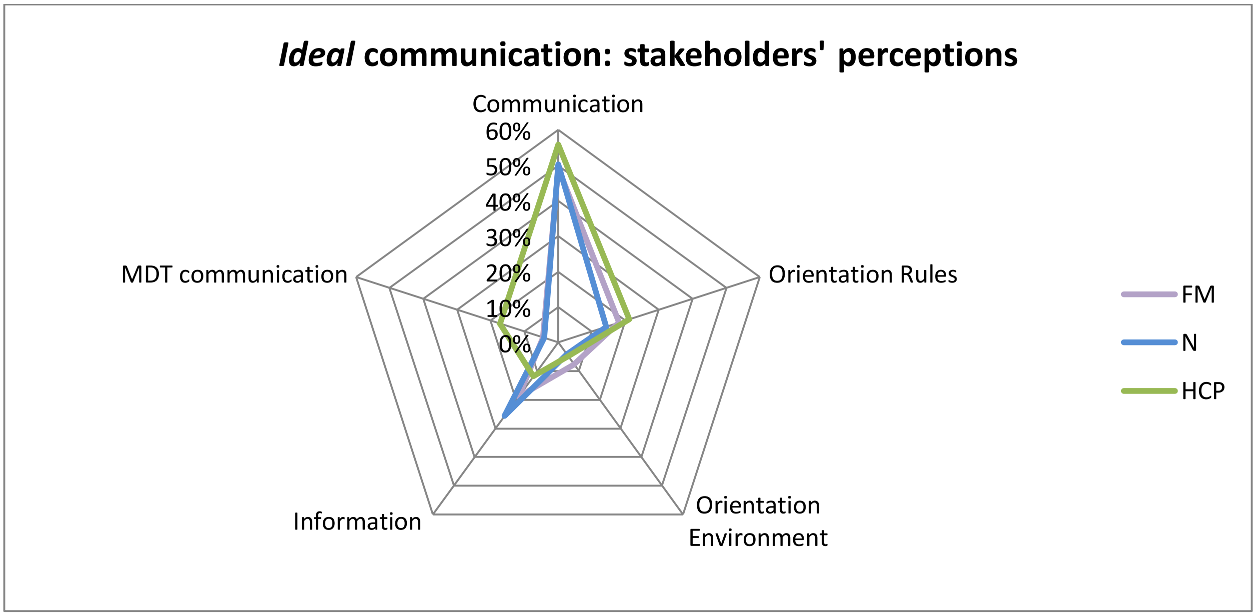


Figure 4.20 *Ideal* communication: stakeholders' perceptions

Nurses vs family members: communication

Current

When comparing free associations amongst nurses and family members, there was a 7% variation with regard to orientation to the rules in the ICU, meaning that family members regarded orientation to rules more important than the nurses did. There was a 1% variance with regard to orientation to the ICU environment between nurses and family members; meaning nurses regarded this as slightly more important than the family members did. There was a 6% variation with regard to information between nurses and family members, meaning that nurses regarded information as more important than family members did. There was a 5% variance with regard to multi-disciplinary team communication between nurses and family members, meaning that nurses regarded multi-disciplinary team communication as more important than family members did.

Ideal

When comparing free associations amongst nurses and family members, there was a 4% variation with regard to orientation to the rules in ICU and orientation to the ICU environment between nurses and family members, meaning that family members regarded this as more important than the nurses did. There was a 7% variation with regard to information between nurses and family members, meaning that nurses regarded information as more important than family members did. Nurses and family members viewed multi-disciplinary team communication as having equal importance.

Healthcare professionals vs family members: communication

Current

When comparing free word associations amongst healthcare professionals and family members, there was a 2% variation with regard to orientation to the rules of the ICU, meaning that this was more important to family members than to healthcare professionals. There was a 1% variation with regard to orientation to the ICU environment, meaning that family members view this as slightly more important than healthcare professionals do. There was an 11% variation with regard to information, meaning that healthcare professionals view information as more important than family members do. There was a 10% variation with regard to multi-disciplinary team communication, meaning that family members view this as less important than healthcare professionals do.

Ideal

When comparing free word associations amongst healthcare professionals and family members, there was a 3% variation with regard to orientation to the rules of the ICU, meaning that this was less important to family members than to healthcare professionals. There was a 3% variation with regard to orientation to the ICU environment, meaning that family members view this as more important than healthcare professionals do. There was a 7% variation with regard to information, meaning that family members view information as more important than healthcare professionals do. There was a 13% variation with regard to multi-disciplinary team communication, meaning that family members view this as less important than healthcare professionals do.

Nurses and healthcare professionals: communication

Current

When comparing free associations amongst nurses and healthcare professionals, there was a 5% variation with regard to orientation to the rules of the ICU, meaning that this was less important to nurses than to healthcare professionals. There was a 2% variation with regard to orientation to the ICU environment, meaning that healthcare professionals view this as more important than nurses do. There was a 5% variation with regard to information, meaning that nurses view information as less important than healthcare professionals do. There was a 5% variation with regard to multi-disciplinary team communication, meaning that healthcare professionals view this to be more important than nurses do.

Ideal

When comparing free associations amongst nurses and healthcare professionals, there was a 7% variation with regard to orientation to the rules of the ICU, meaning that this was less important to nurses than to healthcare professionals. There was a 1% variation with regard to orientation to the ICU environment, meaning that healthcare professionals view this as slightly more important than nurses do. There was a 14% variation with regard to information, meaning that nurses view information as more important than healthcare professionals do. There was a 13% variation with regard to multi-disciplinary team communication, meaning that healthcare professionals view this as more important than nurses do. Looking at the gaps that exist amongst nurses, healthcare professionals and family members, it can be concluded that stakeholders perceive aspects of communication differently with regard to *current* and *ideal* family-centred care in the ICU.

Environment: gaps that exist

Environment was divided into subthemes, namely the physical environment, the care environment, which included nursing competency and workplace culture, patient environment and family environment.

Figure 4.21 is a semantograph of how the *current* ICU environment is perceived by stakeholders in the ICU.

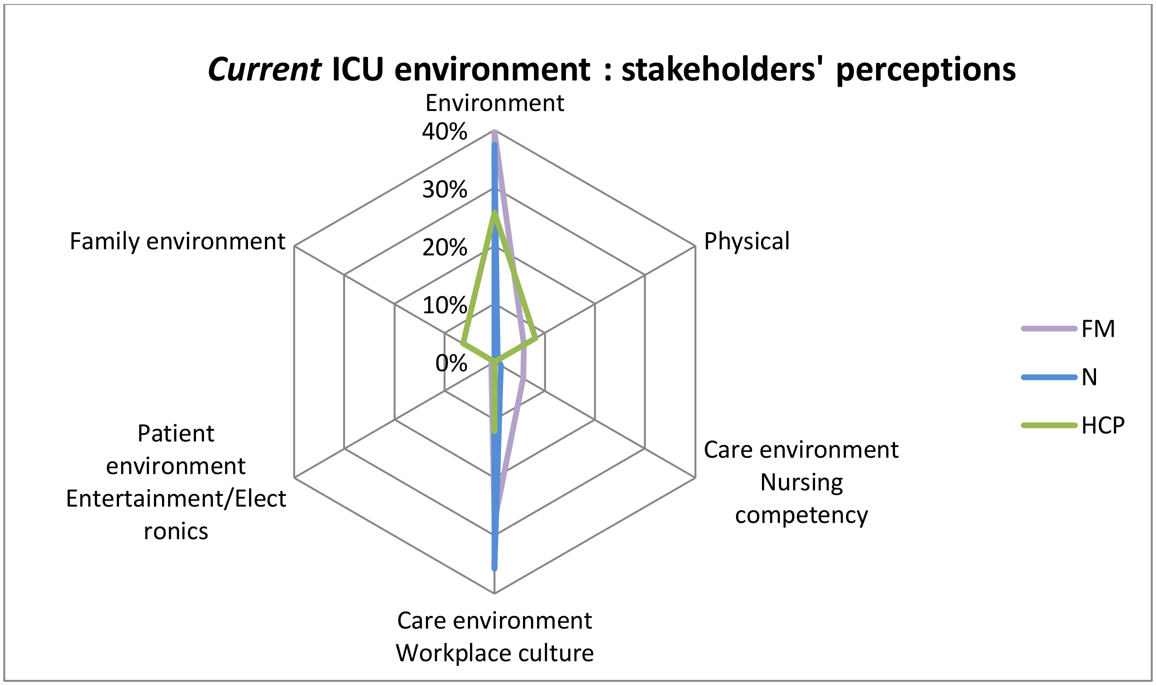


Figure 4.21 *Current* ICU environment: stakeholders' perceptions

Figure 4.22 is a semantograph of how the *ideal* ICU environment is perceived by stakeholders in the ICU.

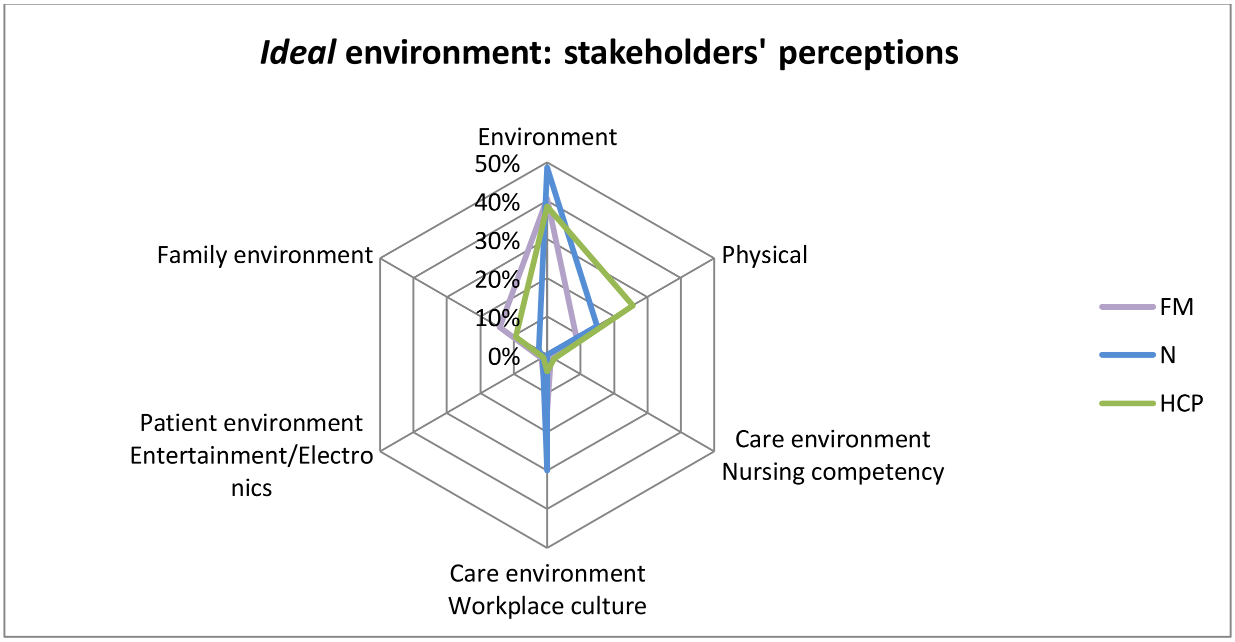


Figure 4.22: *Ideal* ICU environment: stakeholders' perceptions

Nurses and family members: the ICU environment

Current

When comparing free associations between nurses and family members with regard to the ICU environment, there was a 5% variance with regard to the physical environment, meaning that family members regard this as more important than nurses do. There was a 4% variance with regard to nurse competency, meaning that family members regard this as more important than nurses do. There was an 8% variance with regard to workplace culture, meaning that nurses regard workplace culture as more important that family members do. There was a 1% variance with regard to patient environment, meaning that family members regard patient environment as more important than nurses do. There was no difference between nurses and family members with regard to family environment.

Ideal

When comparing free word associations between nurses and family members with regard to the ICU environment, there was a 6% variance with regard to the physical environment, meaning that family members regard this as less important than nurses do. There was a 1% variance with regard to nurse competency, meaning that family members regard this as more important than nurses do. There was a 15% variance with regard to workplace culture, meaning that family members regard workplace culture as less important that nurses do. There was no difference between nurses and family members with regard to the patient environment. There was a 12% variance with regard to the family environment, meaning that this is more important to family members than nurses.

Healthcare professionals and family members: the ICU environment

Current

When comparing free associations between healthcare professionals and family members with regard to the ICU environment, there was a 2% variance with regard to the physical environment, meaning that this is less important to family members than to healthcare professionals. There was a 6% variance with regard to nurse competency, meaning that this is more important to family members than to healthcare professionals. There was a 16% variance with regard to workplace culture, meaning that this is more important to family members than to healthcare professionals. There was a 1% variance with regard to patient environment, meaning that this is more important to family members than to healthcare professionals. There was a 6% variance with regard to family environment, meaning that this is more important to healthcare professionals than to family members.

Ideal

When comparing free word associations between healthcare professionals and family members with regard to the ICU environment, there was a 17% variance with regard to the physical environment, meaning that this is less important to family members than to healthcare professionals. There was a 1% variance with regard to nurse competency, meaning that this is less important to family members than to healthcare professionals. There was a 10% variance with regard to workplace culture, meaning that this is more important to family members than to healthcare professionals. There was a 1% variance with regard to patient environment, meaning that this is more important to family members than to healthcare professionals. There was a 5% variance with regard to family environment, meaning that this is more important to family members than to healthcare professionals.

Nurses and healthcare professionals: the ICU environment

Current

When comparing free associations between nurses and healthcare professionals with regard to the ICU environment, there was a 7% variance with regard to the physical environment, meaning that this is more important to healthcare professionals than to nurses. There was a 1% variance with regard to nurse competency, meaning that this is more important to nurses than to healthcare professionals. There was a 24% variance with regard to workplace culture, meaning that this is more important to nurses than to healthcare professionals. There was no difference between nurses and healthcare professionals with regard to patient environment. There was a 6% variance with regard to family environment, meaning that this is more important to healthcare professionals than to nurses.

Ideal

When comparing free associations between nurses and healthcare professionals with regard to the ICU environment, there was an 11% variance with regard to the physical environment, meaning that this is more important to healthcare professionals than to nurses. There was a 2% variance with regard to nurse competency, meaning that this is more important to healthcare professionals than to nurses. There was a 26% variance with regard to workplace culture, meaning that this is more important to nurses than to healthcare professionals. There was no difference between nurses and healthcare professionals with regard to patient environment. There was a 7% variance with regard to family environment, meaning that this is more important to healthcare professionals than to nurses. Looking at the gaps that exist amongst nurses, healthcare professionals and family members, it can be concluded that stakeholders perceive aspects of the ICU environment differently with regard to *current* and *ideal* family-centred care in the ICU.

Spiritual care: gaps that exist

Spiritual care is the last prominent theme that will be discussed. Figure 4.23 is a semantograph of how the *current* ICU environment is perceived by stakeholders in the ICU with regard to spiritual care.

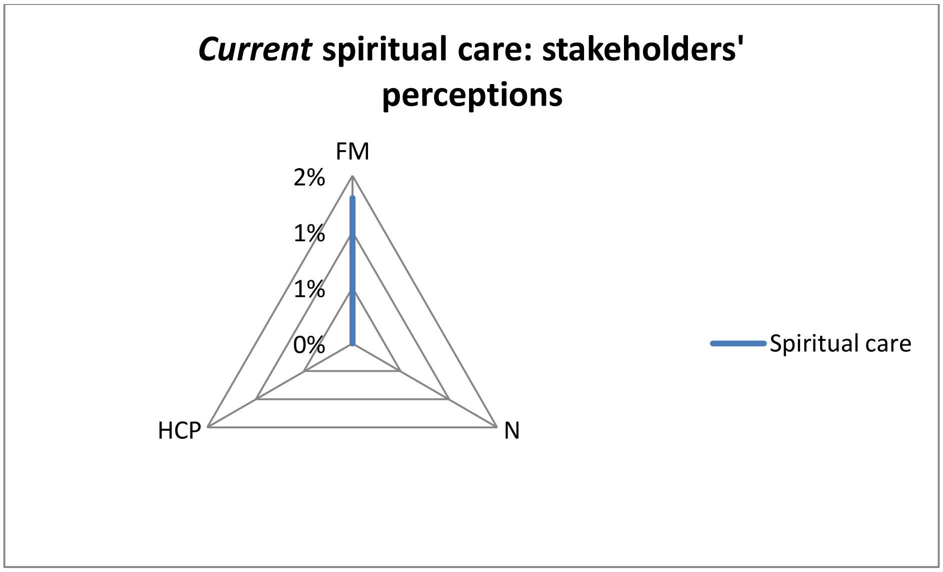


Figure 4.23: *Current* spiritual care-stakeholders perception

Figure 4.24 is a semantograph of how the ideal ICU environment is perceived by stakeholders in the ICU.

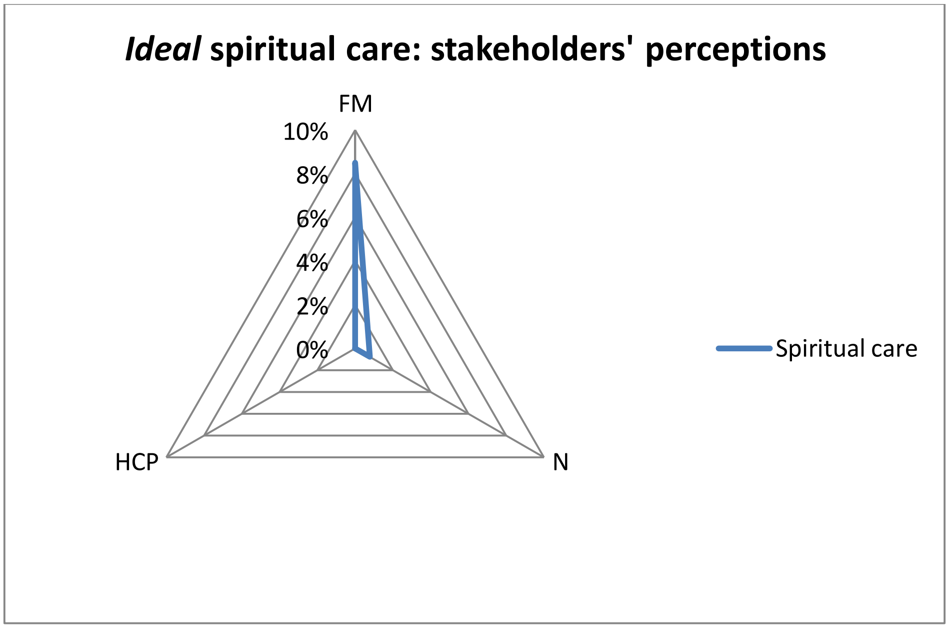


Figure 4.24*:* *Ideal* spiritual care – stakeholders' perceptions

Nurses and family members: spiritual care

Current

When comparing free associations between nurses and family members with regard to spiritual care in the *current* ICU, there was an 1% variance, meaning that this is more important to family members than to nurses.

Ideal

When comparing free associations between nurses and family members with regard to spiritual care in the *ideal* ICU, there was an 8% variance, meaning that this is more important to family members than to nurses.

Healthcare professionals and family members: spiritual care

Current

When comparing free associations between healthcare professionals and family members with regard to spiritual care in the *current* ICU, there was a 1% variance, meaning that this is more important to family members than to healthcare professionals.

Ideal

When comparing free associations between healthcare professionals and family members with regard to spiritual care, there was a 9% variance, meaning that this is more important to family members than to healthcare professionals.

Nurses and healthcare professionals: spiritual care

Current

When comparing free associations between nurses and healthcare professionals with regard to spiritual care in the *current* ICU, there was no difference.

Ideal

When comparing free associations between nurses and healthcare professionals with regard to spiritual care in the *ideal* ICU, there was a 1% variance, meaning that this is more important to nurses than to healthcare professionals. Looking at the gaps that exist amongst nurses, healthcare professionals and family members, it can be concluded that stakeholders perceive aspects of spiritual care in the ICU differently with regard to *current* and *ideal* family-centred care in the ICU.

4.6 SUMMARY

This chapter discussed the data analysis and findings in detail. The discussion focused on main themes, but also reported on subthemes and categories extracted from the data, with reference to literature that supported the discussions. Chapter 5 provides an overview of the conclusions, limitations to the study and implications for practice, management, education and future research.

CHAPTER 5

CONCLUSIONS, IMPLICATIONS FOR PRACTICE AND LIMITATIONS AND RECOMMENDATIONS FOR FUTURE RESEARCH

5.1 INTRODUCTION

In Chapter 4, the research findings were discussed and a comprehensive review of relevant literature was presented. This chapter provides the conclusions to the research findings and discusses the implications for family-centred care in the ICU in practice; briefly describes the limitations of the study, makes recommendations for future research and concludes with the researcher's personal reflection on her research journey.

There is no denying the value and importance of family-centred care in the ICU. Although widely researched, there are still inconsistencies in implementing family-centred care in practice (Hetland, 2018:74), which influences the ability to transfer research findings into practice. Neglecting the opportunity to try to improve family-centred care may lead to increased emotional turmoil amongst family members (Christensen & Probst, 2015:67; Kentish-Barnes, 2015:1342; Wong et al., 2015:51) and this may lead to an increased emotional burden on the healthcare professionals (Cypress & Frederickson, 2017:231). Nurses and healthcare professionals need to customize strategies in individual ICU's to improve family-centred care (Davidson et al., 2017:118). In this study the researcher sought to explore and describe the perceptions of stakeholders of family-centred care in the intensive care unit, using associative group analysis.

5.2 AIM AND OBJECTIVES

The aim of this study was to explore and describe stakeholders' perceptions of family-centred care in the intensive care unit. To address the aim of the research, the objectives were to:

- describe nurses', healthcare professionals' and family members' perceptions of *current* family-centred care in the intensive care unit;

- explore nurses', healthcare professionals' and family members' perceptions of *ideal* family-centred care in the intensive care unit
- describe the gaps between nurses, healthcare professionals' and family members' perceptions of *current* and *ideal* family-centred care in the intensive care unit.

5.3 OVERVIEW OF RESEARCH DESIGN AND METHODS

Data collection took place over a period of one month. A total of sixty (60) research participants took part in the study, which included twenty (20) nurses, twenty (20) healthcare professionals and twenty (20) family members (see chapter 4, table 4.1,4.2 and 4.3 4.3).

The researcher used a quali-quanti research design. Qualitative and quantitative data were collected concurrently and analyzed simultaneously; the qualitative data was transformed into quantitative data. The researcher conducted structured interviews to collect the data from the research participants. The interviews were done on a one-on-one basis or in small groups of two or three. Data was collected by means of associative group analysis. The research participants wrote down free associations in response to the stimulus word "family-centred care". A detailed description of data analysis is provided in chapter 3, section 3.7.6.

5.4 CONCLUSIONS AND IMPLICATIONS

The conclusions relating to *current* and *ideal* family-centred care as perceived by the stakeholders and the *gaps* that exist around these perceptions, have been discussed in relation to the five overarching themes that were identified during the data analysis session. The researcher identified five (5) overarching themes, namely communication, environment, continuum of feelings, reflections and spiritual care. The conclusions will be discussed in relation to the aim and objectives of the research study. Implications with regard to the overarching themes and related sub-themes will follow.

5.4.1 Theme 1: Communication

Communication was a consistent theme that emerged from all research participants when asked to describe *current* and *ideal* family-centred care in the intensive care unit. Communication was further divided into subthemes, namely orientation, information and communication and presented to the multi-disciplinary team.

Current perceptions of communication

Thirty-five per cent (35%) of nurses, 52% of healthcare professionals and 32% of family members wrote down free associations related to communication as it *currently* is in the ICU. Nurses, healthcare professionals and family members all wrote down free associations related to information, making this the most important aspect to them with regard to communication as it currently is in the ICU. Nurses and healthcare professionals ranked multi-disciplinary team communication as second most important, where family members ranked orientation to the rules in the ICU as second most important.

Current perceptions of communication: orientation

Orientation to the rules was perceived to be one of the highest priorities amongst family members and healthcare professionals. Orientation to the rules was further divided into two categories, namely orientation to the rules and orientation to the ICU environment.

Current perceptions in relation to orientation were consistent amongst *nurses*, although there were contrasting views regarding current visiting hour policies and rules in the ICU. Some nurses believed that their visiting hour policy is flexible and that family members can come in at any time, although the family members may be asked to leave if the nurse needs to perform a procedure. Contrary to that, some described visiting time as a huge challenge, since family members do not adhere to visiting times. They believe that family members have misunderstandings around rules in the ICU. As with nurses, *healthcare professionals* had conflicting views around orientation to the ICU. Some viewed visiting hours as unduly strict and felt that family members should be allowed more time with the patient. They found that family members' presence at the bedside was restricted due to visiting hours. According to one healthcare professional, family members were allowed to come in outside of visiting hours for a few minutes under special circumstances.

Healthcare professionals believed that the various roles of the members of the multi-disciplinary team should be explained to the family members, as they often do not know whom to ask questions. Attention should be paid to explaining contact precautions to the family members, as well as their expected strict adherence to visiting hours. *Family members* did not place much emphasis on orientation to the ICU. Most free associations were made around visiting hours. As with nurses and healthcare professionals, there were inconsistent views amongst family members regarding visiting hours and what they were experiencing. Most family members stated that visiting hours and rules in the ICU were very strict; with only one person allowed at the bedside at a time. One family member commented that it was emotionally exhausting to sit at the bedside for one hour. Another family member stated that staff have no consideration around visiting hours and that visiting hours were policed. Contrary to that, some family members stated that visiting hours were flexible and that the staff were lenient, as they were allowed to come in outside visiting hours. One family member stated that the rules in the ICU were inconsistent, as it was stated that no children under twelve years were allowed, yet children did go into the ICU. Regarding orientation to the ICU, some family members stated that no one explained the equipment or procedures, while another family member stated that he did receive orientation to the ICU.

In summary, when emphasis was placed on visiting hours in the ICU, it became clear that views around visiting hours differed from one individual to the next. This is why inconsistencies around rules in the ICU are experienced by family members.

Current perceptions of communication: information

Current perceptions of family-centred care by *nurses* in relation to information revealed that they believe that it is important to provide regular updates to family members, ensure that they have a clear understanding of their family member's condition and provide feedback on information from the doctors. *Healthcare professionals* believe that there is a lack of communication to family members and that family members tend to have a lack of understanding around the patient's condition. A few healthcare professionals viewed providing information to family members as important in current family-centred care. One healthcare professional stated that a family spokesperson should be identified to whom all information can be relayed. *Family members* felt that they did not receive proper information from the nurses and doctors. They revealed that regular updates were not given and that, in some instances, family members had to insist on being given updates by the nurses and doctors. However, other family members felt that they received regular updates from the nurses and that the information received from the doctors and nurses was transparent.

In summary, it can be deduced that nurses and healthcare professionals believe that it is important to provide information to family members. However, healthcare professionals stated that the family is not always well-informed and that they do not have a clear understanding around the patient's condition. Most family members expressed that there was a lack of information provided.

So even though nurses and healthcare professionals identified the importance of providing information to family members, it does not seem to be translated into practice.

Current perceptions of communication: multi-disciplinary team communication

Multi-disciplinary team communication was the last subtheme under communication. *Current* perceptions of family-centred care related to multi-disciplinary team communication were of higher importance to healthcare professionals, followed by nurses and then family members. *Nurses* feel that there is lack of communication from doctors, that doctors tend to be unapproachable and often unavailable and that they do not give nurses or family member's information on the patient's condition. Nurses are often the messengers between the family and the doctor, but they feel as though they cannot give detailed information to family members around the patient's condition. *Healthcare professionals* perceive that there is lack of communication amongst the multi-disciplinary team. Doctors do not always involve the family and often avoid speaking to the family. Nurses are often more involved with the family. Family members are expected to make appointments in order to see the doctor. *Family members* perceived that there is consistency regarding feedback, but the condition of the patient is not always known by all the members of the multi-disciplinary team.

In summary, there seem to be gaps when it comes to communication amongst members of the multidisciplinary team. These gaps are most evident when one looks at the family perceptions of not getting information from nurses. Nurses may not have the information to give, due to lack of multidisciplinary team communication. Nurses may be afraid to disclose information, as they are not sure what the doctor has already communicated to the family. There is often a breakdown in multi-disciplinary team communication. Perhaps the translation of information will improve if multi-disciplinary team communication improves. Doctors need to take more time to spend with family members to explain the condition of the patient.

Ideal perceptions of communication

When describing the *ideal* environment, 50% of nurses, 56% of healthcare professionals and 49% of family members wrote down free associations related to communication. Information was ranked as the most important aspect of communication by the nurses, followed by orientation to rules. *Healthcare professionals* ranked orientation to rules as most important, followed by multi-disciplinary team communication. *Family members* ranked information as most important followed by orientation to rules.

Ideal perceptions of communication: orientation

There were conflicting views when it came to the nurses' perceptions of *ideal* family-centred care. *Nurses* believe that visiting times should be strictly adhered to and that family members should receive orientation to the visiting time policy and the rules of the ICU. Some feel that family members coming in or phoning all the time is disruptive. Contrary to this, there are some nurses who perceive ideal family-centred care as having open visiting times or extended visiting times and that children should be allowed into the unit. Some believe that family should be allowed to spend as much time as they wish to with the patient and should only be asked to leave when the nurses need to preform procedures. The perceptions of *healthcare professionals*, revealed that the majority believe that ideal family-centred care means keeping strict visiting hours, limiting the number of visitors allowed at the bedside per patient and having age restrictions for visiting hours. One healthcare professional went so far as to say that visiting hours should be manned to ensure adherence. A small minority of healthcare professionals felt that visiting hours should be open, flexible and balanced.

Healthcare professionals believe that family members should receive orientation to the rules of the ICU and orientation to the ICU environment, including educating family members on who are involved in the care of the patient, so that they know who to direct their questions to. They also find it important to educate family members on rules around infection control. *Family members* perceived an ideal ICU as one with open or longer visiting hours and wanted to spend more time with their family member after they had been admitted. Some family members said that they understood why they were not being allowed to sit at the patient's bedside the whole time and why they would sometimes be asked to leave. Family members expressed the need to be informed on what was expected of them in the ICU and what they were to expect when they saw their family member for the first time. Most family members understood the need for rules, but just wished the rules would be explained to them.

In summary, as with current perceptions around orientation to rules and the ICU environment, most emphasis was placed on visiting hour policies. *Nurses* had contrasting ideas: on the one hand some felt that visiting hours should be open and flexible and that family members should be welcome anytime, while others felt that visiting hour policies needed to be strictly enforced. *Healthcare professionals* strongly agreed with enforcing and keeping strict visiting hours, while only a small minority felt that visiting hours should be more flexible. *Family members* expressed the need to be able to spend more time with their loved one, yet most family members understood the importance of rules in the ICU and were not opposed to them, but wished for the rules to be explained. It is clear that a gap exists between individuals' views of visiting hour policies on the one hand and the other rules in the ICU on the other.

Ideal perceptions of communication: information

Ideal family-centred care was perceived by *nurses* as providing timely, factual and clear information to family members on a daily basis. Some *nurses* suggested that family members should choose one member of the family to act as a spokesperson to receive information. *Healthcare professionals* provided two suggestions on how to improve information provided to the family. Firstly, in keeping with the nurses, they suggested identifying one family member to receive all the updates and information and secondly, they suggested that information brochures be provided to family members. One healthcare professional believed that the registered nurse should communicate with the family. *Family members* believed that information provision in the ideal setting would mean that family members were kept updated at all times and that the information that was provided was open, honest and comprehensive. One family member suggested having a contact person in the waiting area to give the family members regular updates.

In summary, all stakeholders concurred that the family members need to receive open, honest information. Strategies to improve information provision were suggested. The nurses and healthcare professionals concurred that one family member should be identified to receive the updates. The healthcare professionals also suggested providing brochures to family members with information on the ICU. The gap that exists between the current situation and the ideal, can be eliminated. Both the nurses and the healthcare professionals have clear and consistent views around information sharing, but these need to be put into practice.

Ideal perceptions of communication: multi-disciplinary team communication

Ideal perceptions of family-centred care relating to multi-disciplinary team communication were of higher priority to the healthcare professionals than the family members and lastly the nurses.

Nurses perceived ideal multi-disciplinary team communication as nurses being well-informed about the patient's condition, doctors having more contact and interaction with the family members, improved communication between the doctors and the nurses and increased doctor availability. *Healthcare professionals* perceived the ideal as an ICU where all members of the multi-disciplinary team are involved in the care of the patient, with a platform for equal, open communication amongst the multi-disciplinary team. Some healthcare professionals felt that the doctors should be more available and approachable and that the family should have regular appointments with the doctor/s to stay updated. Family rounds and multi-disciplinary team rounds were also mentioned as part of ideal family-centred care. *Family members* perceived ideal multidisciplinary team communication as having regular meetings with the multi-disciplinary team, where all the team members involved in the care of the patient are well-informed, where making contact with the doctor is easy and where there is regular communication from the multi-disciplinary team. Some family members also suggested that the doctor/s communicate information about the patient to the nurses on a regular basis so that the nurses can explain the patient details to the family members more effectively, since the doctor is not always available.

In summary, nurses, healthcare professionals and family members have the same or similar views on ideal multi-disciplinary communication. Looking at current and ideal perceptions, it is clear that gaps exist and there is room for improvement.

5.4.1.1 Implications

The researcher recognized the following implications for practice to ensure improved communication for families and patients:

- Inconsistencies around visiting hour policies need to be addressed. Nurses and healthcare professionals could have team meetings and include family members to come up with strategies that would suit everyone. Once these strategies have been identified, the organization should formulate policies around visiting times.
- Policy development around visitors in the ICU, specifically including visiting times, flexibility around visiting times, number of visitors at the bedside, age restrictions and circumstances under which rules are flexible should be revisited. The amended policy should then be implemented to ensure that there is consistency around visiting hour practices in the ICU.

- The ICU could look into a formal orientation program for family members. This orientation program could include orientation to the ICU environment, orientation to the rules around visiting policies, becoming familiar with infection control principles and formulating a rationale for the rules. Family members should also be brought up to date about the members of the multi-disciplinary team and their roles. Additionally, orientation should include information on how to get in touch with the doctor and when they would be receiving updates.
- In order to improve the information that the family members receive, each family could identify a spokesperson who would then receive all the information on the patient’s condition. The information provided should be consistent, truthful, comprehensive and the identified family member should receive updates on a regular basis.
- In order to improve multi-disciplinary team communication, the ICU could come up with a strategy that would allow regular team meetings where all the members involved in the care of the patient have the opportunity to give input. This would ensure that all members of the multi-disciplinary team have the same information and expectations. If all the members of the multi-disciplinary team are well-informed, it may eliminate inconsistencies in the information provided to the family member.
- The organization and ICU could engage with doctors to come up with strategies which could enable them to be more available and approachable to the multi-disciplinary team and to family members.

5.4.2 Theme 2: Environment

The intensive care environment was a theme that emerged amongst nurses, healthcare professionals and family members when asked to describe *current* and *ideal* family-centred care in the intensive care unit. The environment was further divided into subthemes, namely the physical environment, the care environment, the patient environment and the family environment.

Current perceptions of environment

Thirty-eight per cent (38%) of nurses, 26% of healthcare professionals and 40% of family members wrote down free associations related to the intensive care environment. Workplace culture was viewed by *nurses*, *healthcare professionals* and *family members* to be the most important aspect of the ICU environment. *Nurses* viewed nursing competency as the second most important subtheme, followed by physical environment. *Healthcare professionals* viewed the physical environment as the second most important sub-theme followed by the family environment. *Family members* viewed the physical environment and nursing competency as the second most important sub-themes related to the ICU environment as it is currently perceived.

Current perceptions of environment: physical environment

Current perceptions of family-centred care related to the physical environment were of higher priority to healthcare professionals, followed by family members and then nurses. *Nurses* perceived silence in the ICU to be an important part of the current physical environment. *Healthcare professionals* perceived a lack of privacy for family members, cold and unfriendly isolation rooms and poorly positioned beds to be problems in the current ICU. *Family members* perceived the current physical environment as being cold and noisy, yet well-organized.

In summary, nurses, healthcare professionals and family members all have different perceptions of the current physical ICU environment. Nurses perceive the ICU to be a quiet environment, yet family members think it is noisy. Healthcare professionals place emphasis on the layout, which does not seem to concern family members.

Current perceptions of environment: care environment

The care environment was the second subtheme that was identified under ICU environment. *Current* and *ideal* perceptions of family-centred care as these relate to the care environment were of higher importance to nurses than family members and lastly healthcare professionals. The care environment was further divided into nurse competency and workplace culture. Workplace culture was significantly more dominant than nurse competency amongst nurses, healthcare professionals and family members. *Nurses* perceived the current care environment as supporting family members, being respectful, friendly, greeting family members, being caring towards them, showing sympathy and demonstrating understanding. Some nurses also believe that the nurses need to demonstrate competence in their work and never show a lack of self-confidence in front of the family. Nurses expressed that family members were often appreciative of what the nurses did and that some nurses and family members formed bonds. According to some nurses, family members could sometimes be rude and disrespectful, not trusting the nurses. Nurses believe that they need to stay calm and be forgiving towards family members. Some nurses also expressed that they sometimes got caught up in family disputes with regard to those who may or may not be allowed to visit the patient.

Healthcare professionals perceived the current care environment as one where the staff members greet the family when they enter and provide emotional support. Some healthcare professionals perceived family members as being hostile towards the staff members. *Family members* perceived the care environment as being filled with staff who are friendly, caring, positive and professional, welcoming family members into the unit. Some family members perceived nurses not always being at the bedside. One family member commented that the nurse did not check up on their relative once. Some family members felt that they were treated negatively by nurses and that family members were ignored and disregarded. Some family members viewed the nurses as being unsympathetic and incompetent.

In summary, family members in the ICU are perceived differently by different individuals. Family members perceive the reception they get from nurses differently. A nurse who has a negative perception of family members, will come across as disconnected and rude. Nurses who do not engage with family members, may be perceived as being incompetent.

Current perceptions of environment: patient environment

Patient environment was the third subtheme that was identified under ICU environment. Current perceptions of patient environment were of importance to family members, but less so to *nurses* and *healthcare professionals*. *Family members* perceived that there was a lack of entertainment for the patient in terms of electronics. Family members stated that they were not allowed to have electronic devices due to the risk of theft.

Patient environment was not viewed as important by nurses and healthcare professionals, which indicated a gap. Eliminating the boredom experienced by the patients is something that can be considered as a way of improving the patients' ICU experience, for patients who are awake and orientated.

Current perceptions of environment: family environment

Family environment was the fourth and final subtheme that was identified under ICU environment. *Current* perceptions of family-centred care relating to family environment were of importance to the healthcare professionals. Nurses and family members did not view this as an important component of current family-centred care. *Healthcare professionals* perceived the waiting area for family members to be cold, unfriendly, too small to accommodate all family members and without restroom facilities for the family members.

In summary, nurses and family members did not regard family environment as important. Healthcare professionals placed more emphasis on the visiting area, where family members tended to place more emphasis on aspects that concern the patient in the ICU.

Ideal perceptions of environment

The results of this study indicate that 49% of nurses, 38% of healthcare professionals and 40% of family members wrote down free associations related to the ICU environment, when asked to describe ideal family-centred care. *Nurses* viewed workplace culture as the most important subtheme related to the ideal environment, followed by physical environment. *Healthcare professionals* viewed physical environment as the most important subtheme related to the ideal environment, followed by family environment. *Family members* viewed workplace culture as the most important subtheme related to the ideal environment, followed by family environment and then physical environment.

Ideal perceptions of environment: physical environment

Ideal perceptions of family-centred care related to physical environment were of higher priority to healthcare professionals, followed by nurses and then family members. *Nurses* perceived the ideal physical environment as having privacy for family members that were emotional, and being a quiet, clean unit. *Healthcare professionals* perceived it as being a clean environment and suggested changing the layout of the ICU, having bigger windows installed to allow for natural lighting towards improved space and time orientation for the patient and ensuring more space around the bed, privacy for the patient and family and improved staffing, which includes an intensivist for the ICU and doctors who are permanently in the unit. *Family members* were in agreement with the nurses and healthcare professionals around privacy for the patients and family members.

In summary, nurses, healthcare professionals and family members were in agreement regarding the need for privacy for the patient and the emotional family member. Nurses placed emphasis on a quiet, clean environment, whereas healthcare professionals placed more emphasis on the physical layout of the ICU. Nurses and healthcare professionals focused on the physical aspects which were of less concern to the family members. The family members appeared to merely want privacy with their loved one. The greatest gap that exists between the current and ideal ICU is around privacy for family members and patients.

Ideal perceptions of environment: care environment

Ideal perceptions of the care environment as part of family-centred care was perceived by *nurses* to be family respecting nursing staff, keeping relationships professional, showing empathy towards family members, welcoming family members into the unit, nurses introducing themselves to the family, determining the needs of family members and being present at the patient’s bedside. *Healthcare professionals* perceived the ideal care environment as being a welcoming environment for family members, with competent staff who are more visible at the bedside. *Family members* viewed the ideal care environment as having competent staff who care for their loved one, have been trained to care for the family members and show empathy towards family members.

In summary, nurses and healthcare professionals concur on aspects around the ideal care environment; however, this is not being translated into practice, since family members do not perceive what they are proposing to be in place. Nurses and healthcare professionals need to be trained in dealing with family members, there needs to be more nurse presence at the bedside during visiting hours and family members need to be shown empathy. These are the gaps that exist between the current and ideal care environment in the ICU.

Ideal perceptions of environment: patient environment

Ideal perceptions of family-centred care relating to patient environment were of high importance to family members and of equal importance to nurses and healthcare professionals. *Nurses* perceived the ideal ICU environment as an environment that ensures patient comfort and is a place where the patient’s basic needs are met. *Healthcare professionals* perceived it *as* an environment where there is a radio, television and cellphone for the patient, as well as a wifi that works. *Family members* perceived the ideal patient environment as one where there is a television or some form of entertainment for the patient.

In summary, family members and healthcare professionals have similar views around the patient environment. The nurses do not view patient entertainment or electronic devices as part of the patient environment. Nurses tend to be more skills-focused and perhaps view the patient as too ill for electronic devices, or perhaps they are afraid of theft or damage to the devices. There is a gap that exists between the current and ideal patient environment due to lack of electronic devices for the purpose of patient entertainment.

Ideal perceptions of environment: family environment

Ideal perceptions of family-centred care related to family environment were of the highest priority to family members, followed by healthcare professionals and then nurses. *Nurses* perceived the ideal family environment as being a proper environment for family members with refreshments and adequate restroom facilities. *Healthcare professionals* perceived it as an environment where family can relax outside of visiting hours, a friendlier more comfortable waiting area for family members which includes more chairs and facilities where they can make tea or coffee. Healthcare professionals also perceived a need for comfortable seating at the patient’s bedside. The ideal family environment was perceived by *family members* as having a lounger or comfortable chair to sit on next to the patient’s bedside, more chairs in the waiting area and an adequate rest area for family members where refreshments are available.

Nurses, healthcare professionals and family members tend to agree on aspects regarding the ideal family environment in the ICU. A gap exists between what the family environment is currently like and what the ideal would be. There is room for improvement regarding facilities for family members.

5.4.2.1 Implications

The researcher identified the following implications for practice to improve the ICU environment for family members and patients:

- Stakeholders in family-centred care could identify cost-effective ways to improve the layout of the ICU to ensure a more family-friendly environment.
- Stakeholders could work collaboratively in identifying a private area that could be utilized for the family member who is emotionally upset and where nurses and healthcare professionals could have conversations with family members in private.
- Stakeholders could work collaboratively in identifying strategies to introduce natural lighting into the unit, allowing the patient to have a view of the outdoors, thus enhancing time and space orientation.

- Healthcare professionals should work together to reduce noise levels in the unit.
- Inconsistencies in perceptions of the care environment need to be addressed in order to improve family-centred care.
- Nurses and healthcare professionals should work collaboratively to form strategies to ensure family members are welcomed by friendly staff in the unit.
- Issues around nurse competency should be addressed, problems identified and nurse training offered to address the issues.
- Stakeholders in the ICU should work collaboratively to identify strategies to introduce patient entertainment devices in the unit, where the acuity and condition of the patient allow it.
- Nurses and healthcare professionals should collaborate with hospital management to improve waiting areas for family members, adopting strategies such as providing more and comfortable seating and having an area where family members can get refreshments.

5.4.3 Theme 3: Continuum of feelings

Continuum of feelings was the third theme that emerged amongst nurses and family members. No healthcare professionals mentioned the continuum of feelings. Continuum of feelings was of a higher priority to nurses than to family members.

Current perceptions of continuum of feelings: current feelings

Sixteen per cent (16%) of nurses and 11 % of family members wrote down free associations related to the continuum of feelings. *Current* perceptions of the continuum of feelings amongst *nurses* included emotions that family members have when their loved one is admitted to the ICU. These emotions included feelings of sadness, stress, anger, anxiety, fear, uncertainty and hopefulness. Current perceptions of the continuum of feelings amongst *family members* included emotions that they as family members felt whilst their loved one was in the ICU. These emotions included feelings of anxiety, trauma, loneliness, stress, helplessness, uncertainty and relief when receiving positive news.

Nurses and family members share the same perceptions around what a family may be experiencing when a loved one is admitted in the ICU and recognize the emotional turmoil that a family goes through. Healthcare professionals did not write down free associations related to the continuum of feelings. An awareness of the emotional turmoil felt by family members is important to be able to support family members in the ICU. No free associations related to the continuum of feelings were mentioned with regard to the ideal family-centred care environment.

5.4.3.1 Implications

The researcher identified the following implications for practice to improve the family experience of family members in the ICU:

- Nurses and healthcare professionals need to be mindful of the emotional turmoil experienced by family members in order to best support them.

5.4.4 Theme 4: Reflections

Reflections was the third theme that emerged amongst nurses, healthcare professionals and family members when asked to describe current and ideal family-centred care in the ICU. Reflections refer to nurses', healthcare professionals' and family members' *current* views on family-centred care, the factors that may influence family-centred care and family involvement in the care of patients.

Reflections was further divided into four subthemes, namely current perceptions, nurse dependency, expectations and family involvement.

Reflections on current family-centred care

Eleven per cent (11%) of nurses, 22% of healthcare professionals and 16% of family members wrote down free associations related to reflections as they currently are. Current perceptions and family involvement were ranked as equally important by nurses, followed by expectations. Family involvement was ranked as most important by healthcare professionals, followed by current perceptions and expectations. Current perceptions were ranked as most important by family members, followed by family involvement and nurse dependency.

Reflecting on current family centred-care: current perceptions

Current perceptions were the first subtheme identified under reflections. Nurses, healthcare professionals and family members reflected on current perceptions of family-centred care in the ICU. *Nurses'* reflections on current perceptions of family-centred care revealed that family members are of high priority, although some family members place pressure on nurses and are demanding. *Healthcare professionals'* reflected that family-centred care is not always possible in the ICU and that some healthcare professionals do not usually interact with family members. One healthcare professional believes that family-centred care is currently good. *Family members'* reflections on current perceptions of family-centred care revealed that some family members feel that the family-centred care is very good and that they had a positive experience. On the other hand, some family members felt that family-centred care does not exist, that the family is completely neglected and ignored and that they feel like they are intruding.

In summary, nurses view family-centred care as important although family members can be demanding and place added pressure on nurses. *Healthcare professionals* have conflicting views, some believing it to be good the way it currently is and others believing that family-centred care is not possible. These conflicting opinions are reflected in the contrasting perceptions of *family members*, some family members having had a positive experience and others believing that family-centred care does not exist and that family members are neglected. Conflicting perceptions around family-centred care need to be addressed to address the inconsistencies.

Reflections on current family-centred care: nurse dependency

The second subtheme identified under reflections was nurse dependency. *Current* perceptions of family-centred care related to nurse dependency were that it was of higher importance to family members than to healthcare professionals. *Nurses* did not perceive nurse dependency as being an important factor for family-centred care. Neither nurses, nor healthcare professionals nor family members regarded nurse dependency as part of ideal family-centred care. *Healthcare professionals* perceived family-centred care to be dependent on the nurse looking after the patient. *Family members* were in agreement with healthcare professionals that family-centred care consisted of being dependent on the nurse looking after the patient, and they went on to add that some nurses provided a positive experience whilst others provided a negative experience.

Nurse dependency is in keeping with the previous inconsistencies identified. A family member's experience is influenced by the nurse whom they encounter at the bedside. Individual nurses who provide a negative experience need to be identified and trained on how to support the family member/s visiting patients in the ICU. Nurses who provide a positive experience should be applied to mentor those who are not equipped to deal adequately with family members.

Reflections on current family-centred care: expectations

Expectations was the third subtheme identified under reflections. Expectations influencing family-centred care were of higher priority to healthcare professionals than to nurses. Family members did not mention expectations when reflecting on current family-centred care in the ICU. When asked to describe *ideal* family-centred care in the ICU, neither nurses nor healthcare professionals nor family members mentioned expectations. *Nurses* perceived that some family members have false hope and unrealistic expectations. Dealing with family members is sometimes challenging, when they expect miracles and have false hope. *Healthcare professionals* revealed that some family members have unrealistic expectations; they express disbelief and doubt towards healthcare professionals, they have false perceptions of the severity of the patient's illness and this leads to false hope.

In summary, findings around expectations from family members were the same for nurses and family members. Linking back to communication, perhaps if consistent, honest, comprehensive information was provided to the family members, there would be fewer unrealistic expectations around the prognosis of the patient.

Reflections on current family-centred care: family involvement

The last theme that was identified under reflections was family involvement in the ICU. *Current* perceptions of family-centred care in the ICU related to family involvement were of higher importance to healthcare professionals, followed by nurses and then family members. *Nurses* perceived family members to be involved in patient care currently and felt that the ICU was open to family members being involved in care. According to the nurses, family members are involved in providing a family history in order to know the patient better. Some nurses believe that engaging with the family makes the nurse's job easier as they can help to reduce the patient's anxiety. *Healthcare professionals* revealed that family members provide valuable information on the patient and that they need to be involved in end-of-life decision-making. According to the healthcare professionals, family members are involved in patient care, they should be incorporated into the care plan of the patient and they can help to calm the disorientated patient. *Family members* had a different perception. They stated that they were not allowed to be involved in patient care, that no participation was encouraged and that family members only provided information about the patient.

In summary, nurses and healthcare professionals believed that family members were currently involved in caring for the patient. Family members felt that they were not allowed to be involved and were not given the opportunity to do so. There is a gap that exists between what the nurses and healthcare professionals perceive and what the family members perceive.

Reflections on ideal family-centred care

Fourteen per cent (14%) of nurses, 6% of healthcare professionals and 2% of family members wrote down free associations related to reflections on ideal family-centred care. Nurses ranked family involvement as the most important priority when it came to reflecting on ideal family-centred care. Healthcare professionals ranked family involvement as most important followed by expectations. Family members also ranked family involvement as most important.

Reflecting on ideal family centred-care: current perceptions

Only one nurse reflected on a perception of what *ideal* family-centred care should look like. This *nurse's* reflection on *ideal* family-centred care is that family members are of high importance. No healthcare professional or family member wrote down free associations related to reflections on ideal family-centered care in the ICU.

Reflecting on ideal family centred-care: family involvement

Ideal perceptions of family-centred care in the ICU related to family involvement were of higher importance to nurses, followed by healthcare professionals and then family members. *Nurses* perceived ideal family involvement as family members being incorporated into decision-making and family members being allowed to participate in patient care. *Healthcare professionals* revealed that ideal family-centred care would mean an ICU where family members are involved in decision-making and patient care. *Family members* perceived it would mean an ICU where family members are able to be involved in nursing care and where staff asks more questions about the patient regarding who he/she was as a person before being admitted to the ICU.

In summary, nurses, healthcare professionals and family members have consistent views around family involvement in the ICU. There is a gap in translating this into practice though. When comparing the current versus the ideal ICU environment around family involvement, nurses and healthcare professionals believe that family members are involved in patient care, while family members perceive that they are not allowed or given the opportunity to be involved in patient care.

5.4.4.1 Implications

The researcher identified the following implications for practice, based on the reflections of nurses, healthcare professionals and family members:

- Nurses and healthcare professionals need to be mindful of the emotional turmoil that family members go through when their loved one is admitted to ICU, in order to help family members and be more willing to engage and support them.
- Current perceptions around family-centred care are inconsistent. Inconsistencies need to be recognized and the gaps identified in order to collaboratively address these inconsistencies.
- Family-centred care being dependent on the nurse working with the patient needs to be addressed to address inconsistencies. Individual nurses who are a detriment to family-centred care need to be identified and adequately trained and mentored into supporting family members.
- Unrealistic expectations by family members need to be addressed through proper communication and engagement with the family members in the ICU.
- Inconsistencies around family involvement need to be addressed. Stakeholders in family-centred care could work collaboratively on strategies to involve family members in patient care. Policies could to be put into place to ensure unity and structure with regard to family involvement in patient care.

5.4.5 Spiritual Care

The last theme that was identified was spiritual care.

Current perceptions: spiritual care

Current perceptions of family-centred care in the ICU relating to spiritual care were of importance to family members. *Nurses* and *healthcare professionals* did not regard spiritual care as an important aspect of family-centred care. One per cent (1%) of family members wrote down free associations related to the current spiritual care in the ICU. *Family members* perceived that they had freedom to pray for their family members in the ICU.

Although only 1% of family members wrote down free associations related to spiritual care, this is perhaps something that is overlooked by nurses and healthcare professionals in the ICU.

Ideal perceptions: spiritual care

Ideal perceptions of family-centred care in the ICU relating to spiritual care were of higher importance to family members, followed by nurses. Healthcare professionals did not regard spiritual care as an important component of ideal family-centred care; 1 % of nurses and 9% of family members wrote down free associations related to spiritual care in the ideal ICU.
Nurses perceived ideal family-centred care as an ICU where family members are able to practice their religion. *Family members* revealed that ideal family-centred care would mean an ICU where pastors or spiritual leaders would come and pray for the patients every day and a facility where family members could pray for their loved ones.

In summary, nurses and family members recognized spiritual need as an important component in family-centred care. Family members placed more emphasis on spiritual care than nurses. *Healthcare professionals* did not regard this as an important component of family-centred care. A gap exists and this is an area that needs to be managed when looking into family-centred care practices.

5.4.5.1 Implications

The researcher identified the following implications for practice to improve spiritual care provided for family members in the ICU:

- Nurses and healthcare professionals could address the patients' and family members' spiritual needs, they could respect the family members' and patients' spiritual needs and they could refer pastors or spiritual leaders to them when needed.

5.5 LIMITATIONS

The study addressed questions around family-centred care as perceived by nurses, healthcare professionals and family members in a selected intensive care unit. This was done by means of associative group analysis to identify potential gaps that may exist in an attempt to improve family-centred care practices. Nevertheless, owing to the nature of the study there were some limitations. The responses given by the research participants may have been influenced by the circumstances on the day that the data was collected. Responses may differ for the family member who has a patient admitted for a short time period as opposed to one for a longer period of time. Data may also differ depending on how critical the patient is.

It was often difficult to set up appointments with the doctors and family members. Associative group analysis has its limitations as a research method. Whether responses were positive or negative was not indicated in the data interpretation, research participants moved away from using key words and most wrote only sentences. Some research participants had difficulty thinking of something to write down in such a short time period and many research participants had a lot of extra input to give after the answer cards had been collected, indicating that more comprehensive data may have been collected if they had been given the opportunity to elaborate more. The issues encountered regarding the participants' responses may have been the result of English not being the participants' first language.

5.6 ADDITIONAL IMPLICATIONS

Based on the research findings, the researcher suggests the following additional implications related to family-centred care in the ICU. These implications relate to practice, education, management and future research.

5.6.1 Practice

- The findings of this study could be shared with nurses and healthcare professionals involved in family-centred care in the relevant ICU. This may raise awareness on the current and ideal perceptions of family-centred care in the unit. Once nurses and healthcare professionals are aware of the perceptions and the gaps that exist regarding family-centred care, they may be more open to collaboration in trying to improve family-centred care.
- Nurses, healthcare professionals and family members could be given an opportunity to sit together, discuss and reach a consensus on strategies that could be implemented to improve family-centred care in the unit.
- Once strategies to improve family-centred care have been identified, there needs to be a collaborative effort in implementing them.
- Family-centred care should be re-evaluated on a continuous basis in order to provide feedback on the findings and re-examine or adapt implementation strategies where needed, in order to optimize family-centred care in the unit.

5.6.2 Education

- Institutions involved in the training of nurses and healthcare professionals should introduce principles of family-centred care into their training programs.
- Educators should examine and evaluate nurses’ and healthcare professionals’ competency in interacting with family members.
- Educators should include the family members as part of holistic patient care.
- In-service training programs should include family-centred care practices and methods to support family members.

5.6.3 Management

- Hospital management should collaborate with the ICU nurses and healthcare professionals in order to draw up policies related to family-centred care practices.
- Hospital management should regularly engage with family members in the ICU to determine their satisfaction with the care provided and provide feedback to nurses and healthcare professionals.
- Hospital management should regularly engage with nurses and healthcare professionals to identify challenges around family-centred care and work collaboratively to come up with strategies to improve family-centred care.

5.6.4 Future Research

Furture research should include the following:

- Collaboratively compiling a policy for visiting hours in the ICU.
- Collaboratively compiling strategies to improve communication amongst the multi-disciplinary team in the ICU.
- Exploring the spiritual needs of family members in the ICU.
- Exploring the needs of family members of long-term patients versus short term patients.
- Identifying how the family member’s environment in the ICU influences their satisfaction with family-centred care.
- Collaboratively compiling strategies to include family members in caring for the patient in the ICU.

5.7 PERSONAL REFLECTION

Starting off on this journey, I knew it would be tough, but I did not realize how tough. Completing this study is the most challenging and rewarding task I have ever undertaken in my entire life. I wanted to give up many times and was frustrated along the way. Completing this study has taught me many life lessons; every piece of feedback, constructive criticism and encouragement along the way made me stronger and gave me the willpower and motivation to continue. I realized early on that embarking on this study is like running a marathon and not a sprint. I was mindful that every word typed, much like every kilometer run, is one step closer to the final stretch. Much like the aches and pains experienced towards the end of a marathon when one is so close to the end yet it feels so far, it is imperative to just keep pushing through and eventually that finish line is reached.

In my nursing career family members have always tugged at my heartstrings, and now even more so after having had a personal experience where one of my family members was admitted to the ICU. It made me realize how fear of the unknown is all-consuming and almost suffocating. One hangs on to every piece of information and update that you get. Interaction with healthcare professionals as a family member can either give you peace of mind or add fuel to the fear that engulfs you.

At the start of my research journey I knew there was a gap in how nurses dealt with family members in the ICU and how the family members desired to be dealt with. I realised that my research topic would be around caring for the family members in the ICU. After reading many articles, it became clear that this problem was not unique; there are challenges around supporting family members in the ICU, both nationally and internationally. Family-centred care is a well-researched area; yet gaps still exist. It became clear that there were issues in implementing family-centred care and that inconsistencies exist amongst professionals in understanding family-centred care. At first, navigating my way through the thousands of research articles was challenging and incredibly time-consuming, but it eventually became natural and I developed skills in deciphering the different research methods used and was quickly able to establish whether articles would be applicable and add value to my research study. As I became what felt like an expert in the field of family-centred care, it was nice to be able to relate the findings to my study. I now feel a sense of obligation every time I see a family member in the ICU, as I know we can do so much more to support them. I notice myself watching the interactions between family members and healthcare professionals with a watchful and critical eye.

During my data analysis I came to realize that different people view family-centred care differently. Themes that emerged as important to individuals were not necessarily what I had assumed as being most important. I was also taken aback in realising how individuals in the same ICU could have such completely opposing viewpoints. During data analysis I became aware of the fact that there are struggles and challenges that nurses and healthcare professionals face that are often out of their control when it comes to family-centred care. I enjoyed the opportunity to connect with the research participants and believe that they also enjoyed a moment to reflect and give their input in a safe, non-judgmental space. Asking research participants for their perceptions of the ideal family-centred care environment, I believe gave them an opportunity to contemplate what could be. I perceived that the majority of research participants welcomed the data collection process, which confirmed to me that my topic was relevant. It is my hope that my research study will improve family-centred care practices in the ICU.

I learnt that there are a number of gaps that need to be addressed when it comes to supporting family members, but there is also a lot of hope in the little things. Family members do not need a lot; they just want the basics of human caring and compassion when it feels as though their lives have been turned upside down.

In general I have gained so much knowledge around research methodology and the research process through this journey. I not only read an article now, but critically analyze it. Through my research I have developed a new mind of enquiry, not accepting everything that is said in practice as the gold standard, but rather wishing to know what the evidence says to support such practices. Reaching the final chapter in my research project gave me a great sense of relief, but more importantly I was humbled by the experience and proud that I had come so far. I am proud to think that my research may be used by other researchers in future and that I have made a small contribution to family-centred care. I feel that, if this study could lighten the load and provide comfort and support to just one family member, then I have done my part. However, my dream is that its impact goes beyond that and that my research has a ripple effect that extends from this one ICU into many.

5.8 SUMMARY

This study was presented in five chapters. In chapter 1 an orientation to the study was provided. It focused on the problem statement and provided background information in support of its formulation.

In chapter 2 an in-depth literature review was presented with a historical overview. A definition of family-centred care, the importance of family-centred care and requirements for implementing family-centred care were discussed. The literature presented findings on family-centred care from national and international studies. These findings were used to underpin the research done for this study.

Chapter 3 provided an overview of the research design and the methodology used to address the research questions of the study. The quali-quanti research design utilized in this study and the data collection method of structured interviews, using associative group analysis, were also discussed. The population, the sample and the data analysis methods were described. In addition, the specific strategies implemented to enhance rigour were explained and summarized.

In chapter 4 the research findings were presented. The themes, subthemes and categories extracted from the data were reported on, with reference to literature that supported the discussions. Themes, subthemes and categories were presented in figures that allowed for easy interpretation and comparison. The predominant themes identified were communication, environment, continuum of feelings, reflections and spiritual care. Differences in the current and ideal perceptions of family-centred care amongst nurses, healthcare professionals and family members were presented in semantographs. The main variances that exist regarding current and ideal family-centred care in the ICU amongst nurses, healthcare professionals and family members were communication, environment and spiritual care. These findings were presented in a semantograph to easily visualize where there are gaps.

Chapter 5 provided an overview of the conclusions and implications related to the identified themes and subthemes. The limitations of the study were noted and suggestions for future research opportunities were proposed. The chapter concluded with a personal reflection on the study by the researcher.

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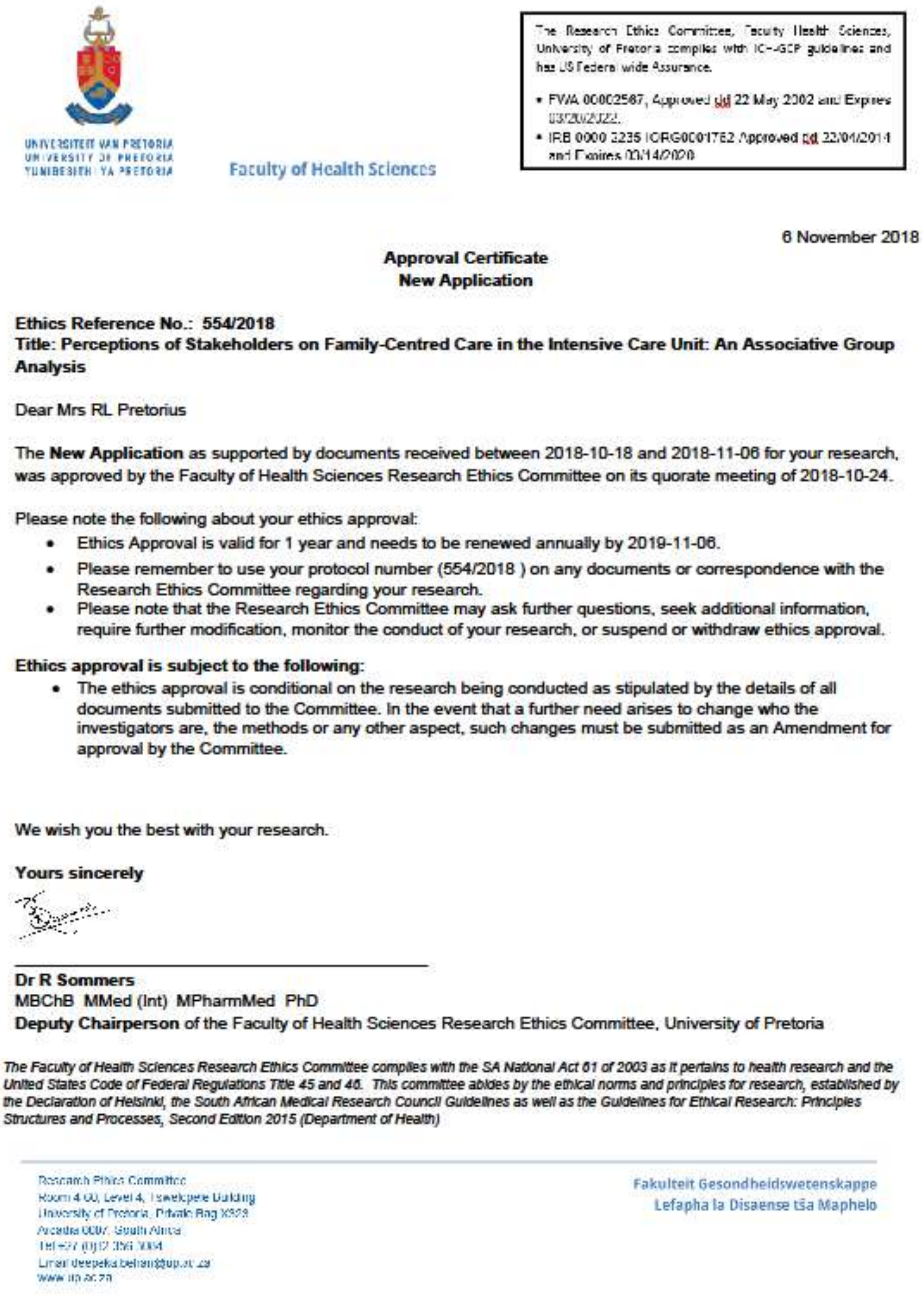
ANNEXURE A1

FACULTY OF HEALTH SCIENCES, UNIVERSITY OF PRETORIA: ETHICAL APPROVAL



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- FWA 00002567, Approved dd 22 May 2002 and Expires 03/20/2022.
- IRB 0000 2235 IORG0001762 Approved dd 22/04/2014 and Expires 03/14/2020.

6 November 2018

Approval Certificate
New Application

Ethics Reference No.: 554/2018
Title: Perceptions of Stakeholders on Family-Centred Care in the Intensive Care Unit: An Associative Group Analysis

Dear Mrs RL Pretorius

The **New Application** as supported by documents received between 2018-10-18 and 2018-11-06 for your research, was approved by the Faculty of Health Sciences Research Ethics Committee on its quorate meeting of 2018-10-24.

Please note the following about your ethics approval:

- Ethics Approval is valid for 1 year and needs to be renewed annually by 2019-11-06.
- Please remember to use your protocol number (554/2018) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, monitor the conduct of your research, or suspend or withdraw ethics approval.

Ethics approval is subject to the following:

- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

We wish you the best with your research.

Yours sincerely

Dr R Sommers
MBChB MMed (Int) MPharmMed PhD
Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health)

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Fakulteit Gesondheidswetenskappe
Lefapha la Disaense tša Maphelo

ANNEXURE A2

THE HOSPITAL GROUP:
ETHICS APPROVAL LETTER

[redacted]

[redacted]

National Health Research Ethics Committee registration: **REC 251015-048**

REF: 20181128C

04 December 2018

Dear Rachele Pretorius

RE: APPLICATION TO CONDUCT RESEARCH:

Title of study: Perceptions of Stakeholders on Family-Centred Care in the Intensive Care Unit: An Associative Group Analysis

The Human Research Ethics Committee of [redacted] hereby grants permission with no conditions for your study to be conducted at [redacted]

General conditions:

1. If patient or institutional confidentiality is breached, [redacted] is entitled to withdraw this permission immediately. The Higher Education institution under which the research is taking place will be notified and legal action may follow. If the research is part of a non-degree research project, Life Healthcare reserves the right to take legal action against you, should the company feel that this is warranted.
2. An electronic copy of the research report must be submitted to the [redacted] Ethics Committee prior to publication. For students, failure to do this may result in permission to continue to examination being withdrawn. The Higher Learning institution and/ or external sponsor will be notified of this withdrawal. For non-degree research projects, failure to provide an electronic copy of the research report prior to publication will result in immediate withdrawal of ethical clearance to utilise information gathered within Life Healthcare Group.
3. No direct reference may be made to [redacted] its subsidiaries or any of its facilities or institutions in the research report or any publications thereafter. The Company and its facilities, patients and staff must be de-identified in the study, and remain so for any other studies which may utilise this information.
4. The research must be completed within the time allotted by the Higher Learning institution. If the research is being done in an individual capacity by an employee of the [redacted], the research must be conducted within one year of permission being given by the Company, OR the proposed time period must be specified in the proposal, and approved. Permission may be withdrawn if the research extends beyond the approved time period.
5. [redacted] will not take responsibility for any unforeseen circumstances within its institutions which may materially change the context and potential outcomes of the research. Should this occur, the principal researcher will be required to make alternative arrangements to conduct their research. Reapplication may be required if the conditions outlined in the proposal require amendment. Students doing research for degree purposes should approach their Higher Learning institution for guidance around alternatives.
6. After completion of the research, a copy of the electronic research report and any publications will be placed on the Company's research register and will be made available to [redacted] This research report will be held for a period of 10 years, whereupon it will be removed from access and archived in the Company's digital storage system.
7. [redacted] will not be liable for any costs incurred during or related to this study.

Yours sincerely,

[redacted]

On behalf of the Research & Scientific Committee

[redacted]

ANNEXURE B1

PERMISSION LETTER:
HOSPITAL MANAGER

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Denkleiers • Leading Minds • Dikgopolo tša Dihlalefi

Navrae / Enquiries:
☎ : (012) 354-2125
🖷 : (012) 354-1490
💻 : tanya.heyns@up.ac.za

Private Bag X323 ARCADIA 0007 Pretoria – Republic of South Africa
Web: https://www.up.ac.za Tel: (012) 354-2125
Fax: (012) 354-1490

Permission to conduct research at [redacted]

[redacted]Hospital Manager)

Re: Permission to do research

TITLE OF STUDY: Perceptions of Stakeholders on Family-Centred Care in the Intensive Care Unit: An Associative Group Analysis.

The request is lodged with you in terms of the requirements of the Promotion of Access to Information Act. No. 2 of 2000.

I am a masters student at the University of Pretoria, Nursing Department. I am working with Professor Tanya Heyns and herewith request permission, on behalf of us all to conduct a study on the above topic on your hospital grounds. The study involves access to patient files, record books and data bases.

I worked as a Clinical Training Specialist, at [redacted] from August 2015-June 2018, so I am familiar with the staff and surroundings. The study is contextual so therefore will be confined to the General Intensive Care Unit.

The researcher intends to collect data through short interviews with nursing staff, doctors, dieticians, physiotherapists and family members in the General ICU. Interviews will take approximately 15 minutes and will only be conducted once participants have agreed to do so and have signed informed consent.

The researcher will ensure [redacted] is protected ethically and legally by ensuring the following considerations when conducting the study at its facilities: Ethical Approval has been granted from the University of Pretoria's Ethics committee as well as [redacted] research committee. The researcher will adhere strictly to the 3 principles on which ethical conduct are based as outlined in the Belmont report. The 3 principles are: beneficence, respect for human dignity and justice, privacy and equal chance to participate. The researcher will conduct herself in a professional manner and shall not

act in a manner which in anyway negatively impacts the reputation of the facility where the research will be conducted. The researcher will provide feedback on research findings once study is complete.

We intend to publish the findings of the study in a professional journal and/ or at professional meeting like symposia, congresses, or other meetings of such a nature.

We intend to protect the personal identity of all the participants.

Yours sincerely

Signature of the Principle Investigator
R.L Pretorius

Permission to do the research study at this hospital and to access the information as requested.

Title and Name of Hospital Manager: [redacted]

Name of Hospital: [redacted]

Signature: [redacted]

Date: 14/12/2018

[redacted]

ANNEXURE B2

PERMISSION LETTER:
NURSE MANAGER

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
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☎ : (012) 354-2125
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💻 : tanya.heyns@up.ac.za

Private Bag X323 ARCADIA 0007 Pretoria –
Republic of South Africa
Web: https://www.up.ac.za Tel: (012) 354-2125
Fax: (012) 354-1490

Permission to conduct research at [redacted]

[redacted]

Re: Permission to do research

TITLE OF STUDY: Perceptions of Stakeholders on Family-Centred Care in the Intensive Care Unit: An Associative Group Analysis.

The request is lodged with you in terms of the requirements of the Promotion of Access to Information Act. No. 2 of 2000.

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We intend to publish the findings of the study in a professional journal and/ or at professional meeting like symposia, congresses, or other meetings of such a nature.

We intend to protect the personal identity of all the participants.

Yours sincerely

Signature of the Principle Investigator
R.L Pretorius

Permission to do the research study at this hospital and to access the information as requested.

Title and Name of Nurse Manager: [redacted]

Name of Hospital: [redacted] hospital

Signature: [redacted]

Date: 14/12/2018

[redacted]

ANNEXURE B3

PERMISSION LETTER:
ICU UNIT MANAGER

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
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Navrae / Enquiries:
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💻 : tanya.heyns@up.ac.za

Private Bag X323 ARCADIA 0007 Pretoria –
Republic of South Africa
Web: https://www.up.ac.za Tel: (012) 354-2125
Fax: (012) 354-1490

Permission to conduct research at [redacted]

[redacted]

Re: Permission to do research

TITLE OF STUDY: Perceptions of Stakeholders on Family-Centred Care in the Intensive Care Unit: An Associative Group Analysis.

The request is lodged with you in terms of the requirements of the Promotion of Access to Information Act. No. 2 of 2000.

I am a masters student at the University of Pretoria, Nursing Department. I am working with Professor Tanya Heyns and herewith request permission, on behalf of us all to conduct a study on the above topic on your hospital grounds. The study involves access to patient files, record books and data bases.

I worked as a Clinical Training Specialist, at [redacted] from August 2015-June 2018, so I am familiar with the staff and surroundings. The study is contextual so therefore will be confined to the General Intensive Care Unit.

The researcher intends to collect data through short interviews with nursing staff, doctors, dieticians, physiotherapists and family members in the General ICU. Interviews will take approximately 15 minutes and will only be conducted once participants have agreed to do so and have signed informed consent.

The researcher will ensure [redacted] is protected ethically and legally by ensuring the following considerations when conducting the study at its facilities: Ethical Approval, has been granted from the University of Pretoria's Ethics committee as well as [redacted] [redacted] research committee. The researcher will adhere strictly to the 3 principles on which ethical conduct are based as outlined in the Belmont report. The 3 principles are: beneficence, respect for human dignity and justice, privacy and equal chance to participate. The researcher will conduct herself in a professional manner and shall not

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We intend to publish the findings of the study in a professional journal and/ or at professional meeting like symposia, congresses, or other meetings of such a nature.

We intend to protect the personal identity of all the participants.

Yours sincerely

Signature of the Principle Investigator
R.L Pretorius

Permission to do the research study at this hospital and to access the information as requested.

Title and Name of Unit Manager: [redacted]

Name of Hospital: [redacted]

Signature: [redacted] Date: 18/12/18

[redacted]

ANNEXURE C

PARTICIPANT’S LEAFLET AND INFORMED CONSENT

PARTICIPANT'S INFORMATION & INFORMED CONSENT DOCUMENT

STUDY TITLE: Perceptions of Stakeholders on Family-Centred Care in the Intensive Care Unit: An Associative Group Analysis

Principal Investigators: Rachele Pretorius

Institution: University of Pretoria, Faculty of Health Sciences

DAYTIME AND AFTER HOURS TELEPHONE NUMBER(S):

Daytime numbers: 082 367 4944

Afterhours: 082 367 4944

DATE AND TIME OF FIRST INFORMED CONSENT DISCUSSION:

Day	**Month**	**Year**

:
Time

Dear potential research participant,

1) INTRODUCTION

You are invited to volunteer for a research study. This information leaflet is to help you to decide if you would like to participate. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this leaflet, do not hesitate to ask the investigator. You should not agree to take part unless you are completely happy about all the procedures involved.

2) THE NATURE AND PURPOSE OF THIS STUDY

You are invited to take part in a research study.

The aim of this study is to **explore the perceptions of stakeholders on family-centered care in the intensive care unit (ICU).**

3) EXPLANATION OF PROCEDURES TO BE FOLLOWED

This study involves answering two questions related to family-centered care in the ICU.

4) RISK AND DISCOMFORT INVOLVED.

The only possible risk and discomfort involved is time related, questions will take approximately 15 minutes in total.

5) POSSIBLE BENEFITS OF THIS STUDY.

Improving care to family members in the ICU.

6) I understand that I have the right to decline participation in the study.

7) I may at any time withdraw from this study.

8) HAS THE STUDY RECEIVED ETHICAL APPROVAL?

This Protocol was submitted to the Faculty of Health Sciences Research Ethics Committee, University of Pretoria, telephone numbers 012 356 3084 / 012 356 3085 and written approval has been granted by that committee. The study has been structured in accordance with the Declaration of Helsinki (last update: October 2013), which deals with the recommendations guiding doctors in biomedical research involving human/subjects. A copy of the Declaration may be obtained from the investigator should you wish to review it.

9) INFORMATION

If I have any questions concerning this study, I should contact:

Rachele Pretorius at *082 367 4944*

10) CONFIDENTIALITY

All records obtained whilst in this study will be regarded as confidential. Results will be published or presented in such a fashion that patients remain unidentifiable.

11) CONSENT TO PARTICIPATE IN THIS STUDY.

I have read or had read to me in a language that I understand the above information before signing this consent form. The content and meaning of this information have been explained to me. I have been given opportunity to ask questions and am satisfied that they have been answered satisfactorily. I understand that if I do not participate it will not alter my management in any way. I hereby volunteer to take part in this study.

I have received a signed copy of this informed consent agreement.

....	....
Participant name	Date

....	....
Participant signature	Date

……………………………………………… ………………………

Investigator's name Date

……………………………………………… ………………………

Investigator's signature Date

……………………………………… ………………………

Witness name and signature Date

VERBAL PATIENT INFORMED CONSENT (applicable when participants cannot read or write)

I, the undersigned, ……………………………………….…, have read and have explained fully to the patient, named ……………….. and/or his/her relative, the patient information leaflet, which has indicated the nature and purpose of the study in which I have asked the patient to participate. The explanation I have given has mentioned both the possible risks and benefits of the study and the alternative treatments available for his/her illness. The patient indicated that he/she understands that he/she will be free to withdraw from the study at any time for any reason and without jeopardizing his/her treatment.

I hereby certify that the patient has agreed to participate in this study.

Participants Name ___________________________

(Please print)

Participants Signature ____________________ Date _____________

Investigator's Name ____________________

(Please print)

Investigator's Signature ____________________ Date ______________

Witness's Name ___________________ Witness's Signature _______ Date ______________

(Please print)

(Witness - sign that he/she has witnessed the process of informed consent)

ANNEXURE D1

DEMOGRAPHIC DATA: NURSES AND OTHER HEALTHCARE PROVIDERS

Demographical information Nurses and Other Healthcare Professionals

Please provide us the following information, by indicating your option with a ***cross (x)*** and/or ***providing further information*** if required.

Gender	Male		Female	
How old are you today?				
Cultural Group	African		Coloured	
	Indian		White	
	Other			
Professional qualification	Medical doctor		Registered nurse	
	Physiotherapist		Enrolled Nurse	
	Dietician		Infection Prevention specialist	
Do you have additional post-graduate qualifications	Yes		No	
*If **yes**, please list your additional post-graduate qualifications*				
Years of experience working in the Intensive Care Environment				

Thank you!

ANNEXURE D2

DEMOGRAPHIC DATA:
FAMILY MEMBERS

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Denkleiers • Leading Minds • Dikgopolo tša Dihlalefi

Demographical information Family Members				
Please provide us the following information, by indicating your option with a ***cross (x)*** and/or ***providing further information*** if required.				
Gender	Male		Female	
How old are you today?				
Cultural Group	African		Coloured	
	Indian		White	
	Other			
Are you currently employed?	Yes		No	
If Yes, What line of work are you in?				
What is your current job title?				
How long has your family member been admitted in the ICU?	1-3 days		4 days to 7 days	
	1 – 2 weeks		2 – 6 weeks	
	More than 6 weeks		More than 2 months	
	3 – 6 months		More than 6 months	

Thank you!

ANNEXURE E1

INTERVIEW GUIDE AND RESPONSE CARDS: PILOT STUDY

Interview guide: Pilot Study

Question 1 to research participant:

Write down what comes to mind first when you think of the family-centered care in the ICU.

Question 2 to research participant:

Write down what comes to mind first when you think of the ideal family-centered care environment.

ANNEXURE E2

INTERVIEW GUIDE AND RESPONSE CARDS: PARENT STUDY

Interview guide

Question 1 instruction to participants:

I want you to take a moment and think about family members in GICU.

I am going to give you a piece of paper, I am then going to mention a concept. I want you to think about this concept as it is in GICU at the moment.

Is that clear? Do you have any questions?

Give the participant the paper and then state the concept "**FAMILY-CENTRED CARE**"

Question 1 to research participant:

Write down key words to describe family-centred care in GICU.

Question 2 instruction to participants:

Now I am going to ask you to do the same thing but think of the perfect world or ideal setting.

Question 2 to research participant:

Write down key words that come to your mind when you think of "IDEAL FAMILY-CENTRED CARE"

ANNEXURE E3

INTERVIEW GUIDE AND RESPONSE CARDS: PILOT STUDY

Participant response cards

Participant Code: ____ Question 1 Response ____ ____ ____ ____ ____ ____ ____ ____ ____

Participant Code: ___

Question 2 Response

ANNEXURE E4

INTERVIEW GUIDE AND RESPONSE CARDS: PARENT STUDY

Annexure E4: Participant response cards

Participant Code: ___

Question 1 Response

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________
5. ______________________________
6. ______________________________
7. ______________________________
8. ______________________________

Participant Code: ___

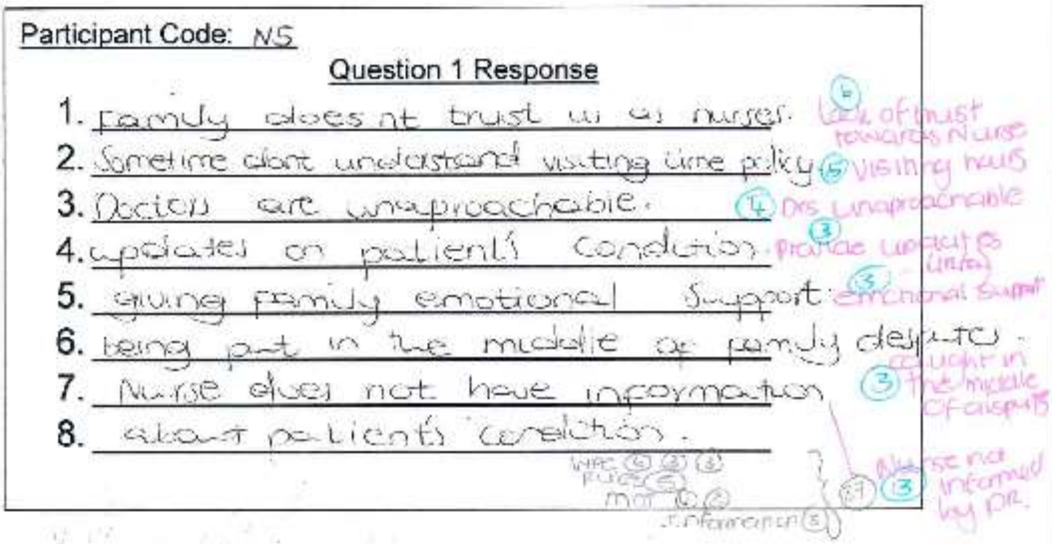
Question 2 Response

1. ______________________________
2. ______________________________
3. ______________________________
4. ______________________________
5. ______________________________
6. ______________________________
7. ______________________________
8. ______________________________

ANNEXURE F1

DATA COLLECTION AND WEIGHTING OF RESPONSES: EXAMPLE OF DATA FROM NURSES

Annexure B: Participant response cards

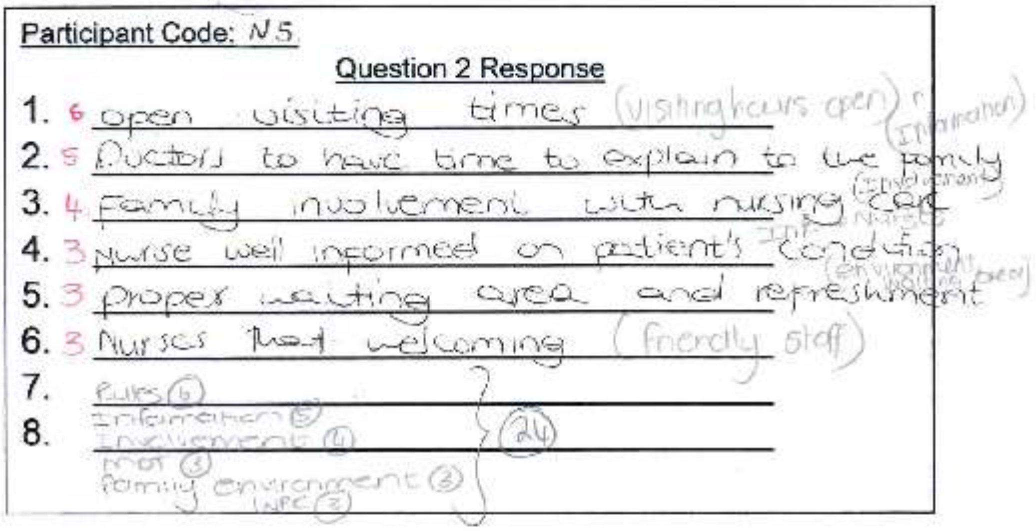


Participant Code: N5

Question 1 Response

1. family does nt trust us as nurses. ⑥ Lack of trust towards Nurse
2. Sometime dont understand visiting time policy ⑤ Visiting hours
3. Doctors are unaproachable. ④ Drs unapproachable
4. updates on patient's condition. ③ Practice updates (info)
5. giving family emotional support. ③ emotional support
6. being put in the middle of family disputes. ③ caught in the middle of disputes
7. Nurse does not have information ③ Nurse not informed by Dr.
8. about patient's condition.

WPC ⑥ ③ ③
Rules ⑤
MOT ④ ②
Information ⑤
㉗



Participant Code: N5

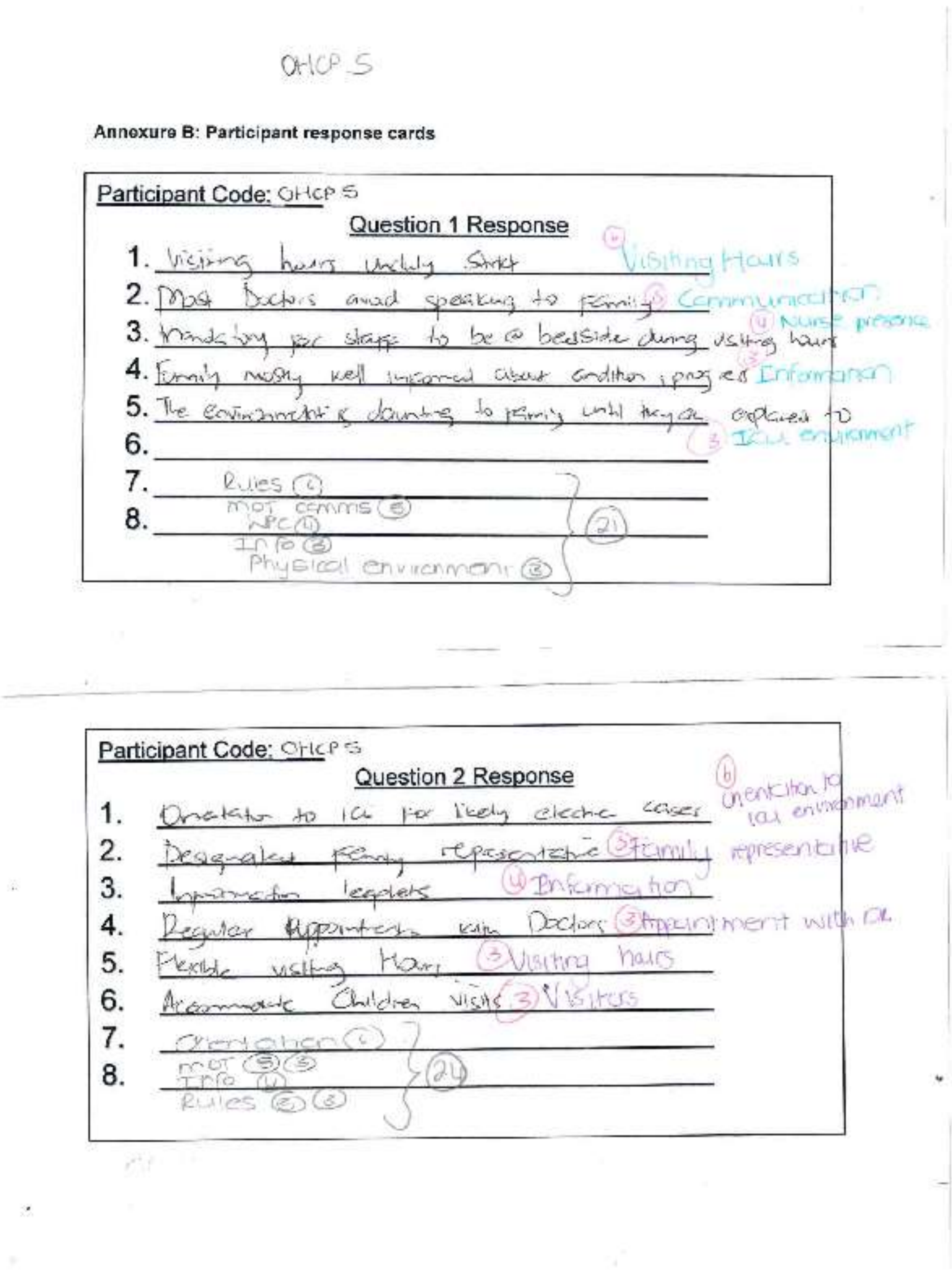
Question 2 Response

1. 6 open visiting times (visiting hours open)
2. 5 Doctors to have time to explain to the family (Information)
3. 4 family involvement with nursing care (Involvement)
4. 3 Nurse well informed on patient's condition Inf Nurses
5. 3 proper waiting area and refreshment (environment waiting area)
6. 3 Nurses that welcoming (friendly staff)
7.
8.

Rules ⑥
Information ⑤
Involvement ④
mot ③
family environment ③
WPC ②
㉔

ANNEXURE F2

DATA COLLECTION AND WEIGHTING OF RESPONSES: EXAMPLE OF DATA FROM OTHER HEALTHCARE PROFESSIONALS AND WEIGHTING



OHCP 5

Annexure B: Participant response cards

Participant Code: OHCP 5

Question 1 Response

1. Visiting hours unduly strict ⑥ Visiting Hours
2. Most Doctors avoid speaking to family ⑤ Communication
3. Mandatory for staff to be @ bedside during visiting hours ④ Nurse presence
4. Family mostly well informed about condition & progress ③ Information
5. The environment is daunting to family until they are explained to ③ ICU environment
6.
7.
8.

Rules ⑥
MOT comms ⑤
NPC ④
Info ③
Physical environment ③
㉑

Participant Code: OHCP 5

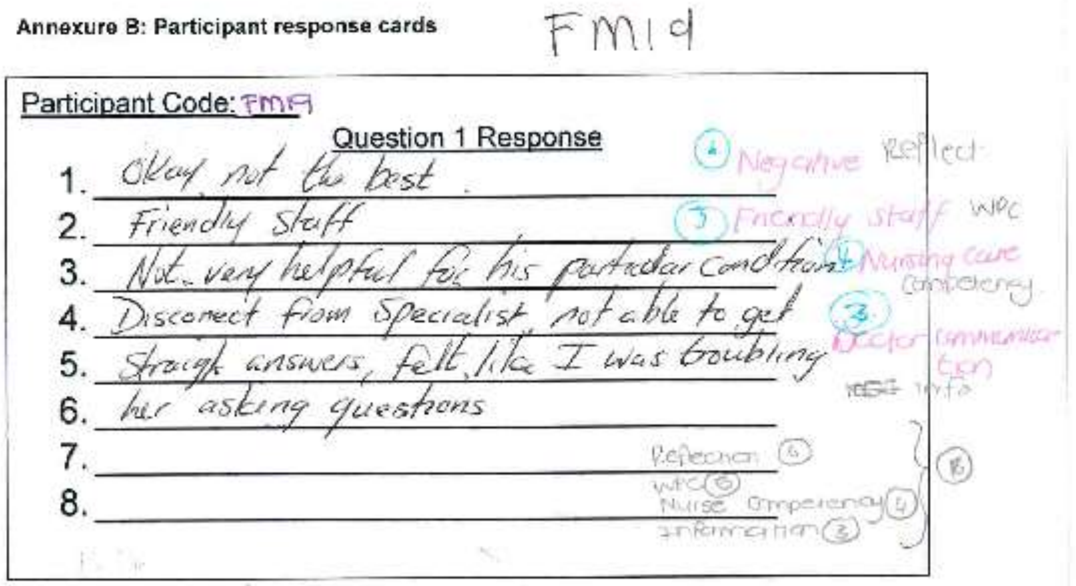
Question 2 Response

1. Orientation to ICU for likely elective cases ⑥ Orientation to ICU environment
2. Designated family representative ⑤ Family representative
3. Information leaflets ④ Information
4. Regular appointments with Doctors ③ Appointment with Dr
5. Flexible visiting hours ③ Visiting hours
6. Accommodate children visits ③ Visitors
7.
8.

Orientation ⑥
MOT ⑤ ③
Info ④
Rules ③ ③
㉔

ANNEXURE F3

DATA COLLECTION AND WEIGHTING OF RESPONSES: EXAMPLE OF DATA FROM FAMILY MEMBERS



Annexure B: Participant response cards FM19

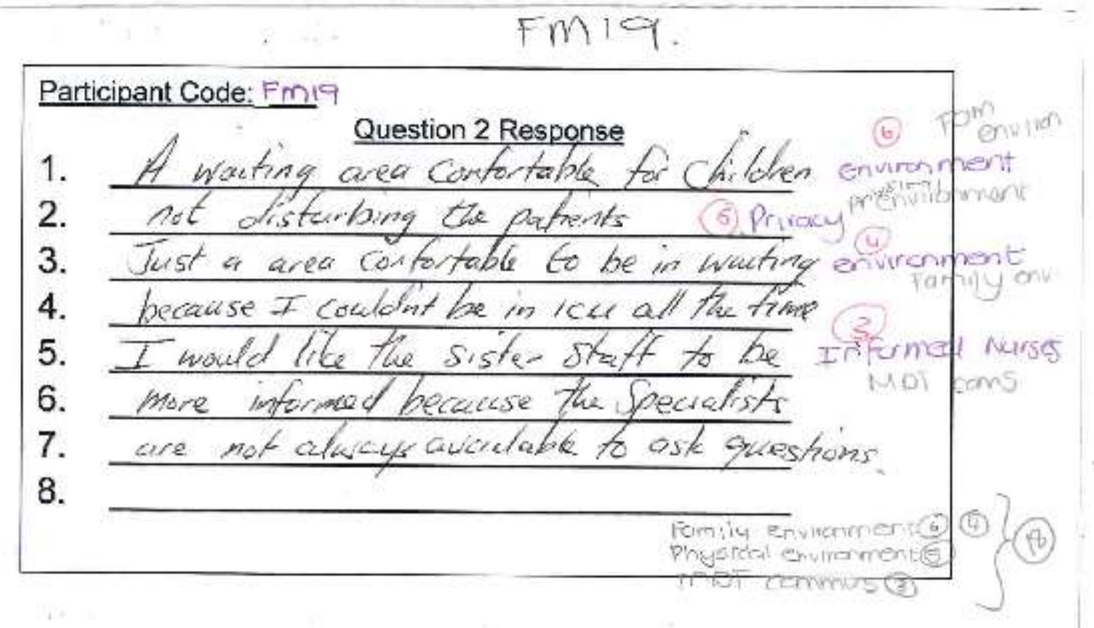
Participant Code: FM19

Question 1 Response

1. Okay not the best
2. Friendly Staff
3. Not very helpful for his particular condition
4. Disconect from Specialist, not able to get
5. Straigh answers, felt like I was troubling
6. her asking questions
7.
8.

① Negative Reflect
⑤ Friendly staff WPC
④ Nursing care Competency
③ Doctor communication info

Reflection ⑥
WPC ⑤
Nurse Competency ④
Information ③
⑱



FM19.

Participant Code: FM19

Question 2 Response

1. A waiting area confortable for children
2. not disturbing the patients
3. Just a area confortable to be in waiting
4. because I couldn't be in ICU all the time
5. I would like the sister staff to be
6. more informed because the Specialists
7. are not always avialable to ask questions
8.

⑥ environment Fam environ
⑤ Privacy physical environment
④ environment Family env
② Informed Nurses MDT coms

Family environment ⑥ ④
Physical environment ⑤
MDT commus ③
⑱

ANNEXURE G1

DATA ANALYSIS:

GROUPING TOGETHER OF SIMILAR RESPONSES

Family members (Question 1)

Communication	Information Communication Updates Education Lack of clear instructions
Orientation to ICU	Orientation to ICU environment Information on rules of ICU
Rules	Visiting hours Visiting time Number of visitors in ICU Children visiting ICU No consistency in implementing rules Strict rules Infection control
Negative	FCC viewed as non existent Not present Neglected FM regarded as a nuisance Lack of compassion
Nursing care	Nursing care Patient care Nurse presence Nurse competency Friendly/warm Professionalism Nurse dependent Knowledge of patient

Emotions experienced by family members	Take on multiple roles Uncertainty Relief Fearful Traumatic Loneliness Reflection Stressful Fearful Helplessness Soft touch/skin to skin contact
Electronics/Entertainment	Not allowed
ICU patient environment	Caring staff Professional Clean Noisy Cold Unfriendly
ICU Family environment	Waiting area Friendly staff Unwelcome Positive staff
Spiritual needs	Able to pray
Privacy	Given time with family member
Support	Support Sympathy

Question 2

Communication	Information Communication Updates Education Team meetings Point of contact for communication
Orientation to ICU	Orientation to ICU environment Information on rules of ICU Preparation on what to expect Point of contact Signage
Rules	Visiting hours Number of visitors in ICU Children visiting ICU Consistency with implementing rules Infection control Staff to also adhere to rules of infection control
Support	Support Empathy Listening Understanding Staff training on how to provide support
ICU patient environment	Quiet Clean Warm Patient is priority Positive staff
ICU family environment	Waiting area comfortable for children Comfortable chair next to the bed Comfortable waiting area Greeting Friendly Welcoming Family journey Coffee and tea facility for family

Electronics/Entertainment	Electronic update system Entertainment for patient
Privacy	Patient privacy
Spiritual Care	Pastor Prayer Pastoral care
Nursing care	Competent staff Informed nurses
Family involvement	Providing history of the patient

Nurses

Question 1

Support	Support Empathy Understanding
Communication	Information Communication Updates Education Doctors unapproachable Doctors unavailable
Increased workload	Demanding Overbearing Rude Pressure on staff Inquisitive Disruptive due to excessive phone calls Lack of trust
Appreciative	Appreciative Grateful
Emotions	Sad Distressed Stress Anger Cold Anxious Aggressive Uncertain Hopeful Fearful
Unrealistic expectations around pt prognosis	False hope Unrealistic expectations Lack of preparedness around prognosis
FCC is important	Important
Family involvement	Family involved Provide information

	Involved in patient care
Financial	Burden to family members
Family disputes	Nurses placed in the middle of family disputes
Nursing care	Lack of knowledge Not competent Not informed
Rules	Obeying rules Visiting times Number of visitors Infection control principles
Nurse-Family bond	Bonds formed
ICU environment	Friendly staff Welcoming Quiet
Counseling	Counseling for family members

Question 2

Involvement	Skin to skin touch Family members involved
Communication	Information Communication Updates Education
Unrealistic expectations around pt prognosis	False hope Unrealistic expectations Lack of preparedness around prognosis
Rules	Obeying rules Visiting times Number of visitors Infection control principles
Needs of family	Important to consider needs Family needs
Professionalism	Staff professional
Counselors	Counseling for family members
Support	Support Empathy
ICU patient environment	
ICU family environment	Friendly staff Greeting Mutual respect
Family spokesperson	
Contact with MDT	Contact with MDT MDT meetings
Orientation to ICU environment	Orientation to ICU environment Information on rules of ICU
Privacy	Private rooms
Nursing care	Nursing care Patient care Nurse presence at the bedside Nurse competency
Electronic devices	Electronic devices Entertainment

Other Healthcare Professionals

Question 1

Family involvement	FM not involved Provide info on family history End of life decision making Surrogate decision makers Family has little say
Rules	Visiting hours Infection control
Emotions	Frustration Emotional Uncertainty Disruption in life
Communication	Information Communication Updates Understanding Truthful information MDT poor communication Speak to one family member Dr appointments for updates Consistency in information Make contact ASAP
Orientation to ICU environment	ID roles of MDT in the ICU Orientation to ICU Environment
ICU family environment	Hostile Daunting environment Space in waiting area Second home for family member Poor facilities for family members
ICU patient environment	Cold environment Unfriendly Friendly
Privacy	Lack of privacy
Nursing care	Nurse presence at the bedside Nurses more involved

	Nurse dependent Perceived nursing care Nurses mostly involved
Negativity	Rude towards nursing staff FCC not possible Time limitations Nurses feel intimidated FM neglected
Unrealistic expectations around pt prognosis	Unrealistic perceptions of illness
Support	Support Empathy

Question 2

Family involvement	Involvement in decision making Involvement in patient care
Information	Appointments with doctors Availability of doctors MDT communication Contact person Understanding Information Information brochure Updates
Family representative	Family representative Family Spokesperson
Rules	Visiting hours Children visitors Number of visitors Infection control
ICU patient environment	Clean Size of ICU Space around bed No equipment on the floor Natural lighting/Big Windows
ICU family environment	Relaxing enviroment Privacy Warm/friendly environment Welcoming staff Relaxing enviroment Welcoming environment Coffee facilities More chairs
Nursing care	Nurse presence Competent staff More nursing staff and other HCP Perceived nursing care
Electronics	Computerised unit

	TV, radio, music, wifi Cellphone available Remote access to central server Media with welcoming msg/instructions
Spiritual care	Pastor
MDT team rounds	Family rounds MDT rounds MDT communication
Unrealistic expectations around pt prognosis	False hope Unrealistic expectations Lack of preparedness around prognosis Reality around prognosis
Dedicated ICU dr	Intensivist
Orientation to ICU environment	ID roles of MDT in the ICU Oreintation to ICU Environment
Privacy	Private rooms for patients

ANNEXURE G2

DATA ANALYSIS:
DIVIDING INTO THEMES, SUBTHEMES AND CATEGORIES

	Family members		Nurses		Healthcare professionals	
Themes	Now	Ideal	Now	Ideal	Now	Ideal
Communication	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Orientation	Yes	Yes	Yes	Yes	Yes	Yes
Rules	Yes	Yes	Yes	Yes	Yes	Yes
Environment	Yes	Yes	?No	Yes	Yes	Yes
Information	Yes	Yes	Yes	Yes	Yes	Yes
Education	Yes	Yes	Yes	Yes	No	No
Multi-disciplinary team	No	Yes	No	Yes	Yes	Yes
Environment	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Physical	Yes	Yes	Yes	Yes	Yes	Yes
Care	Yes	Yes	Yes	Yes	Yes	Yes
Nursing competency	Yes	Yes	Yes	Yes	?No	Yes
Workplace culture	No	No	Yes	Yes	Yes	Yes
Patient	Yes	Yes	No	Yes	No	Yes
Entertainment/electronics	Yes	Yes	No	Yes	No	Yes
Family	Yes	Yes	No	No	Yes	Yes
Continuum of feelings	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**

Compassion	Yes	Yes	No	No	No	No
Reflections	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Roles	Yes	No	No	No	No	No
Needs	Yes	Yes	No	Yes	No	No
Nurse dependant	Yes	No	No	No	No	No
Expectations	No	No	Yes	Yes	Yes	Yes
Family involvement	Yes	Yes	Yes	Yes	Yes	Yes
Spiritual care	**Yes**	**Yes**	**No**	**No**	**No**	**Yes**

	Family members		Nurses		Healthcare professionals	
Themes	Now	Ideal	Now	Ideal	Now	Ideal
Communication	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Including Orientation, Information, Education, Multi-disciplinary team communication						
Orientation	Yes	Yes	Yes	Yes	Yes	Yes
Orientation to ICU rules and environment						

Rules	Yes	Yes	Yes	Yes	Yes	Yes
	Info on rules Visiting hrs & time Numbers of visitors Children in ICU Consistency Strict rules Infection control Lack of clear instructions	Info on rules Visting hrs & time Children Number of visitors Consistency Infection control Staff to adhere to infx control rules	Obeying rules Visiting times Numbers of visitors Infection control principles	Info on rules in the ICU	Visiting hours Infection control	Visiting hours Children visitors Number of visitors Infection control Adherence to infection control
Environment	Yes	Yes	?No	Yes	Yes	Yes
	Orientation to ICU environment	Point of contact for FM to comm with Orientation to ICU environment Prep on what to expect		Orientation to ICU environment	ID roles of MDT in the ICU Orientation to ICU environment	Point of contact ID roles of MDT in the ICU Orientation to ICU environment
Information	Yes	Yes	Yes	Yes	Yes	Yes
	Updates	Updates Signage	Updates	Updates	Updates Understanding Truthful Consistency of info	Understanding Information brochure Updates

						Media with welcoming msg's /instructions
Education	Yes	Yes	Yes	Yes	No	No
	Around pt condition	Around pt condition				
Multi-disciplinary team	No	Yes	No	Yes	Yes	Yes
		Team meetings	Dr's unapproachable Dr's unavailable	Contact with MDT MDT meetings	MDT poor communication Drs appointments for updates Make contact ASAP Opportunity to ask questions Spend time with pt Access to dr in charge	Appointments with drs Avalailability of drs MDT communication Computerised unit, Remote access from a central server Family rounds MDT rounds, MDT communication Regular visits from Treating dr MDT approach
Environment	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Including Physical, Care, Patient and Family Environment						
Physical	Yes	Yes	Yes	Yes	Yes	Yes
	Clean, Cold, unfriendly	Quiet, clean, warm Privacy	Quiet	Privacy (private rooms)	Hostile, daunting, cold, unfriendly, friendly	Clean, Size of ICU, Space around bed, no equipment on the floor, natural lighting, big windows

					Lack of privacy	Privacy, warm, friendly Private rooms for patients
Care	Yes	Yes	Yes	Yes	Yes	Yes
			Counselling for FM	Counselling for FM		
Further divided into Nursing Competency and Workplace Culture						
Nursing competency	Yes	Yes	Yes	Yes	?No	Yes
	Basic nursing care Nurse competency Professional Knowledge of pt	How to provide support Competent staff Informed nurses	Lack of knowledge Not competent, not informed	Professionalism Nursing care Patient care Nurse competency		Competent staff Perceived nursing care
Workplace culture	No	No	Yes	Yes	Yes	Yes
How we do things in the workplace	Friendly/warm Positive staff Nurse presence Caring staff Professional Sympathy	Support, empathy, listening, understanding, positive staff. Greeting, friendly, welcoming	Support, empathy, understanding, Increased workload- Demanding, overbearing, rude, pressure on staff, inquisitive, disruptive due to excessive phone calls, lack of trust, managing conflicts (family conflicts) Friendly staff Welcoming	Support, empathy, friendly staff, greeting, mutual respect Nurse presence	Nurse presence Nurses more involved Nurse dependant Percieved nursing care Nurses mostly involved Rude towards nursing staff Nurses feel intimidated	Welcoming Nurse presence More nursing staff and other HCP Intensivist for the iCU One on one nursing care

					Time limitations Support, empathy	
Patient	Yes	Yes	No	Yes	No	Yes
Including Entertainment/electronics for patients						
Entertainment/electronics	Yes	Yes	No	Yes	No	Yes
	Prohibited	Electronic update system Entertainment for pt		Electronic devices Entertainment		Computerised unit TV, radio, wifi,music, cellphone
Family	Yes	Yes	No	No	Yes	Yes
	Wating area Unwelcome	Comfortable waiting area for FM, for children, comfortable chair next to the bedside, coffee/tea facility for FM			Space in waiting area Second home for FM Poor facilities for FM	Relaxing environment, Coffee facilities, more chairs
Continuum of feelings	**Yes**	**No**	**Yes**	**No**	**Yes**	**No**
	Uncertainty, relief, fearful, traumatic, lonely, stressful, helplessness		Grateful, appreciative, Sad, distressed, stress, anger, cold, anxious, aggressive, uncertain, hopeful, fearful		Frustration, emotional, uncertainty, Disruption in life	
Compassion	Yes	Yes	No	No	No	No
	Lack of compassion					

Reflections	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**	**Yes**
Including Roles, needs, nurse dependant, expectations, family involvement						
	FCC non existent Neglected FM as nuisance	Patient is priority	FCC is important Financial burden to FM Bonds formed	Important to consider needs	FM not involved Family has little say Not always possible FM neglected	
Roles	Yes	No	No	No	No	No
	FM takes on multiple roles			Obeying rules, Visiting times, number of visitors, Infection control principles		
Needs	Yes	Yes	No	Yes	No	No
	Time with FM	Family journey				
Nurse dependant	Yes	No	No	No	No	No
	Depends on nurse working that day					
Expectations	No	No	Yes	Yes	Yes	Yes
			Unrealistic expecations around pt prognosis, false hope, lack of preparedness	False hope Unrealistic expectations Lack of preparedness around prognosis	Unrealistic perceptions of illness	False hope, unrealistic expectations, lack of preparedness around prognosis, reality around prognosis
Family involvement	Yes	Yes	Yes	Yes	Yes	Yes

	Skin to skin contact	Provide history of the pt	Family involved, provide info, involved in pt care	Skin to skin contact Family members involved Family spokesperson	Provide info on family history End of life decision making Surrogate decision makers Provide info to one FM	Involved in decision making Involved in pt care Familly representative Family spokesperson
Spiritual care	**Yes**	**Yes**	**No**	**No**	**No**	**Yes**
	Able to pray	Pastor, prayer, pastoral care				Pastor

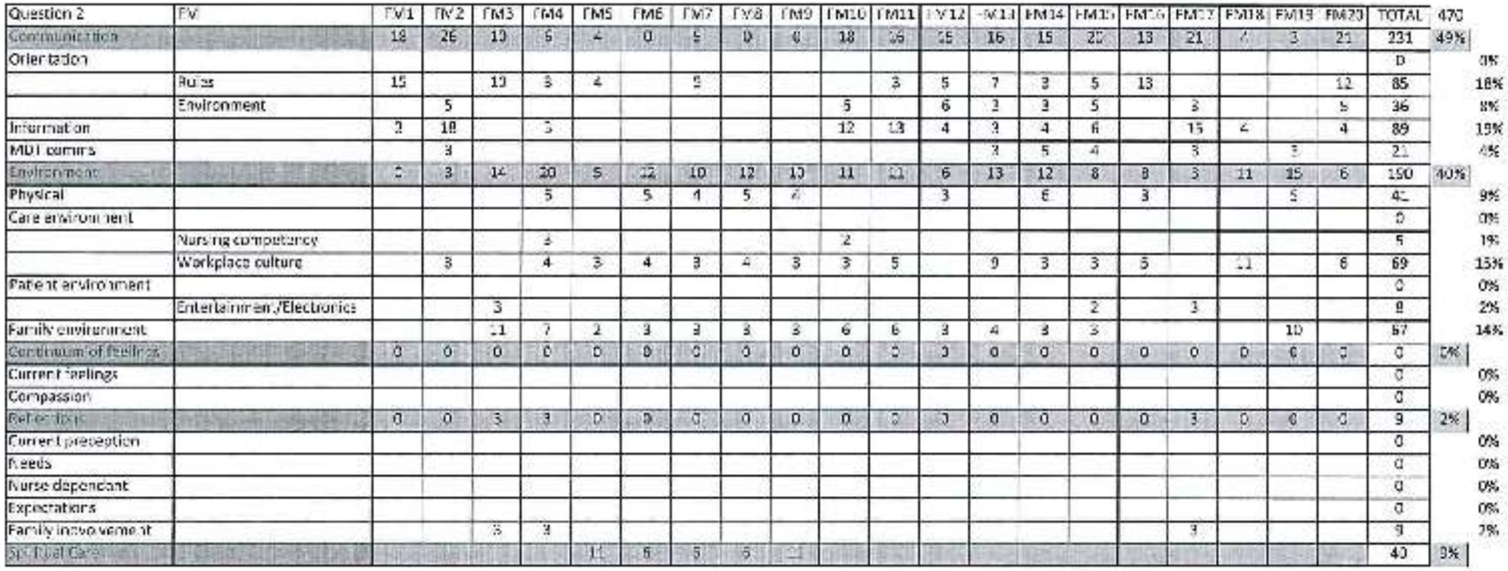
***Friendly staff, unwelcome**

ANNEXURE G3

DATA ANALYSIS: WEIGHTING OF CATEGORIES

	Fam			N			OHCP		
Question 1	Q1	Q2		Q1	Q2		Q1	Q2	
Communication	32%	49%	17%	35%	50%	16%	57%	56%	4%
Orientation Rules	12%	18%	6%	5%	14%	9%	10%	21%	11%
Orientation Environment	1%	8%	7%	0%	4%	4%	2%	5%	3%
Information	17%	19%	2%	24%	26%	2%	28%	12%	-17%
MDT comms	1%	4%	3%	6%	4%	-2%	12%	17%	6%
Environment	40%	40%	1%	38%	49%	11%	26%	38%	13%
Physical	6%	9%	3%	1%	15%	14%	8%	26%	18%
Care enviromnent Nursing competency	6%	1%	-5%	1%	0%	-1%	0%	2%	2%
Care enviromnent Workplace culture	28%	15%	13%	36%	30%	-6%	12%	4%	-8%
Patient environment Entertainment/Electronics	1%	2%	1%	0%	1%	1%	0%	1%	1%
Family environment	0%	14%	14%	0%	3%	3%	6%	9%	3%
Continuum of feelings	11%	0%	-11%	16%	0%	-16%	0%	0%	0%
Current feelings	11%	0%	-11%	16%	0%	-16%	0%	0%	0%
Reflections	16%	2%	-14%	11%	14%	2%	22%	6%	-16%
Current preception	11%	0%	-11%	4%	1%	-3%	7%	0%	-7%
Nurse dependant	3%	0%	-3%	0%	0%	0%	1%	0%	-1%
Expectations	0%	0%	0%	3%	0%	-3%	4%	0%	-3%
Family inovolvement	3%	2%	-1%	4%	13%	8%	11%	5%	-5%
Spiritual Care	1%	9%	7%	0%	1%	1%	0%	0%	0%

Question 1	FM	FM1	FM2	FM3	FM4	FM5	FM6	FM7	FM8	FM9	FM10	FV11	FM12	FM13	FM14	FM15	FM16	FM17	FM18	FV19	FM20	TOTAL	460	
Communication		0	8	13	3	0	9	5	11	0	6	0	3	8	5	14	15	17	13	3	14	147	32%	
Orientation																						0		0%
	Rules		5	12	3									3	2	3	9	6			14	57		12%
	Environment															3		2				5		1%
Information			3	1			9	5	11		6		3	5	3	8	6	9	7	3		79		17%
MDT comms																			6			6		1%
Environment		11	3	7	26	15	0	0	0	11	14	6	9	19	15	7	9	4	8	9	16	183	40%	
Physical												6	9		2	7	6					27		6%
Care environment																						0		0%
	Nursing competency				9									6	4					4	3	26		6%
	Workplace culture	11	3	7	17	15				11	14			13	6	3	3	4	8	5	7	127		28%
Patient environment																						0		0%
	Entertainment/Electronics														3							3		1%
Family environment																						0		0%
Continuum of feelings		0	4	3	0	0	0	0	0	0	0	19	0	6	11	6	0	0	0	0	0	49	11%	
Current feelings			4	3								19		6	11	6						49		11%
Compassion																						0		0%
Reflections		0	6	9	4	0	6	0	0	0	11	4	6	0	0	0	6	11	6	6	0	75	16%	
Current preception			5	6							8	4	6				3	8	3	6		50		11%
Needs																						0		0%
Nurse dependant							6										3		3			12		3%
Expectations																						0		0%
Family involvement				3	4						3							3				13		3%
Spiritual Care								6														6	1%	



Question 2	FV	FM1	FM2	FM3	FM4	FM5	FM6	FM7	FM8	FM9	FM10	FM11	FM12	FM13	FM14	FM15	FM16	FM17	FM18	FM19	FM20	TOTAL	470	
Communication		18	26	10	6	4	0	5	0	0	18	16	15	16	15	20	13	21	4	3	21	231	49%	
Orientation																						0		0%
	Rules	15		10	3	4		5				3	5	7	3	5	13				12	85		18%
	Environment		5								5		6	2	3	5		3			5	36		8%
Information		3	18		3						12	13	4	3	4	6		15	4		4	89		19%
MDT comms			3											3	5	4		3		3		21		4%
Environment		0	3	14	20	5	12	10	12	10	11	11	6	13	12	8	8	3	11	15	6	150	40%	
Physical					5		5	4	5	4			3		6		3			5		42		9%
Care environment																						0		0%
	Nursing competency				3						2											5		1%
	Workplace culture		3		4	3	4	3	4	3	3	5		9	3	3	5		11		6	69		15%
Patient environment																						0		0%
	Entertainment/Electronics			3												2		3				8		2%
Family environment				11	7	2	3	3	3	3	6	6	3	4	3	3				10		67		14%
Continuum of feelings		0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0%	
Current feelings																						0		0%
Compassion																						0		0%
Reflections		0	0	3	3	0	0	0	0	0	0	0	0	0	0	0	0	3	0	0	0	9	2%	
Current preception																						0		0%
Needs																						0		0%
Nurse dependant																						0		0%
Expectations																						0		0%
Family involvement				3	3													3				9		2%
Spiritual Care						11	6	5	6	11												40	9%	

Question 1	N	N1	N2	N3	N4	N5	N6	N7	N8	N9	N10	N11	N12	N13	N14	N15	N16	N17	N18	N19	N20	Total	456	
Socialisation		4	6	3	1	12	12	3	5	15	11	14	5	21	11	16	0	7	0	6	15	173	35%	
Orientation																						0		0%
	Rules					5		5		1	3	3										25		5%
	Environment																					0		0%
Information				3			8	8	5	6	3	12	5	21	11	11		7	8	8	15	117		24%
MDT comms		4				7	9			4	6					5						31		6%
Environment		13	7	4	4	12	9	9	6	7	7	12	15	5	10	5	11	0	18	12	12	186	38%	
Physical															3							3		1%
Care environment																						0		0%
	Nursing competency												3						3			6		1%
	Workplace culture	11	7	4	3	12	2	9	6	9	7	13	16		7	9	11		15	12	12	177		36%
Patient environment																						0		0%
	Entertainment/Necessities																					0		0%
Family environment																						0		0%
Continuum of feelings		8	8	34	17	0	0	0	35	0	6	0	0	0	0	0	10	8	0	0	0	80	16%	
Current feelings		8	8	34	17				35		6						10	8				80		16%
Compassion																						0		0%
Reflection		17	14	3	0	0	0	8	6	0	7	0	0	0	0	4	0	11	5	3	0	57	11%	
Current perceptions		5	6								4								5			20		4%
Needs																						0		0%
Nurse dependent																						0		0%
Expectations		5									3							5		3		16		3%
Family involvement			8					3								4		3				18		4%
Spiritual Care																						0	0%	

Question 2	V	N1	N2	N3	N4	N5	N6	N7	N8	N9	N10	N11	N12	N13	N14	N15	N16	N17	N18	N19	N20	Total	391	
[illegible]		14	6	15	9	14	9	7	16	12	15	5	0	2	10	10	3	6	[illegible]	16	12	197	50%	
Orientation									6						3							9		2%
	Rules	6		7	5	2		5		2	10								4	3	5	56		14%
	Disrespectful							6								4				6		16		4%
Infrastructure		8	8	11	4	3	9		8	5	3	8		2	7	2		8	7	7	5	100		26%
[illegible]						9				4	4					2					9	18		4%
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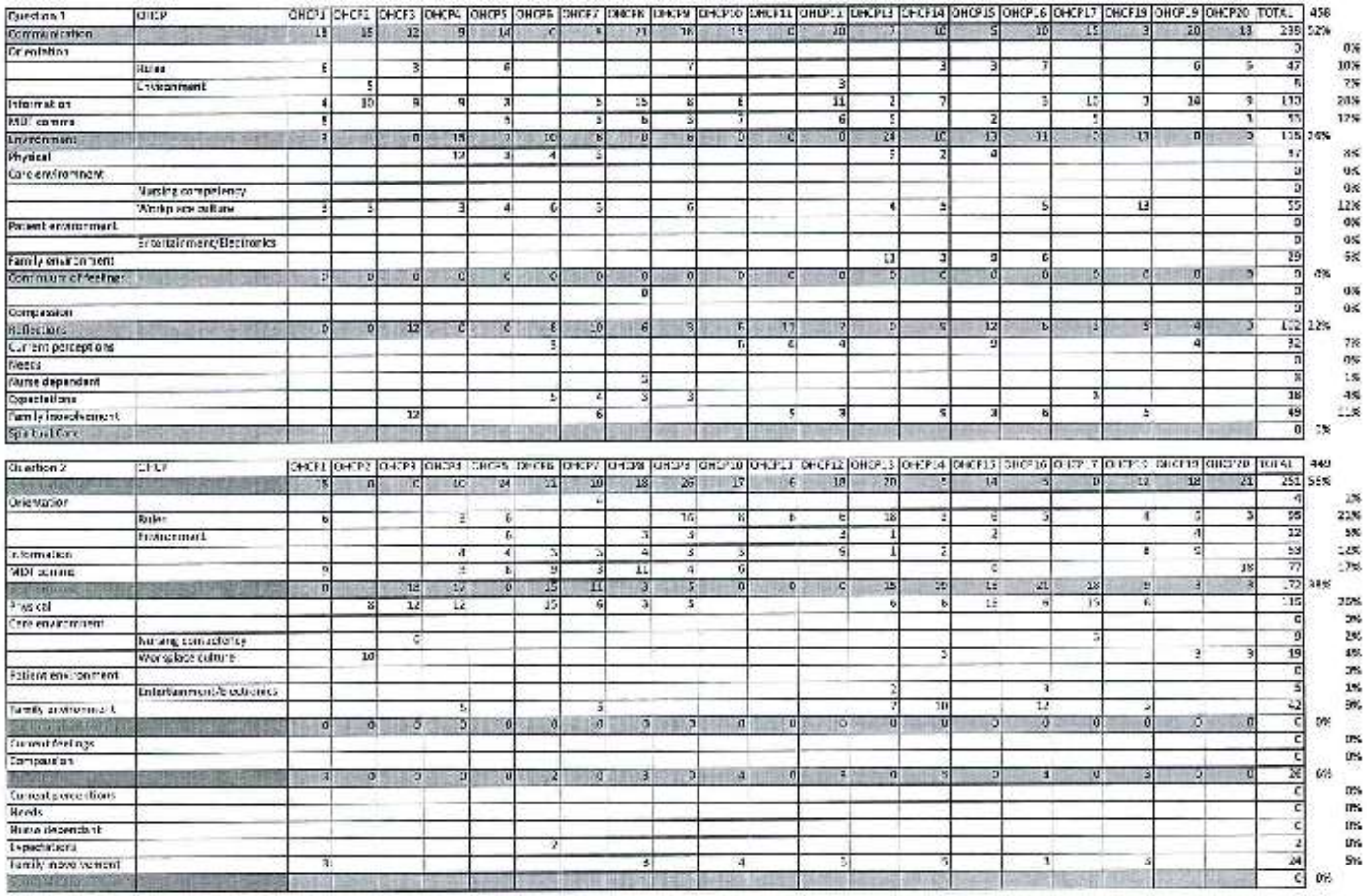
Physical										2		10	13	6	5	9	14					58		15%
Care environment																						9		0%
	Nursing competency																					0		0%
	Workplace culture	3	6	3			5		4			13	12	20	3	10	12	13		3	6	117		30%
Patient environment																						0		0%
	Entertainment/distractions																		5			5		1%
Family environment						5						4									2	10		3%
[illegible]		0	0	3	0	0	0	0	0	0	1	0	3	0	0	0	0	0	0	0	0	3	2%	
Current feelings																								
Compassion																						3		0%
[illegible]		10	12	2	9	4	5	0	0	6	8	0	0	0	0	0	0	8	0	1	0	53	14%	
Care at all times			4																			4		1%
Needs																						0		0%
Nurse dependent																						0		0%
Expectations																						5		1%
Family involvement		10	8		9	4	4			6	6							4				49		9%
[illegible]																						1	1%	

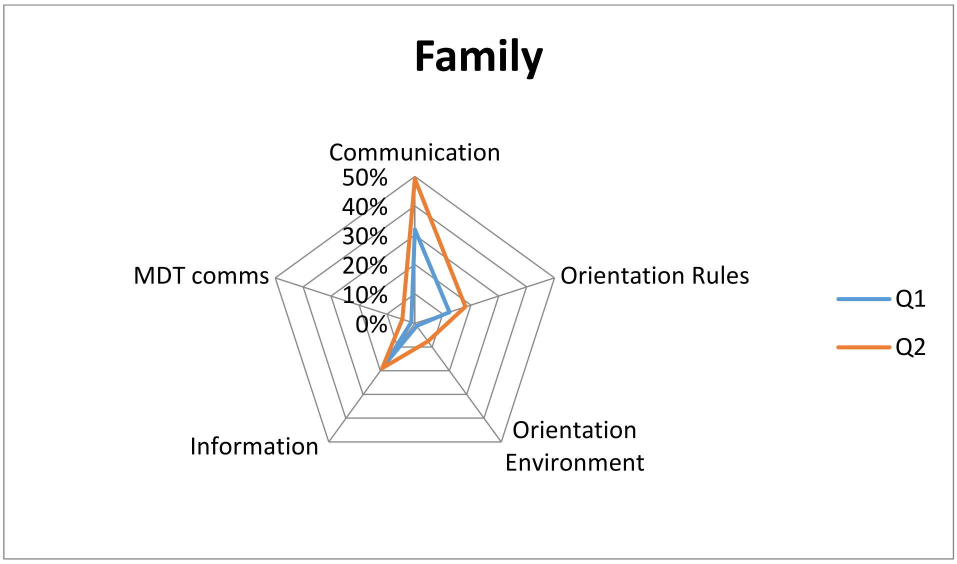


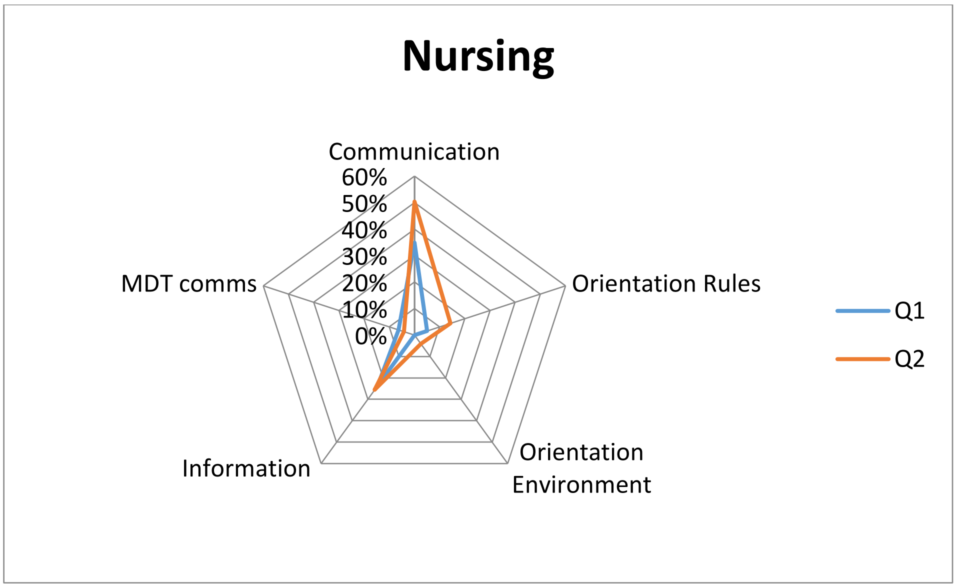
Question 1	OHCP	OHCP1	OHCP2	OHCP3	OHCP4	OHCP5	OHCP6	OHCP7	OHCP8	OHCP9	OHCP10	OHCP11	OHCP12	OHCP13	OHCP14	OHCP15	OHCP16	OHCP17	OHCP18	OHCP19	OHCP20	TOTAL	458	
Communication		13	15	12	9	14	0	8	21	16	15	0	20	7	10	5	10	15	3	20	13	238	52%	
Orientation																						0		0%
	Rules	6		3		6				7					3	3	7			6	5	47		10%
	Environment		5										3									8		2%
Information		4	10	9	9	8		5	15	8	8		11	2	7		3	10	7	14	9	130		28%
MDT comms		5				5		3	6	3	7		6	5		2		5			1	55		12%
Environment		3		0	15	7	10	6	0	6	0	0	0	24	10	13	11	2	13	0	0	135	26%	
Physical					12	3	4	3						5	2	4						37		8%
Care environment																						0		0%
	Nursing competency																					0		0%
	Workplace culture	3	3		3	4	6	3		6				4	5		5		13			55		12%
Patient environment																						0		0%
	Entertainment/Electronics																					0		0%
Family environment														13	3	9	6					29		6%
Continuum of feelings		0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0%	
									0													0		0%
Compassion																						0		0%
Reflections		0	0	12	0	0	8	10	6	8	6	11	7	0	5	12	6	1	5	4	0	102	12%	
Current perceptions							3				6	4	4			9				4		32		7%
Needs																						0		0%
Nurse dependant									5													5		1%
Expectations							5	4	3	3								3				18		4%
Family involvement				12				6				5	3		5	3	6		5			49		11%
Spiritual Care																						0	0%	

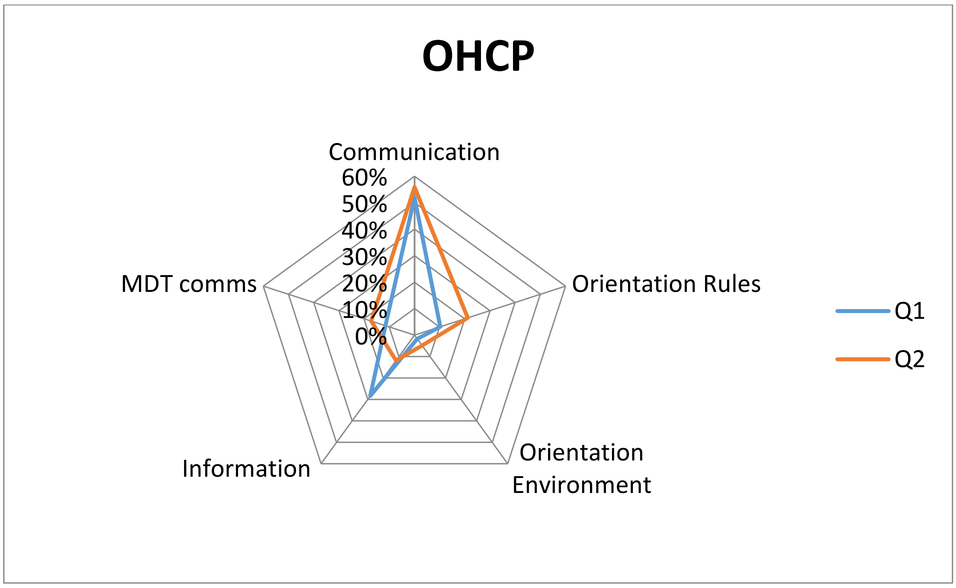
Question 2	OHCP	OHCP1	OHCP2	OHCP3	OHCP4	OHCP5	OHCP6	OHCP7	OHCP8	OHCP9	OHCP10	OHCP11	OHCP12	OHCP13	OHCP14	OHCP15	OHCP16	OHCP17	OHCP18	OHCP19	OHCP20	TOTAL	449	
[illegible]		15	0	0	10	24	21	10	18	26	17	6	18	20	5	14	5	0	12	18	21	251	56%	
Orientation								4														4		1%
	Rules	6			3	6				16	8	6	6	18	2	6	5		4	5	3	95		21%
	Environment					6			3	3			4	1		2				4		22		5%
Information					4	4	5	5	4	5	5		9	1	2				8	5		53		12%
MDT comms		9			3	6	9	3	11	4	6					0					18	77		17%
[illegible]		0		18	17	0	15	11	3	5	0	0	0	15	20	15	21	18	9	3	3	172	38%	
Physical			8	12	12		15	6	3	5				6	6	15	9	15	6			115		26%
Care environment																						0		0%
	Nursing competency			0														3				9		2%
	Workplace culture		10												3					3	3	19		4%
Patient environment																						0		0%
	Entertainment/Electronics													2			3					5		1%
Family environment					5			3						7	10		12		5			42		9%
[illegible]		0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0%	
Current feelings																						0		0%
Comparison																						0		0%
[illegible]		3	0	0	0	0	2	0	3	0	4	0	3	0	5	0	3	0	5	0	0	26	6%	
Current perceptions																						0		0%
Needs																						0		0%
Nurse dependant																						0		0%
Expectations							2															2		0%
Family involvement		3							5		4		5		5		3		5			24		5%
[illegible]																						0	0%	

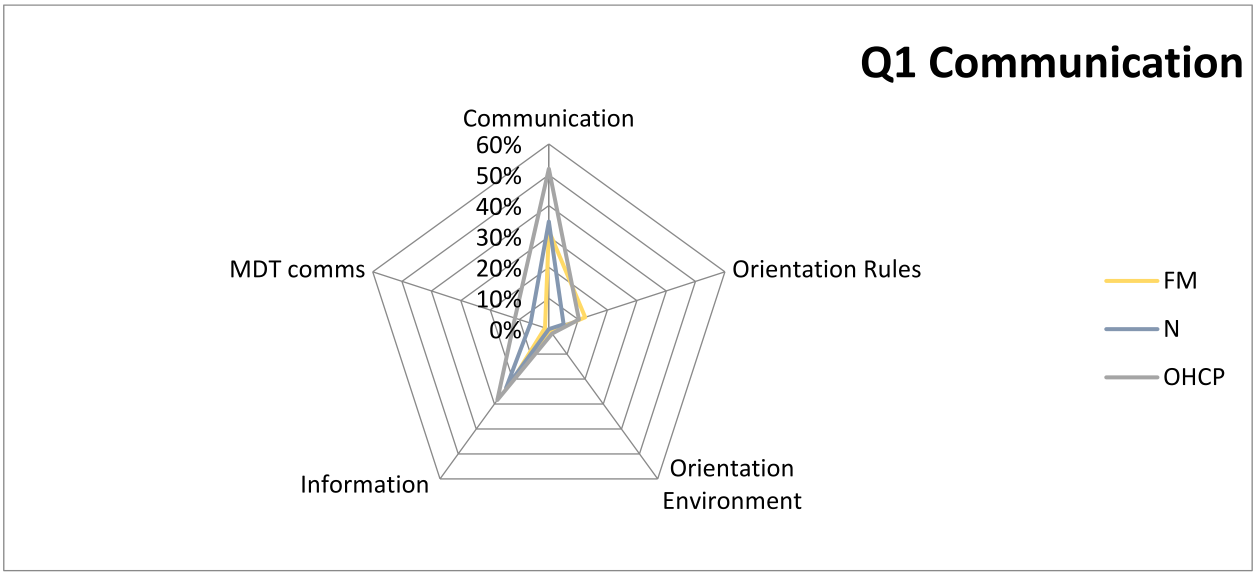
ANNEXURE G4

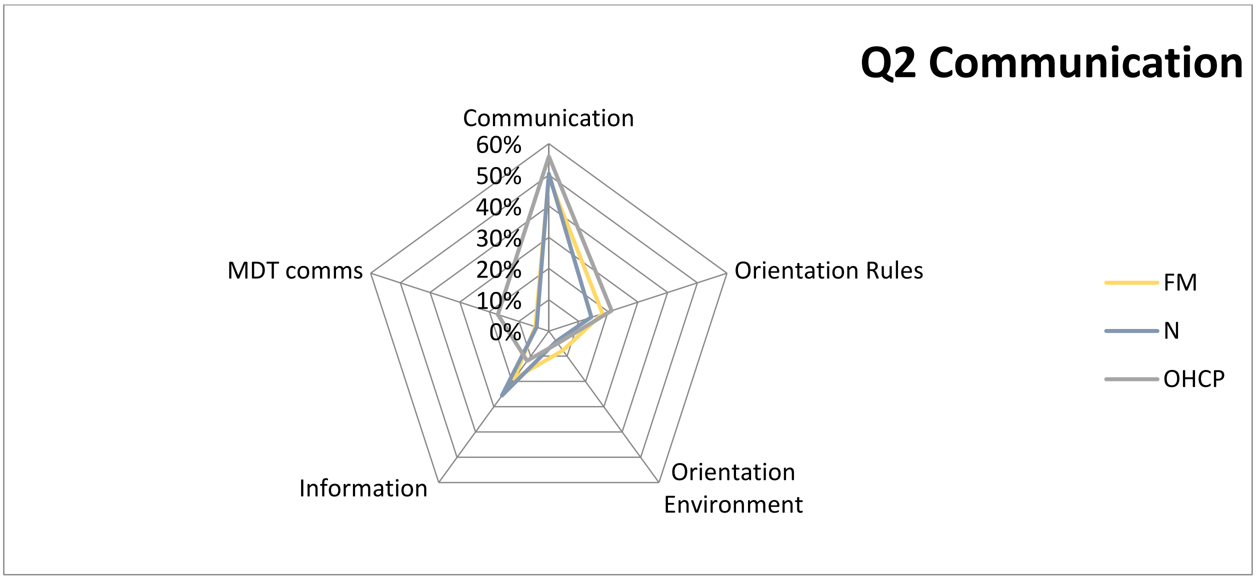
DATA ANALYSIS: SEMANTOGRAPHS

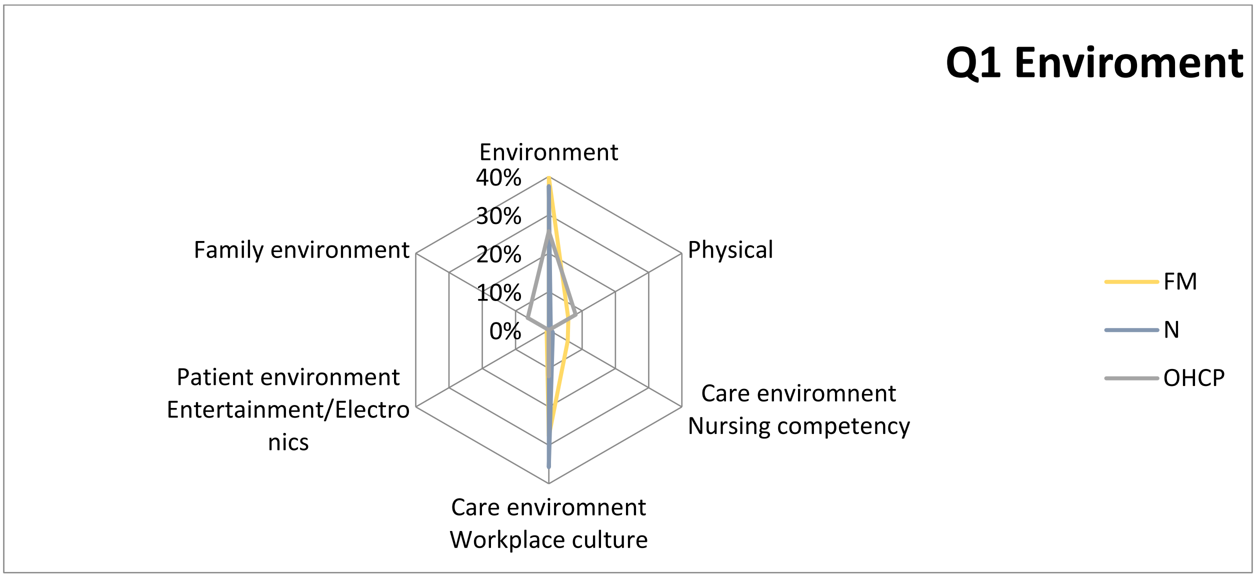

Family
Communication
50%
40%
30%
20%
10%
0%
Orientation Rules
Orientation Environment
Information
MDT comms
Q1
Q2

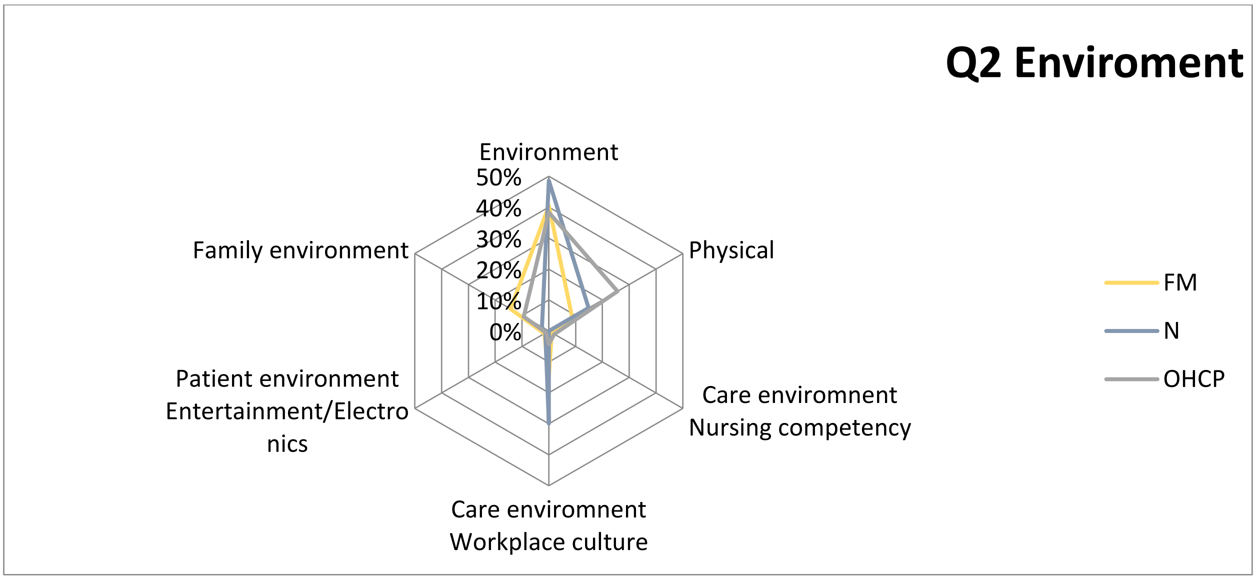

Nursing
Communication
60%
50%
40%
30%
20%
10%
0%
Orientation Rules
Orientation Environment
Information
MDT comms
Q1
Q2

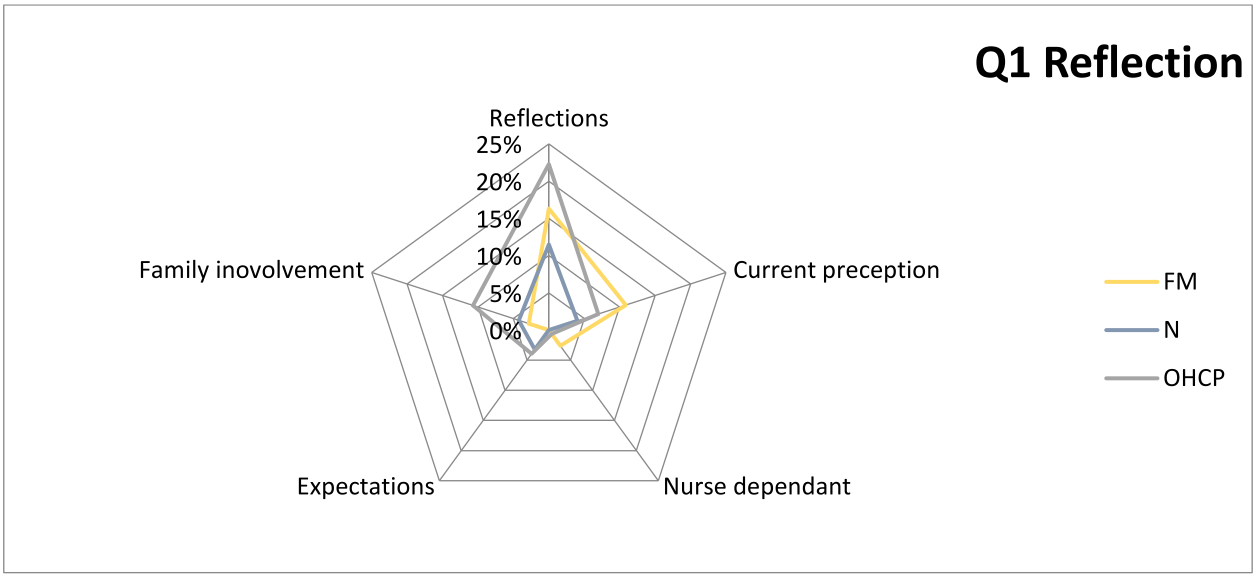

OHCP
Communication
60%
50%
40%
30%
20%
10%
0%
Orientation Rules
Orientation Environment
Information
MDT comms
Q1
Q2

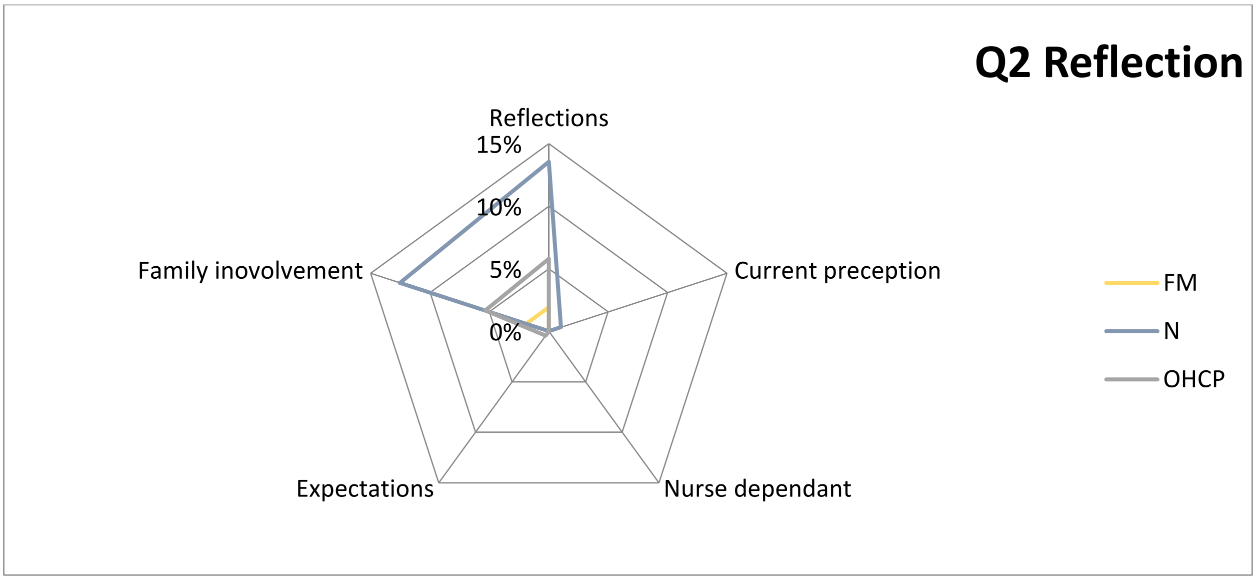

Q1 Communication
Communication
60%
50%
40%
30%
20%
10%
0%
Orientation Rules
Orientation Environment
Information
MDT comms
FM
N
OHCP

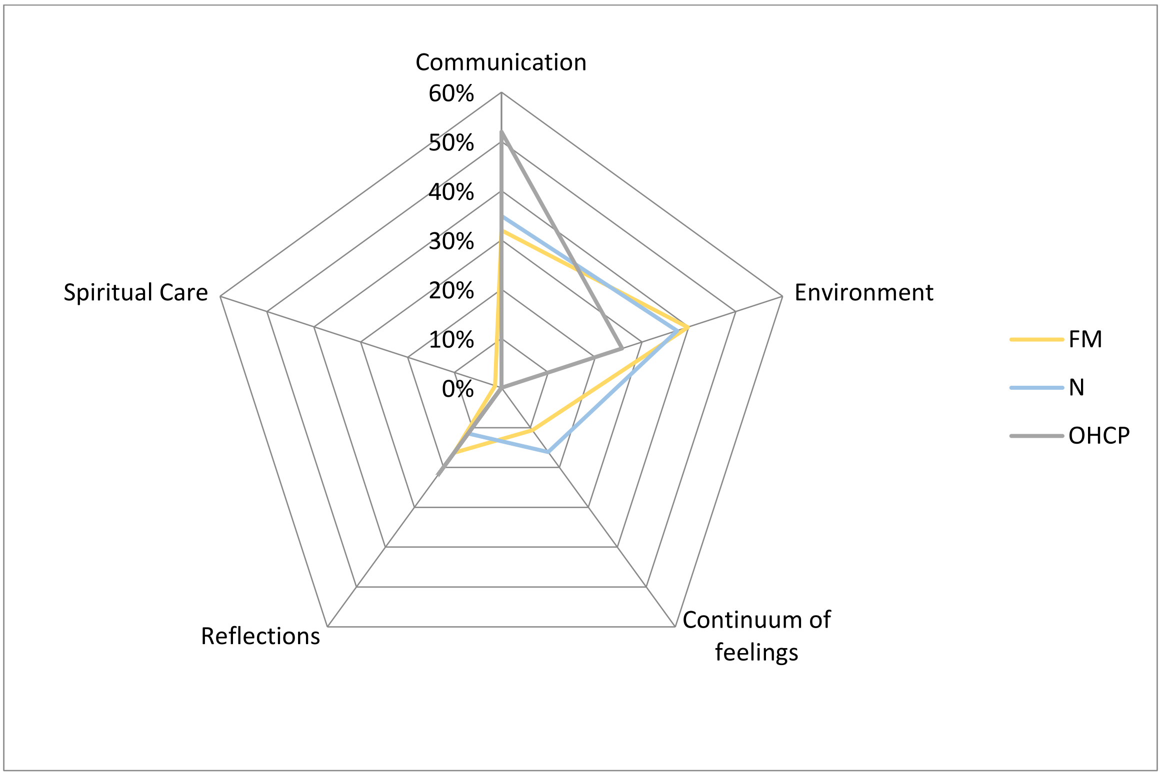

Q2 Communication
Communication
60%
50%
40%
30%
20%
10%
0%
Orientation Rules
Orientation Environment
Information
MDT comms
FM
N
OHCP

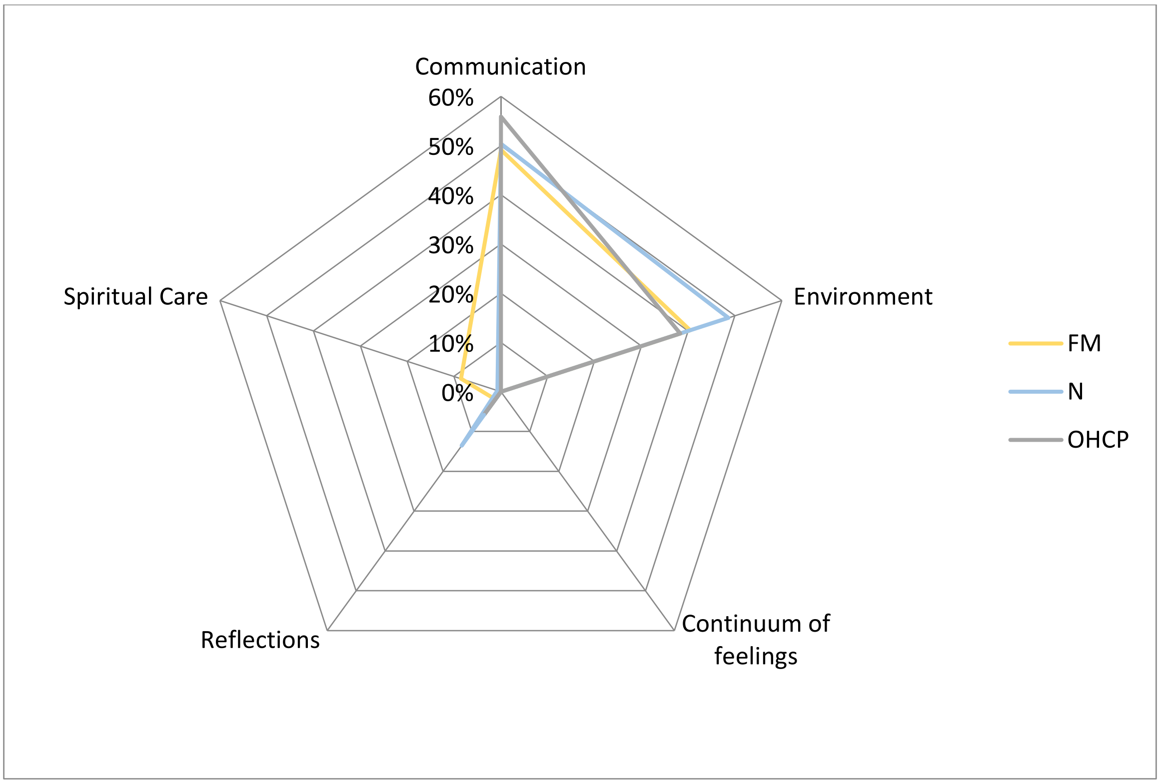

Q1 Enviroment
Environment
40%
30%
20%
10%
0%
Physical
Care enviromnent Nursing competency
Care enviromnent Workplace culture
Patient environment Entertainment/Electronics
Family environment
FM
N
OHCP

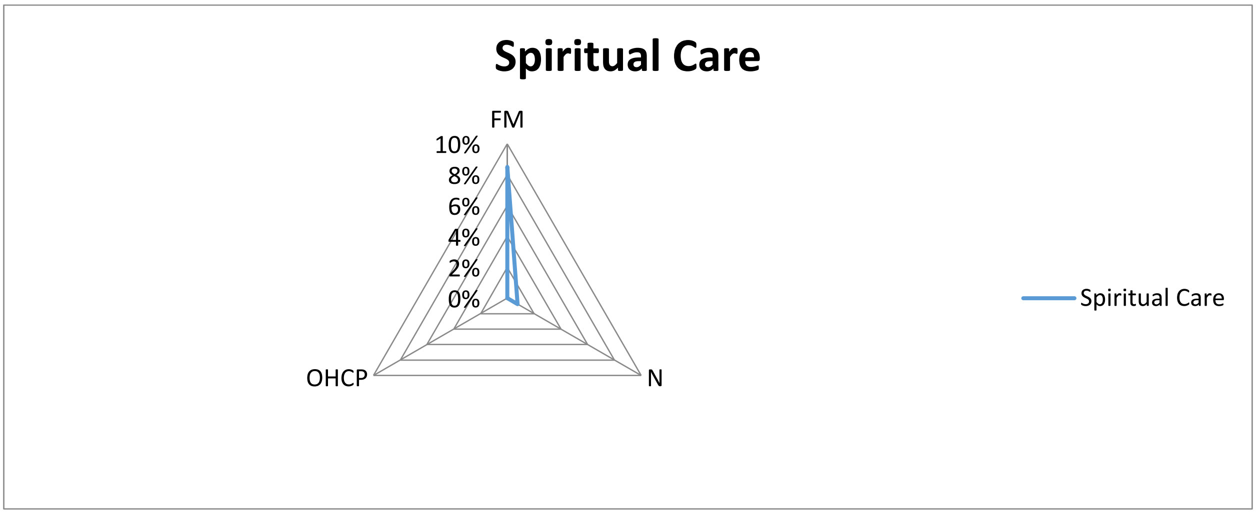

Q2 Enviroment
Environment
50%
40%
30%
20%
10%
0%
Physical
Care enviromnent Nursing competency
Care enviromnent Workplace culture
Patient environment Entertainment/Electronics
Family environment
FM
N
OHCP


Q1 Reflection
Reflections
25%
20%
15%
10%
5%
0%
Current preception
Nurse dependant
Expectations
Family inovolvement
FM
N
OHCP


Q2 Reflection
Reflections
15%
10%
5%
0%
Current preception
Nurse dependant
Expectations
Family inovolvement
FM
N
OHCP


Communication
60%
50%
40%
30%
20%
10%
0%
Environment
Continuum of feelings
Reflections
Spiritual Care
FM
N
OHCP


Communication
60%
50%
40%
30%
20%
10%
0%
Environment
Continuum of feelings
Reflections
Spiritual Care
FM
N
OHCP


Spiritual Care
FM
10%
8%
6%
4%
2%
0%
OHCP
N
Spiritual Care

ANNEXURE H1

LETTER FROM EDITOR

28 Stephen Road
SCOTTBURGH
4180

31 July 2019

TO WHOM IT MAY CONCERN

I, G.H. Henneke, hereby declare that I edited the following document:

A dissertation under the title:

PERCEPTIONS OF STAKEHOLDERS ON FAMLY-CENTRED CARE IN THE INTENSIVE CARE UNIT: AN ASSOCIATIVE GROUP ANALYSIS by Rachele Lara Pretorius, student number 24072461, presented to the Department of Nursing Science, Faculty of Healthcare Sciences, University of Pretoria, in fulfillment of the requirements for the degree Magister Curationis (Clinical), Advanced Medical and Clinical Nursing Science (Critical Care Nursing).

Yours sincerely

MRS G.H. HENNEKE
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