



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

**FAMILY CENTERED CARE IN AN INTENSIVE CARE UNIT IN BOTSWANA: THE
VIEWS OF FAMILIES**

by

Juliet Sejosennye Senabye

27302815

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School of Health Care Science

Faculty of Health Sciences

University of Pretoria

Supervisor: Prof IM Coetzee

Co-supervisor: Prof T Heyns

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DECLARATION

Student Number: 27302815

I, **Juliet Sejosennye Senabye**, declare that **FAMILY CENTERED CARE IN AN INTENSIVE CARE UNIT IN BOTSWANA: THE VIEWS OF FAMILIES** is my own work and that all sources that have been used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted for any other degree at any other institution.

Signed

Date

ABSTRACT

Introduction

Family-centred care (FCC) is a model of care that is focused on promoting collaboration through engagement of nurses and families in information sharing and decision making. This experience is common for families with patients admitted in the intensive care unit (ICU). Disruption of the social system usually manifests in the form of depression, fear and/or anger. Families need to be supported and involved in patient care and decision making, in order to reduce complaints, improve patient outcomes, and hence promote family-centred care.

AIM

The aim of the study was to describe the views of families regarding FCC and collaboratively develop strategies to enhance FCC in the general ICU in Botswana.

Research Design

The researcher used a qualitative, contextual, explorative and descriptive research design in order to explore and describe the lived views of families with patients admitted in the ICU regarding FCC.

Methodology

Ten family members of patients admitted in the ICU were purposively selected and data was collected by means of one-on-one interviews. The data-collection instrument was an Appreciative Inquiry semi-structured and open-ended interview guide.

Findings

The following main themes emerged: 1) workplace culture 2) compassion and 3) counselling.

Conclusion

Supporting and involving families in the care of the critically ill family member may improve family satisfaction, reduce complaints and ultimately lead to positive health outcomes for the patient.

Key words: Family-centred care (FCC), information sharing, Intensive care unit (ICU), partnership

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LIST OF ABBREVIATIONS

FCC	Family centred care
ICU	Intensive care unit

CHAPTER 1

ORIENTATION TO THE STUDY

Better together; partnering with families to achieve optimal healthcare outcomes.

- Institute of Patient and Family Centred Care -

1.1 INTRODUCTION

Nursing care practices have evolved from a patient-centred model to a holistic approach, recognizing family needs as inseparable from the patient's (Yousefi, Karami, Moeini & Ganji 2012:298). Bartz (2009:480) states that nursing "encompasses autonomous, collaborative care of individuals of all ages, families, groups and communities, sick or well in all settings". Therefore nursing care practices should be guided by nursing theories in order to promote holistic quality care delivery.

The family-centred care (FCC) model is a paradigm shift in the healthcare system that strives to change nurses' attitude of viewing families as *visitors* to families as *partners* in healthcare (Institute of Patient- and Family-Centred Care, 2010). Mitchell, Chaboyer, Burmeister and Foster (2010:543) describe the FCC as a model of care that is focused on the principle that the family forms an important part of a patient's psychological and physical health. The FCC is guided by three key elements, namely mutual respect, collaboration, and support. Furthermore, the family is considered the core contributor to the patient's attainment of positive health outcomes, as their presence at the bedside and involvement in routine activities and healthcare decisions is vital (Gooding, Cooper, Blaine, Franck, Howse & Berns 2011:20). Al-Mutair, Plummer, O'Brien and Clerehan (2013:1806) emphasise the importance of caring for the family by giving them support through honest information sharing and involvement in healthcare decisions.

A family is a social institution that functions together, and the inability of one system to function affects the entire system (family) (Mina, Mansoureh, Naima & Nooredin 2014:10). This experience is common to families with patients admitted to the ICU.

Canon (2011:241) points out that the “critical illness of a family member negatively impacts on the entire family”. Nurses have a responsibility to support, understand and address the unique characteristics and needs of individual families in order to promote positive health outcomes and enhance family satisfaction (Bailey, Sabbagh, Loiselle & McVey 2010:115). Huffiness, Johnson, Naranjo, Lissauer, Fishel, Howes, Pannullo, Ralls and Smith (2013:56) maintain that family satisfaction can be achieved through understanding the FCC model and embedding the principles in all patient care activities and communication between families and healthcare professionals.

Coyne, O’Neil, Murphy, Costello and O’Shea (2013:2562) state that the FCC model “is consistent with the envisaged ideals of family empowerment, respect, personal autonomy and recognition of human rights”. Family members need to be provided with adequate information regarding the condition of their family member, treatment plan and prognosis, to enable them to participate fully in patient care activities and healthcare decision making. The plan of care is centred on both the patient and the family as core recipients (Coyne et al 2013:2563). Hardin and Kaplov (2007:356) refer to the synergy model of patient care based on the assumption that the needs and characteristics of the patient and the family should guide and match the nurses’ capabilities.

The FCC model originated in child healthcare and was a seismic shift in healthcare, from patriarchy and paternalism to partnership (Coyne et al 2013:2562). Today, FCC is acknowledged and approved at policy level in many developed countries. In addition, FCC is endorsed by professional organisations such as the Institute of Medicine, the American College of Critical Care Medicine, and the American Academy of Paediatricians (Urden, Stancy & Lough 2010:342). Nevertheless, FCC is not consistently practised and implemented. Barriers to the implementation of FCC include lack of knowledge, support and resources, and health professionals’ attitudes (Yousefi et al 2012:297).

Shields (2012:2632) found that nurses’ generally did not understand and were not committed to implementing the FCC model, which resulted in family dissatisfaction with care provision. Moreover, despite being recognised internationally, FCC is not

well implemented in clinical practice, especially in sub-Saharan developing countries (Kuo, Houtrow, Arango, Kuhlthau, Simmons & Neff 2011:298).

1.2 RATIONALE FOR THE STUDY

The researcher is a registered nurse in a general ICU in Botswana. As part of the ICU staff, the researcher observed that nurses' and physicians' plan of care was guided by set standards and policies approved by the hospital management. However, the policies do not recognise or acknowledge FCC as crucial to patient outcomes or to increased family satisfaction (Brooke & Warren 2014:394). The researcher found that quarterly patient/client satisfaction surveys revealed discontent with verbal and non-verbal communication with family members and general staff members in day-to-day interaction and communication in the ICU. For example, the following complaints were noted in the customer satisfaction surveys:

Nobody explains anything to me; I don't know what is going on with my mother's illness.

I was not allowed to enter the unit outside visiting times.

Nobody talked to me, they all ignored me.

Adopting a holistic, assertive and supportive approach in a critical care setting is important considering the nature of the patients' conditions and the highly sophisticated environment which evoke fear in the family (Choi & Bosch 2013:67).

Family forms an important part of an individual's psychological and physical health and a family has a role to play in the patient's recovery (Mitchell et al 2010:542). Therefore nurses have a responsibility to assess, identify and address family needs in order to ensure family satisfaction with care (Yousefi et al 2012:297). Deficiencies in FCC implementation internationally include nurses' attitudes towards families and unavailability of resources as hindering factors (Coyne et al 2013:2561). Family support and involvement in healthcare and decision making had never been formally evaluated in the researcher's general ICU. Therefore, the lack of a well-established FCC model of care in the ICU contributed to incidents of customer dissatisfaction with care. Accordingly, in order to reduce family complaints, improve family satisfaction and patient health outcomes, and establish a family-centred

environment, the researcher wished to explore the views of families regarding FCC in the ICU. Moreover, based on the study findings, strategies would be recommended to enhance a family-centred critical care environment and thereby improve family satisfaction. This should assist in establishing a family-centred environment in the selected ICU and other ICUs in Botswana.

1.3 PROBLEM STATEMENT

A research problem is “a troubling condition which can be solved by generating evidence through research” (Polit & Beck 2012:73). A problem statement “articulates the problem and describes the need for a study through the development of an argument” (Polit & Beck 2012:73). Family involvement in the care of patients has been found to have a positive effect on the patient’s well-being and recovery (Brooke & Warren 2014:398; Obringer, Hilgenberg & Booker 2012:1651). The concept of “caring” in the context of the family refers to the support and family involvement in the care and decision making of their critically ill family member (Al-Mutair et al 2013:1806). Family support and involvement in healthcare and decision making had never been formally evaluated and the lack of a well-established FCC model of care in the ICU contributed to incidents of customer dissatisfaction with care. In order to reduce family complaints, improve family satisfaction and patient health outcomes, and establish a family-centred environment, the researcher wished to explore and describe the views of families regarding FCC in the ICU and recommend strategies to enhance a family-centred critical care environment and thereby improve family satisfaction.

1.4 AIM OF THE STUDY

Based on the problem, the aim of the study was to explore and describe the views of family members of patients admitted in a general ICU in Botswana regarding family-centred care.

1.5 RESEARCH QUESTION

In order to achieve the aim, the study wished to answer the following question:

What are the views of family members of patients admitted in a general ICU regarding family centred care?

1.6 PHILOSOPHICAL ASSUMPTIONS

Assumptions are basic principles that are assumed to be true based on logic and reason, without proof or verification (Brink, Van der Walt & Van Rensburg 2006:25; Polit & Beck 2012:11). The researcher's philosophical assumptions guide the research design and the study (Polit & Beck 2012:11).

1.6.1 Paradigm

A paradigm refers to a "basic set of beliefs that guide action" (Creswell 2014:6). According to Botma, Greeff, Mulaudzi and Wright (2010:40), a paradigm "explains the phenomenon that the researcher intends to study; the questions to be asked; how to ask them, and the process to be followed in interpreting the answers. Research is underpinned by a paradigm or the researcher's philosophical worldview and it is important to be aware of the underlying philosophical assumptions." This study will follow the constructivist approach and the following assumptions will be discussed.

1.6.2 Constructivism

The researcher used constructivism as the basis for the study. A constructivist paradigm is also referred to as a naturalistic paradigm (Polit & Beck 2012:12). Polit and Beck (2012:12) describe constructivism as an approach that believes that multiple interpretations of reality exist, and that the goal of research is to understand how individuals construct reality within their context. Botma et al (2010:43) define constructivism as the way individuals interpret or give meaning to the world around them. Accordingly, the researcher wished to explore the families' experiences and views of family-centred care in the ICU through interaction with family members with patients admitted in the ICU. The constructivist paradigm shares the same principles as the appreciative inquiry (AI) theoretical framework therefore the researcher included this framework as part of the basis that guided the study. The constructivist paradigm is underpinned by ontological and epistemological assumptions:

1.6.2.1 Ontological

Ontology is the study of being or reality. Botma et al (2010:40) and Denzin and Lincoln (2011:102) describe ontology as the way individuals perceive life. In addition, multiple realities exist and the content and form depend on how individuals interpret them. Ontological assumptions are concerned with the reality that is being investigated (Mouton 2002:124). In this study the researcher investigated the views of family members with patients admitted in the general ICU on family-centred care.

1.6.2.2 Epistemological

Epistemology is concerned with the nature of knowledge, its possibility, scope and general basis. Epistemology refers to the way individuals understand reality from what they know and what is observed through interaction with the environment (Denzin & Lincoln 2011:103; Botma et al 2010:40).

Epistemological assumptions, then, are assumptions about the nature of knowledge and science or about the content of truth and related reality (Mouton 2002:123). The researcher was independent from and had no influence on the participants. This enabled the researcher to generate knowledge and gain insight into the phenomenon (FCC) through interaction with the participants (family members) in the ICU. The interaction took place in one-to-one appreciative inquiry (AI) interviews.

1.6.3 Appreciative inquiry (AI)

A framework is “an abstract, logical structure of meaning” (Burns & Grove 2014:116). The study framework is referred to as the conceptual or theoretical framework and guides the development of the study. The researcher used constructivism and the appreciative inquiry (AI) theoretical framework as the basis for the study.

Every organisation has something that works well. AI is a generative group process that is used to positively challenge the existing assumptions of an organisation by asking questions about the strengths and successes of an organisation or a component thereof with the purpose of developing and implementing an improvement plan for the organisation or the specific component. According to Reed (2007:2), AI is a process that concentrates on exploring ideas that people have

about what is valuable in what they do and then tries to work out ways in which this can be built on and improved. The emphasis is firmly on appreciating people's activities and responses, rather than concentrating on their problems. Cooperrider, Whitney and Stavros (2008:3) describe AI as "an approach to organisational analysis and learning which is intended for discovering, understanding, and fostering innovations in social organisational processes".

1.7 RESEARCH DESIGN

A research design is "a set of logical steps taken by the researcher to answer the research question" (Brink, Van der Walt & Van Rensburg 2006:92). Denzin and Lincoln (2011:118) state that a research design links theoretical paradigms to strategies of inquiry and data-collection methods. The researcher adopted a qualitative approach to the study. Holloway and Wheeler (2013:3) describe qualitative research as "a form of social inquiry that is based on how individuals view the world around them and make sense of it". The researcher used a qualitative, contextual, explorative, and descriptive research design in order to explore and describe the lived views of families with patients admitted in the ICU regarding FCC.

1.7.1 Qualitative

Qualitative research is a means of exploring and understanding people's conduct, perceptions and views of the world in which they live (Creswell 2014:246). Researchers in nursing use a qualitative approach to look at participants' life experiences, actions, beliefs and perceptions. Qualitative research investigates phenomena in an in-depth and holistic manner, through the collection of rich narrative information using a flexible research design (Polit & Beck 2012:739). This study wished to discover and understand the truth individuals (family members) attached to a social or human phenomenon (FCC) within a specific environment (ICU). Table 1.1 lists the characteristics of a qualitative research design and their application to the study.

Table 1.1 Characteristics of a qualitative research design

CHARACTERISTICS	APPLICATION
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Context bound	The researcher collected information in the selected ICU from families with patients admitted for at least 72 hours.
Natural setting	Data was collected in the selected ICU.
Primacy of data	The researcher used the views expressed by the families to generate new information.
Researcher as the research instrument	The researcher was involved in data collection and analysis, and interpretation.
'Emic' perspective	The researcher has 6 years' work experience in the selected ICU and is knowledgeable about the ICU environment.
Analysis of data was on-going	Data analysis commenced simultaneously with data collection until data saturation was reached.
Researcher stays in the field	The researcher, who is also an ICU nurse, was intensely involved throughout the study.

Adapted from: Holloway and Wheeler (2013:3) and Creswell (2014:38)

1.7.2 Contextual

A contextual design aims at gathering in-depth, rich information on the phenomenon being studied in its natural setting. Ideas are psychologically constructed by individual participants in the context of that particular setting (Polit & Beck 2012:246). In this study, the context referred to the ICU and the participants' social framework in which the phenomenon took place. Therefore the researcher wished to understand the participants' (family members) social framework, the environment (ICU) and their experience and perceptions of the phenomenon (FCC in the ICU) (Burns & Grove 2014:38). Accordingly, the researcher conducted the study in the ICU where she works as an ICU nurse.

1.7.3 Explorative

An explorative research design is used when not much is known about the phenomenon under study. Exploratory research investigates the full nature of the phenomenon, the manner in which it is manifested, and other related factors in order to gain a better understanding thereof (Polit & Beck 2012:246).

1.7.4 Descriptive

According to Merriam (2009:7), descriptive designs systematically uncover the meaning of a study phenomenon as perceived by the participants. A descriptive design identifies phenomena of interest and describes variables in a study situation (Burns & Grove 2011:692). Descriptive research has as its main objective to “accurately portray all of the characteristics of persons, situations, or groups, and the frequency with which certain phenomena occur” (Polit & Beck 2012:725). In this study, the researcher explored and described the participants’ (families with patients admitted in the ICU) views of FCC they received in the ICU.

1.8 SETTING

In research, the setting is “the site or location used to conduct a study” (Burns & Grove 2014:373). Holloway and Wheeler (2010:41) describe the setting as “the physical location of the research study”.

The study was conducted in a general ICU of a government District Hospital in Botswana. The hospital has a capacity of 250 beds and admits an average of 150 to 200 patients per month. The following services are provided: general medicine; surgical; obstetrics and gynaecology; paediatric care; maternity care; outpatient, and emergency care. The general ICU admits adults and children with medical, surgical, obstetrics and gynaecological conditions and has a total of six beds. The total number of patients admitted in the general ICU in a month ranges between 10 and 15. There are a total of 11 registered and experienced ICU nurses, including two qualified ICU nurses. This setting was the real everyday environment where critically ill patients are admitted and managed, and where families and ICU nurses interact on a daily basis.

1.9 RESEARCH METHODOLOGY

Research methodology is the plan for conducting the specific steps of a study (Burns & Grove 2014:707). Denzin and Lincoln (2011:104) describe research methodology as “a process of how new knowledge is generated”. Burns and Grove (2014:707) add that qualitative research methodology is both flexible and evolving as the researcher explores the depth, richness and complexity of the information (data). Research methods are the techniques or tools researchers use to collect, structure and analyse data systematically (Polit & Beck 2012:741). The research methodology includes the population, sample and sampling, data collection, analysis and interpretation, and ethical considerations.

1.9.1 Population

According to Polit and Beck (2012:273), a population is “the entire aggregate of cases in which a researcher is interested”. A research population refers to “an aggregation of elements from which the sample is actually selected” (Babbie 2015:199). In this study, the population consisted of families of patients admitted in a selected ICU for at least 72 hours.

1.9.2 Sample

A sample refers to a subset of a population (individuals, elements or objects) or a group selected to act as representatives of the population as a whole (Polit & Beck 2012:275). A sample is a subset of individuals in the population whose composition meets specific inclusion criteria (Babbie 2015:199). The sample consisted of family members of patients admitted in the ICU for at least 72 hours. To be included in the study, the participants had to be

- Family members with a patient admitted in the ICU for more than 72hrs
- Aged 18 years and above
- Fluent in either Setswana or English

1.9.3 Sampling

Sampling refers to the “process of selecting the sample from a population in order to obtain information regarding the phenomenon in a way that represents the population of interest” (Brink et al 2006:124). According to Polit and Beck

(2012:275), sampling is “a process of selecting a portion of the population to represent the entire population, so that inferences can be made about the population”. In this study, non-probability, purposive sampling was used. Purposive sampling refers to selecting “subjects typical of the population in question or particularly knowledgeable about the issues under study” (Brink et al 2006:141). The researcher used purposive sampling to select a total of 8-10 family members with patients admitted in the ICU for at least 72 hours.

1.10 DATA COLLECTION

Data collection is a process of gathering information related to the research question in a systematic way to address a research problem (Polit & Beck, 2012:725). The researcher used an inductive process to collect in-depth information of the families’ views on family-centred care in the ICU.

1.11 DATA-COLLECTION METHOD

Data was collected by means of AI interviews. The researcher wished to explore and describe what the participants viewed as the best FCC rendered to them by the healthcare professionals (HCPs) and what they wished for FCC. The researcher in collaboration with the supervisors developed an AI interview guide, using the AI 5-D cycle, namely **Define** (clarification of the problem); **Discover** (appreciating the best of the situation); **Dream** (envisioning what might be); **Design** (constructing the ideal situation), and **Destiny** (empowering and improvising). See Annexure B for a copy of the AI interview guide.

The interview guide was semi-structured and consisted of three open-ended questions. The participants were given the opportunity to freely express their views of what they appreciated most about FCC, the challenges, wishes and dreams. The participants expressed their views or stories as they wished and not according to the researcher’s preconceptions or bias (Reed 2007:128). The one-to-one interviews were conducted in a private room, using the questions on the interview guide and probing questions, if necessary, and lasted approximately 45 minutes. Following the interview, the participants could ask questions to clarify any aspect of the interview or information they shared with the researcher.

Following data collection the researcher organised the data by transcribing the tape-recorded interviews verbatim, and keeping the transcriptions as well as the field notes taken during the interviews in folders. All the data collected was kept in a safe place accessible only to the researcher and the supervisors.

1.11.1 DATA ANALYSIS

Data analysis is the systematic organization and synthesis of data to establish order, structure and meaning to qualitative data collected (Polit & Beck 2012:725; Botma et al 2010:220). Data analysis started during data collection and continued until the end of the study (Botma et al 2010:222; Polit & Beck 2012:725). Since it was a labour-intensive and time-consuming process, a transcriber assisted the researcher. The researcher used Tech's (1990:142-145) eight-step method of data analysis (Creswell 2014:186; Botma et al 2010:224) (see table 1.2).

Table 1.2 Tesch's (1990) eight-step data analysis method

STEPS	APPLICATION
Step 1: Read through all the transcriptions carefully in order to get a sense of the whole.	The researcher read through all the transcriptions and made notes of the participants' general ideas.
Step 2: Select one document, perhaps the shortest, most interesting one, and read through it to get the underlying meaning. Repeat the same procedure with several documents and write down thoughts in the margin.	The researcher took one transcribed interview, read through it thoroughly and wrote down ideas. The researcher read through more transcriptions and wrote down thoughts in the margins.
Step 3: Make a list of all the topics from the transcriptions. Cluster similar topics together and form them into columns as major, unique and leftover topics.	The researcher listed all the topics, clustered similar topics into columns labelled major, unique and others.
Step 4: Abbreviate the topics as codes next to the appropriate segments of the text to see if new categories and codes	The researcher abbreviated the topics as codes and checked if more categories and codes emerged.

emerge.	
Step 5: Find the most descriptive wording for the topics and turn them into categories.	The researcher described similar topics and turned them into categories.
Step 6: Reduce the total list of categories by grouping topics that related to each other.	The researcher grouped related topics together and reduced the number of categories.
Step 7: Make a final decision on the abbreviation for each category and list alphabetically.	The researcher decided on the abbreviations for the categories and arranged them alphabetically.
Step 8: Assemble the data for each category in one place and perform preliminary analysis. Recode the existing data, if necessary.	The researcher assembled the data for each category together and performed preliminary (initial) analysis.

Adapted from: Creswell (2014:186) and Botma et al (2010:224)

1.12 TRUSTWORTHINESS

Trustworthiness is “the degree of confidence that qualitative researchers have in their data, using the strategies of credibility, dependability, confirmability, transferability and authenticity” (Polit & Beck 2012:745). In this study, the researcher applied the strategies of credibility, dependability, transferability, confirmability and authenticity to ensure trustworthiness (see chapter 3 for full discussion).

1.13 SIGNIFICANCE OF THE STUDY

A research study should be significant to the nursing profession and contribute to the body of knowledge (Brink et al 2006:61). Health policy, education, management, and provision of quality healthcare service should benefit from this study. The findings and recommendations should assist the Ministry of Health and policy makers to develop and introduce strategies to improve family-centred care in ICUs in Botswana. Medical and nursing education and training should include modules on patient-and family-centred care. This would equip healthcare professionals to feel

confident in themselves and their skills in providing quality healthcare. On-going, in-service training should be implemented to boost nurses' morale, competence and work satisfaction. Hospital management would benefit from having clear guidelines and policy for managing the facilities and staff. The implementation of FCC policy and strategies would enable families to understand and assume their partnership, role and contribution to patient outcomes, reduced hospital stay and cost, and aftercare. This, in turn, would increase patient and family responsibility and satisfaction and contribute to the overall health of the community.

1.14 DEFINITIONS OF KEY TERMS

In this study, the following key terms are used as defined below.

- **Family centred care (FCC)**

Family-centred care (FCC) is a partnership approach to healthcare decision making, between the family and healthcare providers (Kuo et al 2011:297). The family forms an important part of individuals' psychological and physical health, therefore the healthcare providers work in collaboration with families regarding care decision making that support and respect the wellbeing of the family and the patient (Mitchell et al 2010:549). Gooding et al (2011:20) describe FCC as a way of caring for the patient that is based on the belief that families have an important role in the attainment of positive health outcomes through physical, psychological and social support. In this study, FCC refers to holistic nursing care that is supportive and respectful of the needs of the critical patient's family through collaborative decision making and information sharing.

- **Family**

A family is a social institution that functions together, and the inability of one system to function affects the entire system (family) (Mina et al 2014:12). This experience is common to families with patients admitted to the ICU. Canon (2011:241) points out that the "critical illness of a family member negatively impacts on the entire family". Sharma (2013:308) describes a family as consisting of "husband, wife and children, though other relatives may find a place close to this nuclear group, which is united by moral, legal, religious and social

rights and obligations”. In this study, family refers to both the nuclear and extended family members; that is, mother, father, children and their relatives.

- **Intensive Care Unit (ICU)**

The intensive care unit is a highly specialised unit within a healthcare facility where patients with acute, life-threatening illness or injury are admitted (Urden et al 2010:5). In this study, a general ICU refers to a highly specialised unit which admits medical, surgical, obstetrics, gynaecology and neurology critically ill, adults and paediatric patients, for advance monitoring, management and life support. More specifically, it refers to the selected ICU where the study was conducted.

- **Registered Nurse (RN)**

In terms of the *Botswana Nurses and Midwives Act, 1 of 2002*, Cap 14.05: “Registered” means registered under this Act, and “registered nurse” or “registered midwife” shall be construed accordingly. In this study, a registered nurse refers to a qualified or experienced Intensive care nurse, registered with the Botswana Nursing Council and providing care in a general ICU.

1.15 ETHICAL CONSIDERATIONS

When humans are used as study participants care must be taken in ensuring that their rights are protected (Polit & Beck 2012:748). Babbie (2015:62) points out that the researcher must adhere to set rules or standards of ethical conduct, in order to safeguard the safety of research participants. Accordingly, the researcher obtained permission to conduct the study, obtained informed consent from the participants, and observed the ethical principles of beneficence, respect for human dignity, and justice (Polit & Beck 2012:748). Chapter 3 discusses the ethical considerations in full.

- **Permission**

The researcher obtained permission to conduct the study from the University of Pretoria: Faculty of Health Sciences Research Ethics Committee; the Ministry of Health, Botswana and the participating hospital to conduct the

study there (see Annexure D). Permission was also obtained from the ICU manager to interview the participants in the ICU (see Annexure D).

- **Informed consent**

The researcher informed the participants of the purpose and significance of the study, that participation was voluntary and that they were free to withdraw from the study at any time should they so wish. The participants then signed informed consent to participate.

- **Respect for human dignity**

Respect for human dignity refers to the right to self-determination and full disclosure (Polit & Beck 2012:173). After the researcher explained the purpose, nature and significance of the study to the participants, they could decide freely to participate or refuse to participate.

- **Beneficence**

The right to protection from discomfort and harm is based on the ethical principle of beneficence. The principle of beneficence states that one should do good and, above all, do no harm (Burns & Grove 2014:165). Accordingly, the researcher ensured that the participants were not exposed to any physical, emotional, social or other harm.

- **Justice**

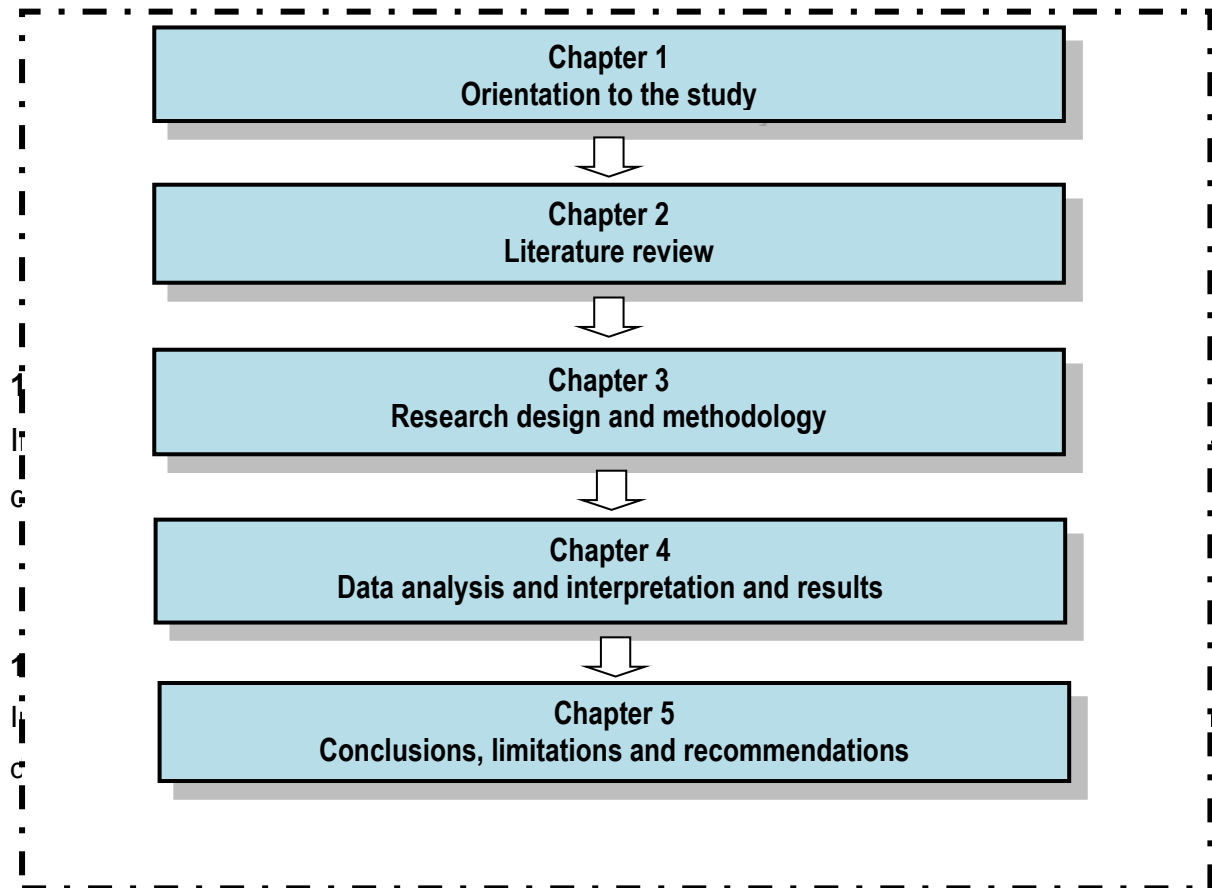
The principle of justice refers to the right to privacy and the right to fair treatment (Polit & Beck 2012:174). The researcher assured the participants of privacy, confidentiality and anonymity, and treated all the participants with respect and fairly (Burns & Grove 2014:186).

1.16 DISSEMINATION OF RESULTS

The researcher will disseminate the research findings to colleagues at the workplace through workshops conducted in the departments or health facility. The findings will also be published in approved nursing journals for peer review, and be presented to the community through the hospital advisory committee.

1.17 LAYOUT OF THE CHAPTERS

The study consists of five chapters. Figure 1.1 illustrates the layout of the study.



1.18 CONCLUSION

This chapter described the problem, purpose and significance of the study as well as the research design and methodology. Key terms were defined and ethical considerations briefly discussed.

Chapter 2 discusses the literature review undertaken for the study.

CHAPTER 2

LITERATURE REVIEW

“...attempt the end and never stand to doubt; nothing is so hard, but search will find it out...”

- Robert Herrick -

2.1 INTRODUCTION

Chapter 1 introduced the study and briefly described the problem, purpose, research design and methodology. This chapter discusses the literature review conducted for the study. Burns and Grove (2014:67) describe a literature review as “a written, well-organised presentation of what has been published on a topic. A literature review lays the foundation for the research as it gives a representation of what is known and not known about the research problem.”

The literature review focused on the history of family-centred care (FCC); definition, principles and models of FCC; application of FCC in the ICU; needs of families, and the benefits of FCC.

2.2 HISTORICAL OVERVIEW

Family-centred care (FCC) is a form of health care provision that recognises the importance of the family for children in hospital. The first hospitals to care exclusively for children were the L’Hopital Des Enfants-Malades in Paris, France in 1802 and the Children’s Hospital of Philadelphia in the USA in 1855. In the hospital setting, families were relegated to a visitor or attendant role (Kuo et al 2011:296). World War II brought about social change and many researchers examined paediatric care in hospitals. In the 1950s, with the increased awareness and recognition of child/family separation trauma in the inpatient setting, hospital policies were altered to allow for rooming-in, open visiting hours, sibling visits, and accompanying children to surgeries (Jolly & Shields 2009:164; Meert, Clark & Eggly 2013:762).

The concept of FCC has been promoted most prominently in the context of child health and originated in the 1940s when clinicians realised the need of families to be

in close proximity to their hospitalised children. Allowing family members to be there for their sick child is believed to have a positive impact on the child's disease outcomes, especially in the neonatal ICU (Gooding, Cooper, Blaine, Franck, Howse & Berns 2011:21). Festini (2014:33) points out that FCC originated from the paediatric philosophy that emphasised physical care, technical abilities, and family-child emotional detachment as a potential threat to a child's path to recovery.

Prior to the mid-20th century, mothers were not allowed to stay in the hospital with their admitted children (Jolley & Shields 2009:165). The separation of mothers and their children resulted in psychological trauma to children who often stayed in the hospital for long periods, especially for chronic illnesses such as tuberculosis, and the exclusion of parents to visit was mainly due to fear of spread of infections (Jolley & Shields 2009:165). However, experiences of World War II resulted in changes in social expectations for the care of hospitalised children, which facilitated the eventual implementation of FCC. The changes in the care of hospitalised children saw the evolution of FCC chiefly as a result of the work of two British theorists, Bowlby and Robertson (Jolley & Shields 2009:166).

In 1992, a group named *Family Voices* was established in Albuquerque, USA to advocate for children's health needs and paediatric health care (Meert et al 2013:762). Later, the Institute for FCC (now Patient- and Family-centred Care) was founded to establish and strengthen partnerships between patients, families and healthcare professionals in all healthcare settings. FCC is now supported by research bodies and organisations such as the Institution of Medicine, which also emphasises partnership, information sharing amongst families and healthcare professionals (Meert et al 2013:762).

Between the 1970s and the 1990s many HCPs and other supporters campaigned for FCC. In 1993, the Institute of Patient and Family-centred Care introduced the principles of FCC (Khalaila 2014:43). The FCC model gained acceptance and understanding amongst healthcare providers in both the neonatal and adult ICU and is endorsed by professional organizations such as the Institute of Medicine, American College of Critical Care Medicine, and American Academy of Paediatrics

(Johnson 2012:14; Meert et al 2013:763). FCC has had a positive effect on healthcare delivery and is widely recommended by medical societies, healthcare systems, and institutes of medicine as an effective strategy for quality healthcare delivery (Kuo et al 2011:301).

2.3 FAMILY-CENTRED CARE (FCC)

Family-centred care (FCC) is a model of care based on the principle that the family plays an important role in determining a patient's psychological and physical wellbeing. Optimal outcomes are achieved with active inclusion of the family in providing emotional, developmental and social support to the patient. It is a partnership approach to healthcare decision making between the family and the healthcare provider (Kuo et al 2011:297; Gooding et al 2011:20). In addition, the FCC model empowers families and moves healthcare professionals towards collaborative care instead of task- or procedure- oriented care (Thompson, Moran, Axelin, Dykes & Flacking 2013:7). Family members effectively contribute to medical decision making when there is open, honest communication between the HCP and the family, and when care is centred in the patient's unique cultural/ethical beliefs, family/community structure and traditions (Gooding et al 2011:26).

The FCC philosophy believes that the family can better explain the standard of care delivery rendered, their experiences, and what can be done better to improve care delivery (Kuo et al 2011:299). Johnson (2012:102) describes FCC as a model of care that shapes policies, programmes, facility design and HCP daily interactions, which ultimately results in better health outcomes, wiser allocation of resources, and greater patient and family satisfaction.

There is no consensus on the definition of FCC practices and processes (Kuo et al 2011:1). FCC comprises four principles or core concepts, namely dignity and respect; information sharing; participation, and collaboration (Brooke & Warren 2014:397).

2.4 PRINCIPLES OF FAMILY-CENTRED CARE

The four principles or core concepts of FCC are dignity and respect; information sharing; participation, and collaboration (Brooke & Warren 2014:397)

2.4.1 Dignity and respect

Healthcare providers (HCPs) need to respect families' values, beliefs and cultural background by including them in the planning and care delivery. HCPs should recognise individual families as unique and therefore honour and respect their views and choices as well as the skills and expertise brought into the relationship (Kuo et al 2011:301; Clay & Parch 2016:43).

2.4.2 Information sharing

There should be open communication and sharing of accurate and unbiased information between the HCP and the family to enable families to make informed decisions, and effectively participate in care decision making. In Bahrain, Fateel and O'Neill (2016:66) found that information related to the management, care and support of the patient should be given at a level and in language that the family can understand.

2.4.3 Participation

HCPs should actively engage families as part of all the planned activities, care and decisions. Families build on their strengths by participating in experiences that promote control and independence. (Khalaila 2014:42; Dudley, Ackerman, Brown & Snow 2015:258).

2.4.4. Collaboration

HCPs and families should interact together in all care planning and performance of patient care activities. Families must be included in all institutional policies and programme development and implementation, in order to promote partnership and greater patient and family satisfaction (Khalaila 2014:43). The FCC philosophy centres on the family as the core contributor to the patient's attainment of positive health outcomes (Mitchell et al 2010:545). Therefore HCPs have a responsibility to

provide families with physical and psychological support by building mutual, respectful relationships, open communication and information sharing in order to facilitate positive outcomes (Gooding et al 2011:26).

Kuo et al (2011:299) maintain that families are “experts” in describing the standard of care rendered, their experiences and what can be done better to improve care processes. The continuous evaluation of care processes by the family may lead to HCPs’ change of attitude towards clinical care delivery.

2.5 FAMILY-CENTRED CARE MODELS

The FCC models of care include holistic nursing care vs. paternalistic care, and the synergy model.

2.5.1 Holistic nursing care vs. paternalistic care

A family-centred care environment aligns itself with the FCC principles of partnership, information sharing, negotiation, respect for the family, and care that is in the context of the family and the community (Kuo et al 2011:298). In an Iranian study, Yousefi et al (2012:296) found that nursing care in the ICU evolved from a patient-centred model to a holistic approach, appreciating the family needs as crucial to the outcomes of the patient’s disease process. Therefore Al Mutair et al (2013:1806) point out that ICU nurses have a responsibility to assess family needs, and support, understand and address their unique characteristics.

Coyne et al (2013:2531) maintain that illness is a family affair, the patient is only half of the patient and the other half is the family. A family is a social institution that functions together, and the inability of one system to function affects the entire system (Mina et al 2014:8). Furthermore, Mitchell et al (2010:544) stress that the family greatly influences the patient’s health outcomes by participation in care activities and being in close proximity with the patient, emotionally and physically. The family also acts as the “voice” of the very ill relative who is either unconscious or unable to make decisions.

Bailey et al (2010:115) emphasise the importance of providing support to families with critically ill patients, through timely assessment and addressing of their needs, because family members are often distressed by the illness and admission of their loved one. Lack of family support by clinicians often results in psychological trauma to the family, which manifests in the form of anger, anxiety, depression and fear, and leads to dissatisfaction with care and poor patient outcomes. According to Yousefi et al (2012:296), this phenomenon is common in families with patients admitted in the ICU, because clinicians focus their attention mainly on the patient's physiological aspect of the disease, and do not recognise the family as part of the care process. The paternalistic model of care is more patient centred and focuses on getting the work done (Jolley & Shields 2009:58). Consequently, according to Gooding et al (2011:21), the "physician's role was more authoritative, nurses played the role of gate keepers and families were bystanders". Therefore a holistic model of care in ICU is mandatory.

Holistic nursing care has extended its scope to include family members (Gooding et al 2011:21). Holistic nursing care not only focuses on the physiological aspect but also on the psychological and physical health of the patient (Gooding et al 2011:22). Family members play an active role in the provision of emotional, social and developmental support therefore they should be considered an important part of the patient management by collaborating and supporting them through mutual respect (Yousefi et al 2012:297). Consequently, Bailey et al (2010:112) emphasise that clinicians have a responsibility to assess and understand the unique needs and characteristics of family members so as to enhance the FCC principles of partnership, collaboration and mutual respect.

Family needs are an integral part of FCC and are considered crucial determinants of the patient's disease outcome (Brooke & Warren 2014:396). According to Brooke and Warren (2014:396), FCC "moves beyond patient-clinician interaction by considering the needs of family members, not just the patient".

Families have five main needs, namely assurance; information; proximity; comfort, and support (Al Mutair et al 2013:1807). Furthermore, families highlighted the need

for information and assurance as the most important amongst the five categories (Al-Mutair et al 2013:1808). According to Obringer, Hilgenberg and Booker (2012:1653), family members need to be given honest information about the status of their patient's illness and their management; they need to be reassured and supported through engaging them in decisions and care activities of their patient. Consequently, it is important for clinicians to continuously assess the family's perceptions of care needs in order to effectively provide quality care which is centred on the patient's family as the core contributor to optimal health outcomes (Obringer et al 2012:1654). Creating a family-centred ICU requires more than organizing care delivery around the family but includes having clinicians adequately trained in the implementation of the FCC model of care (Al Mutair et al 2013:1810; Obringer et al 2012:1654).

2.5.2 Synergy model

The synergy model describes the needs and characteristics of patients and family as the fundamental drive that determines the nurse's characteristics and competencies (Hardin & Kaplov 2008:4). Ultimately, the interconnection that develops between patient, nurse and environment results in the achievement of the desired health outcomes for the patient. The synergy model regards nursing as more than merely a set of tasks, but defines nursing through highest level characteristics and competencies (Hardin & Kaplov 2008:3). The synergy model aims at re-inventing care practices and improving nursing skills appropriate for the care of critically ill patients (Hardin & Kaplov 2008:6). The model's meta-paradigms are based on evidence from nursing interventions and are synonymous with the FCC principles, namely mutual respect, collaboration, and support (Mitchell et al 2010:155; Hardin & Kaplov 2015:120). Although individual patients and families are unique with differing vulnerability to illness, basically they possess similar needs experienced along a scale ranging from health to illness. Therefore the role of the nurse is guided by the needs of the patient and the family (Swickard, Swickard, Reimer, Lindell & Winkelman 2014:24).

Table 2.1 summarises the eight patients' characteristics, and Table 2.2 summarises the eight nurses' competencies (Swickard et al 2014:18; Hardin & Kaplov 2015:10).

Table 2.1 Patients' characteristics

CHARACTERISTICS	DESCRIPTION
Resilience	The ability to recover quickly during an illness using compensatory mechanisms
Vulnerability	High risk to potential stressors that may likely have a negative impact on the disease outcomes.
Stability	The ability to maintain a stable condition throughout the disease
Complexity	Complicated entanglement of two or more systems
Resource availability	Refers to the technical, fiscal, personal, psychological and social support rendered
Participation in care	The extent to which the family is involved in care aspects
Predictability	A situation that allows one to foretell certain changes in events
Participation in decision making	The extent to which the family is involved in care decision making.

Adapted from: Swickard et al (2014:18); Hardin and Kaplov (2015:10)

The patient's degree of illness can be described by a number of interrelated characteristics that assist the nurse to prioritize care activities aimed at restoring the patient to an optimal level of health (Swickard et al 2014:18; Hardin & Kaplov 2015:10). Table 2.2 reflects the nurse's competencies that match the patient characteristics and the family needs in order to promote and achieve positive patient's outcomes and family satisfaction.

Table 2.2 Nurses' competencies

CHARACTERISTICS	DESCRIPTION
Clinical judgment	The ability to make clinical decisions regarding patient care management through formally gained knowledge and experience
Advocacy/moral agency	The ability to act as the voice for the patient, family and community in resolving clinical and ethical issues.
Caring practices	Nursing activities compatible with the needs and characteristics of the patient and family. Creation of a compassionate and therapeutic environment
Facilitation of learning	The ability to facilitate patient and family education
Collaboration	Being responsible for identifying, initiating and supporting consultation with supportive services, such as pastoral care and social services
Systems thinking	An appreciation of the care environment and the holistic interrelationship existing within the healthcare facility
Diversity of responsiveness	The ability to respond, anticipate and integrate personal differences into patient care
Clinical inquiry	The ability to question and evaluate practice through research initiatives to promote best practice.

Adapted from: Swickard et al (2014:18) and Hardin & Kaplov (2015:10)

This study was based on the American Association of Critical Care Nurses (AACN) synergy model to explore the family's perceptions of FCC in an ICU because of the critical nature of the environment being studied and the seriousness of the patient's condition (Hardin & Kaplov 2015:10). It is imperative for the critical care nurse to understand the patient's needs and characteristics in order to prioritize care activities for the patient and family with the aim of achieving desirable outcomes (Swickard et al 2014:22; Hardin & Kaplov 2015:10). Moreover, the AACN model incorporates core concepts essential for the attainment of a family-centred environment in the ICU. Consequently, this model aims at restructuring the nursing care practices and highlighting the desired nursing skills required to care for the critically ill patient (Hardin & Kaplov 2015:223). The core or central concepts are interrelated and the core building blocks for promoting an FCC environment. The AACN model is based on five assumptions (Hardin & Kaplov 2015:7-8):

- Patients are biological, psychological, social, and spiritual entities, the patient presents at a particular developmental stage. The whole patient (body, mind and spirit) must be considered.
- The patient, family and community all contribute to a context for the nurse-patient relationship.
- Patients can be described by a number of characteristics that are all connected and contribute to each other. These characteristics cannot be looked at in isolation.
- Nurses can likewise be described on a number of dimensions; the interrelated dimensions paint a profile of the nurse.
- The goal of nursing is to restore a patient to optimal level of wellness as defined by the patient. Death can be an acceptable outcome in which the goal of nursing care is to move a patient towards a peaceful death.

2.6 FAMILY NEEDS IN THE ICU

The family is considered the single greatest social institution that influences the patient's health outcomes and is regarded as the "voice" of the critically ill patient who may be unable to communicate or participate in care decisions (Mitchell et al 2010:543). However, Gundol, Badole, Lengu and Maluwa (2014:313) point out that admission of a patient to the ICU usually occurs as an emergency, family members

are caught off guard and not psychologically prepared to cope with the critical illness. Consequently, this traumatic experience results in the family failing to cope with the patient's illness. The FCC concept acknowledges "patients as part of a larger whole", therefore one of the core principles of the nursing process is that care rendered should be holistic, taking into consideration the patient, family and the environment (Gundol et al 2014:313).

Nurses and doctors' responsibility stretches beyond the patient to include the families of patients admitted in the ICU. Bandari, Heravi-Karimooi, Rejeh, Mirmohammadkhani, Vaismoradi and Snelgrove (2015:404) emphasize that nurses and doctors should be knowledgeable about the family needs of patients admitted in the ICU. Acknowledging the importance of identifying and prioritizing family needs within the socio-cultural context will assist nurses and doctors to provide appropriate information and support to the family members. Furthermore understanding family needs is critical for the improvement of quality of services and attainment of the patient's right to be well informed in a timely manner (Buyokcoban, Cicekloglu, Yilmaz & Civaner 2015:2).

Meeting the needs of families of patients admitted in the ICU may ultimately assist to reduce the psychological trauma experienced by the family. Moreover routine assessment of family needs may improve the standard and quality of care (Gentry, McArthur, Millegan, White, Scott & Williams 2013:2). However, Nolen (2013:393) found that nurses and doctors were still uncomfortable about including families in the routine care processes, and family needs were not considered of priority in patient care management. Nurses focused on stabilizing the physiological aspect of the patient's disease, ignoring the psychological and social aspects (Nolen 2013:394). Furthermore, nurses considered the presence of family members as distracting them from routine activities, especially with high patient acuity and limited staffing (Nolen 2013:394).

According to Gundol et al (2014:313), ICU admission can be very stressful to the family therefore ICU nurses have a responsibility to support families during this stressful time. The Critical Care Family Need Inventory was developed to assess family needs of critically ill patients (Gundol et al 2014:312). However, there is no

adequate evidence to confirm implementation of remedial action to address family needs (Gentry et al 2013:32). The Critical Care Family Needs Inventory (Gundol et al 2014:313) identifies the following need categories: information, support, comfort, proximity and assurance.

2.6.1 Information

Patients' critical illness renders them incapable of communicating with their families, but HCPs have a responsibility to share honest information about their condition with the family members (Hashim & Hussin 2012:103). According to Mehta, Basnet, Bhattarai and Rai (2012:132), HCPs have the important task of providing family members with appropriate, clear and compassionate information to assist them to participate in decision making regarding the illness of their loved one.

2.6.2 Support

Admission of a family member in the ICU is usually very stressful for the entire family which can result in psychological and physical instability. Consequently this will negatively affect the family support given to the patient. Moreover, HCPs need to identify and develop supportive measures to assist the family members (Segaric & Hall 2015:36). Segaric and Hall (2015:36) add that nursing support for families in ICU strengthens and enables families to cope with the illness of their patient.

2.6.3 Comfort

When the patient and the family's comfort needs are fulfilled, they are strengthened and better able to cope with treatment. Al Ghabeesh, Abu-Shieneh, Abu-Shahrer, Abu-Sneineh and Alhawamdeh (2014:3009) describe comfort as a multidimensional need that is defined as a state of fulfilment of the physical, psychological, environmental and social needs.

2.6.4 Proximity

Families need to be in close proximity with their critically ill loved ones (Al Ghabeesh et al 2014:3010). Al Ghabeesh et al (2014:3010) add that "to see the patient frequently provides direct information about the patient's progress and enables the family to cope better with the illness".

2.6.5 Assurance

Assurance refers to the trust, confidentiality and honest relationship between the HCP and the family (Bandari et al 2015:421).

2.7 FAMILY-CENTRED CARE IN AN ADULT ICU

FCC in the ICU is widely recognized and endorsed. In 2001, the Institute of Medicine advocated for changes in the healthcare system, emphasising the need for collaboration and information sharing between nurses, doctors and the family (Meert et al 2013:761). Meert et al (2013:762) point out that the decision to endorse FCC as the best patient care model in ICU was driven by the recognition that critically ill patients admitted in ICU are at times unable to communicate and participate in care decisions due to their condition (e.g., mechanically ventilated patients). Therefore family members take over the responsibility of being the surrogate or voice for the patient. Yet families are still poorly informed and excluded from decision making and daily care of their loved one (Meert et al 2013:762).

The transition to family participation in care is evident in several policy statements and directives, but is poorly defined on literature on critical and intensive care settings (Olding, McMillan, Reeves, Schmitt, Puntillo & Kitto 2015:1185). Olding et al (2015:1185) maintain that FCC in the ICU requires nurses' and doctors' commitment to the "right care, right now" with more focus on the provision of the right care at exactly the right moment to achieve optimal health outcomes. Moreover, the transition from disease-centred practice to holistic patient care has not been smooth and without contestation (Olding et al 2015:1187). FCC practices in ICU range from inclusion of families on bedside multidisciplinary rounds; family meetings to share information with regard to patient care management; presence during invasive procedures, and family observation of cardiopulmonary resuscitation to open visitation times (Meert et al 2013:761). There are still inconsistencies in the implementation of FCC practices, however, and inadequate agreement on the most effective practices to render the right care at the right time (Gil et al 2014:317). Current clinical practice does not conform to the basic principles of FCC and is in

contrast to the CACCN (2009:5) standards for critical care nursing practice. 'The CACCN (2009:5) emphasises that critical care nurses should foster mutually beneficial partnerships with patients and families based on trust, dignity, respect, communication and collaboration.

Despite FCC endorsement by international bodies, the concept remains unclear in the critical care setting. Nurses and doctors have different perceptions of what FCC actually entails in the context of the critical care environment and the family (Olding et al 2015:1185). Gil, Pasco, Monterosso, Young, Burr, Tamer and Shields (2014:317) found that although FCC is the best model of care in ICU, there was inadequate implementation by nurses and doctors largely due to their judgmental attitudes towards the family. In Indonesia, Thailand and the United Kingdom (UK), Gil et al (2014:318) found gaps between nurses' and families' perceptions of FCC.

2.8 BENEFITS OF FCC

The practice of FCC has many benefits for the healthcare system, providers, patients and families. FCC promotes partnerships in care between families and HCPs, and the principles of FCC concur with traditional ways in which healthcare was taught and practised. In addition, FCC concepts and strategies are being included in legislation and policy statements, while "funding agencies are encouraging researchers to study FCC policies and practices" to advance quality and safe patient- and family-centred care with bedside rounding (Schmidt 2014:35).

2.8.1 Patient-related benefits

Partnership with families improves patient safety, satisfaction with care delivery, and positive health outcomes. The patients as part of the team gain respect of their own values and beliefs that are incorporated in daily care plans. Information sharing on treatment plans enhances compliance with medication, speedy recovery, reduced length of stay in the hospital, and reduction of hospital bills (Clay & Parch 2016:42; Kynoch 2016: 93).

2.8.2 Family-related benefits

Recognition of the family through mutual respect, psychological support, information sharing and partnership in decision making reduces the stress and anxiety related to the complex environment and critical illness of their loved relative. Families as part of the health management team value the opportunity to make informed decisions regarding treatment plans and this improves family satisfaction with care (Sarhadi, Navidian, Harandi & Kheykhaee 2014:258). Family health education provided by the nurses and doctors empower families for the future care of the patient after discharge from the hospital. Open visitation times allow the family more time to be in close proximity with their patient to provide physical and emotional support. Consequently, the family are reassured of their patient's safety and care (Dudley et al 2015:261).

2.8.3 Healthcare provider benefits

The quality of care delivery is improved, which increases nurses' and doctors' job satisfaction. Moreover, nurses' knowledge and skills improve through continuous, consistent practice (Dudley et al 2016:260).

2.8.4 Healthcare system benefits

FCC promotes positive health outcomes thereby reducing mortality and morbidity rates. Implementation of the FCC principles improves the quality of service and increases patients' satisfaction. Healthcare quality improvement in the ICU requires the creation of a professional relationship between nurses, doctors and families that is pinned on respect and open, honest information sharing. The ICU environment which is highly technical, coupled with the severe threatening illness of their relative, often provokes fear and anxiety (Moghaadasian, Simalak & Mokhtar 2013:197).

In examining models of care, Shields (2012:2634) found a general "lack of shared understanding and commitment to FCC amongst all clinicians and families" and the philosophy is at a "crossroads today" (Shields 2012:2638). In a study nurses' perceptions of FCC in developing and undeveloped countries, Coyne et al (2013:2562) found gaps in the implementation of the philosophy in practice due mainly to nurses' attitude to families and lack of support and resources.

Nursing has evolved from a patient-centred model to a holistic model, which recognizes family needs as intertwined with those of the patient. However, the nurses and doctors have a responsibility to support, understand and attend to the needs and unique characteristics of families (Bailey et al 2010:115). Inclusion of families in the daily patient care plans assists nurses to know their mechanically ventilated patient better, improve patient outcomes, and consequently patient and family satisfaction (Gondol et al 2014:313). In Iran, Yousefi et al (2012:296) found that the most commonly reported family needs were information sharing, reassurance, and proximity.

The continuous growth in the healthcare system is coupled with the need to improve the standard of care in order to provide high quality care to patients. Therefore nurses and doctors must address all aspects of care to provide holistic nursing care. Incorporating the AACN synergy model for patient care in the ICU as a framework can assist in developing and designing practice and competencies that are a necessity for patient care in the ICU (Hardin & Kaplov 2015:9). This requires more research on the gaps in the implementation of FCC in the ICU.

2.9 CONCLUSION

This chapter discussed the literature review conducted for the study. The literature review focused on the history of family-centred care (FCC); definition, principles and models of FCC; application of FCC in the ICU; needs of families, and the benefits of FCC.

Chapter 3 discusses the research design and methodology used in the study.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

Good designers design what they would design before they start designing it.

- JC Jones -

3.1 INTRODUCTION

Chapter 2 covered the literature review on FCC conducted for the study. This chapter describes the research design and methodology used, including the population, sampling and sample, data collection and analysis, trustworthiness, and ethical considerations.

3.2 AIM OF THE STUDY

The aim of the study was to explore and describe the views of family members of patients admitted in a general ICU in Botswana regarding family-centred care.

3.3 RESEARCH DESIGN

A research design is “a set of logical steps taken by the researcher to answer the research question” (Brink et al 2006:92). According to Kumar (2011:94) and Polit and Beck (2012:68) a research design is a plan, structure and strategy that guides the researcher to address the research problem and answer the research question. Denzin and Lincoln (2011:118) state that a research design links theoretical paradigms to strategies of inquiry and data-collection methods. The research design connects the conceptual research problem to the pertinent empirical research. It articulates what data is required, and the methods to be used to collect and analyse the data in order to get answers to the research question (Hofstee 2009:113; Vasmoradi, Turner & Bondas 2013:398).

The researcher used a qualitative, contextual, explorative, and descriptive research design to explore and describe the views of families with patients admitted in the ICU regarding FCC.

3.3.1 Qualitative

Qualitative research designs focus on understanding social settings; facilitate exploration of relationships and human experiences, and usually require personal contact in data collection (Moule & Goodman 2014:175). A qualitative design is focused on exploring the study phenomenon to gain an understanding of underlying reasons, opinions and motivations (Wyse 2012:1).

Holloway and Wheeler (2013:3) refer to a qualitative design as “a form of social inquiry that focuses on the way individuals view and make sense of their experiences and the world in which they live”. Burns and Grove (2011:20) add that a qualitative design is used when little is known about the study phenomenon or the research context is poorly understood. Qualitative research is carried out in a natural setting, because realities are wholes that need to be understood from their context and not in isolation (Lincoln & Guba 1985:39). In this study the researcher collected data from families with patients admitted in a specific general ICU. The researcher collected rich, in-depth data from the participants, which was used as the foundation for theorising (Holloway & Wheeler 2013:4). This inductive approach allowed the researcher to go from the specific to the general or analytic description of the data, and enabled the researcher to generate recommendations for an ideal FCC environment.

Burns and Grove (2011:356) add further that a qualitative design refers to an inductive, holistic, emic, subjective and process-oriented approach to understand, interpret, describe and develop a theory or a phenomenon. Qualitative researchers adopt a person-centred and holistic perspective without focusing on specific concepts in order to understand wholly the human experience (Holloway & Wheeler 2013:4). A qualitative design enables the researcher to accurately comprehend the world as it exists; therefore it is useful in finding truth from the unknown (de Vos, Strydom, Fouche & Delport 2011:74). Holloway and Wheeler (2013:5) state that

“different types of qualitative research share common characteristics and use similar procedures though differences in data collection and analysis do exist”. Table 3.1 summarises the characteristics of qualitative research.

Table 3.1 Characteristics of qualitative research

CHARACTERISTICS	APPLICATION
Views the phenomenon holistically in order to understand it in its entirety	Data was collected from the participants for analysis, in order to gain rich, detailed descriptions of the study phenomenon.
Qualitative research is conducted in the natural setting	Data was collected from the participants in the ICU, which was the natural setting where the phenomenon occurred.
The researcher remains in the field for a lengthy period of time.	The researcher was closely involved with the participants.
The researcher becomes the research instrument.	The researcher was involved in data collection and analysis.
Ongoing analysis of data	Data analysis commenced with data collection and continued throughout the study.
The “emic” perspective	The researcher developed and maintained a reflective journal in order to bracket out her own experiences and ideas.
Reflexivity	The researcher reflected on her own experiences.
Contextualisation	The researcher was sensitive to the context of the participants’ experience.
The primacy of data	The researcher used the participants’ views to generate new information.

Adapted from: Holloway and Wheeler (2013:3) and Creswell (2014:38)

3.3.2 Contextual

Qualitative studies aim to understand a phenomenon as it exists in the real world and as it is constructed by individuals in the context of that world (Polit & Beck 2012:247). In this study, the context was the social framework of the culture in which the phenomenon took place as well as the people considered relevant to the interaction in the study setting. The study was conducted in a general ICU in Botswana and data was collected from families with patients admitted in the general ICU. The study focused on the participants' views of FCC in the general ICU.

3.3.3 Explorative

Exploratory studies focus on gaining insight into a phenomenon or situation (de Vos et al 2011:95; Khan 2014:300). The researcher's concern was to explore and describe fully the nature of the phenomenon and the manner in which it manifested, together with factors related to it (Polit & Beck 2012:18). Terre'Blanche, Durrheim and Painter (2008:44) that explorative designs are used when little or nothing is known about the phenomenon. The researcher used the AI approach to explore the views of families with patients admitted in the ICU on FCC in the ICU.

3.3.4 Descriptive

Descriptive studies wish to observe, describe and portray accurately the characteristics of specific situations and phenomena as they occur naturally (Polit & Beck 2012:226; Khan 2014:300). A systematic description of a situation or phenomenon explains what individuals think, feel and perceive about what was seen and remembered (Kumar 2011:10; Polit & Beck 2012:228). The researcher considered a descriptive design appropriate for this study in order to explore and describe the participants' views regarding FCC in the ICU.

3.4 RESEARCH METHODOLOGY

Research methodology is the process or plan for how the study will be conducted and includes the population, sample and sampling, data-collection instrument, and data collection and analysis (Burns & Grove 2014:264; Streubert & Carpenter 2011:366). Research methods are the techniques used to structure a study and to gather and analyse information relevant to the research questions systematically

(Polit & Beck 2012:741). The research methodology includes the population, sample and sampling, data collection and analysis, and ethical considerations.

3.4.1 Population

A research population refers to the entire set of elements, individuals or objects with some common characteristics in which a researcher is interested (Babbie 2015:199; Polit & Beck 2012:337). Burns and Grove (2013:544) describe the population as all the individuals that meet certain criteria for inclusion in a study. Polit and Beck (2010:338) distinguish between the target and the accessible population. The target population refers to the entire group of individuals about which the researcher would like to generalise. The accessible population is the subset of the target population that are accessible as participants for the study.

In this study, the target population consisted of all family members with patients admitted in the selected ICU for at least 72 hours. The researcher was able to gain access to the population through the Head of the District Health Management Team and the ICU nursing manager.

3.4.2 Sample

A sample is a subset of a population (individuals, elements or objects) or a group selected to act as representatives of the population as a whole (Moule & Goodman 2014:290; Polit & Beck 2012:275). A sample is a subset of individuals in the population whose composition meets specific inclusion criteria (Babbie 2015:199). The sample consisted of family members of patients admitted in the ICU for at least 72 hours. To be included in the study, the participants had to be

- Family members with a patient admitted in the ICU for more than 72hrs
- Aged 18 years and above
- Fluent in either Setswana or English

The sample for this study consisted of ten (10) family members with patients admitted in the general ICU for at least 72 hours. The advantage of selecting a portion from the population was that it was more economical and practical to work with (Polit & Beck 2010:307). The size of the sample depends on the richness or depth of information desired to gain insight into the study phenomenon, and the

focus is on the quality rather than the quantity of data (Polit & Beck 2012:308; Burns & Grove 2011:361).

3.4.3 Sampling

Sampling refers to the “process of selecting a sample from a population in order to obtain information regarding the phenomenon in a way that represents the population of interest” (Brink et al 2006:124). According to Polit and Beck (2012:275), sampling is “a process of selecting a portion of the population to represent the entire population, so that inferences can be made about the population”. The researcher selected a sample instead of the entire population because it reduced the cost and the data-collection time (Gerrish & Lancy 2010:22).

In this study, non-probability or purposive sampling was used. Purposive sampling refers to selecting “subjects typical of the population in question or particularly knowledgeable about the issues under study” (Brink et al 2012:141). The researcher used purposive sampling to select a total of 8-10 family members with patients admitted in the ICU for at least 72 hours.

The main aim in non-probability sampling is not to generalize, but to unveil the truth about a particular phenomenon (Gerrish & Lancy 2010:144). The researcher used her knowledge about the population to consciously select certain participants from the population (Polit & Beck 2012:311; Burns & Grove 2011:353). Purposive sampling selects individuals likely to be “information rich” to enable the researcher to obtain in-depth information needed for the study (Streubert & Carpenter 2011:90). The reason for using purposive sampling was to select participants who would yield the most comprehensive information on the study phenomenon.

3.4.4 Data collection

Data collection is the precise, systematic gathering of information relevant to the research purpose or objectives of the study (Burns & Grove 2011:52; Polit & Beck 2012:60). In qualitative research, data collection is flexible due to the continuous evolution in the already collected data (Burns & Grove 2011:507).

Data was collected in one-to-one interviews, using a semi-structured interview guide (see Annexure B). An interview guide specifies the wording of all questions to be

asked to the participants (Polit & Beck 2012:416). Constructivism and the appreciative inquiry (AI) theoretical framework were used as the basis for the study. AI is “an approach to organisational analysis and learning which is intended for discovering, understanding, and fostering innovations in social organisational processes” (Cooperrider et al 2008:3). Accordingly, the researcher in collaboration with the supervisors developed an AI interview guide, using the AI 5-D cycle, namely **Define** (clarification of the problem); **Discover** (appreciating the best of the situation); **Dream** (envisioning what might be); **Design** (constructing the ideal situation), and **Destiny** (empowering and improvising).

The AI approach focuses on exploring people’s ideas of what they perceive to be valuable and emphasises appreciating the positive responses of people rather than concentrating on the problems (Reed 2007:128). The AI approach encourages people to think creatively beyond what is currently in practice to discover the best situation that is beneficial to both the concerned group and the organization (Dupuis, McAiney, Fortune, Ploeg & Witt 2016:12). AI is based on story-telling as a way of understanding the perceptions of other people through engaging them in a dialogue (MacCoy 2014:106). Therefore the researcher used this approach to explore the participants’ views of FCC in the general ICU. Permission to conduct the interviews was obtained from the ICU nurse manager.

The interview guide was semi-structured and consisted of three open-ended questions. In the interviews, the participants could freely express their views of what they appreciated most about FCC, the challenges, wishes and dreams. The participants expressed their views or stories as they wished and not according to the researcher’s preconceptions or bias (Reed 2007:128). The one-to-one interviews were conducted in a private room, using the questions on the interview guide and probing questions, if necessary, and lasted approximately 45 minutes.

3.4.5 Data analysis

Polit and Beck (2012:725) define data analysis as “the systematic organisation and synthesis of research data”. Data analysis is a process of bringing order, structure and meaning to collected data (De Vos et al 2011:339). In this study, the researcher analysed the data by means of content analysis. In content analysis, data is

organised by means of coding to identify themes and categories, and the results are presented in tables and figures (Creswell 2014:147). Creswell (2014:147) refers to coding as “the process of organizing the material into ‘chunks’ before bringing meaning to those ‘chunks’”. The data was categorized and labelled. Burns & Grove (2011:523) describe a code as a symbol used to classify words or phrases in the data. The researcher used Tesch’s (1990) eight step method to analyse the data (Creswell 2014:192):

- First read through all the transcriptions carefully in order to get a sense of the whole.
- Then pick up one document, perhaps the shortest, most interesting one, and read through it to get the underlying meaning. Repeat the same procedure with several documents and write down thoughts in the margin.
- Make a list of all the topics from the documents. Cluster similar topics together and form them into columns as major, unique, and leftover topics.
- Abbreviate the topics as codes next to the appropriate segments of the text.
- Find the most descriptive wording for the topics and turn them into categories.
- Reduce the total list of categories by grouping topics that relate to each other.
- Make a final decision on the abbreviation for each category and list alphabetically.
- Assemble the data for each category in one place and perform preliminary analysis. Recode the existing data, if necessary.

3.5 TRUSTWORTHINESS

Trustworthiness is “the degree of confidence that qualitative researchers have in their data, using the strategies of credibility, dependability, confirmability, and transferability” (Polit & Beck 2012:745). The criteria allow the researcher to demonstrate how the interpretations of the data and conclusions drawn reflect participants’ experiences (Moule & Goodman 2014:191).

To ensure the trustworthiness of the study, the researcher used credibility, dependability, confirmability, transferability and authenticity (Lincoln & Guba 1985:301; Polit & Beck 2012:769).

3.5.1 Credibility

Credibility is a criterion for evaluating integrity and quality in qualitative studies, referring to the confidence in the truth of the data and interpretations of them (Polit & Beck 2012:724). Credibility validates that there is a match between the participants' experiences and the researcher's reconstruction and representation of them (de Vos et al 2011:420). Anney (2014:276) states that credibility establishes whether the findings represent the original views intended by the participants. In this study, the researcher ensured credibility by establishing rapport and trust and through prolonged engagement with the participants (Polit & Beck 2012:725). The researcher's supervisor reviewed, validated and verified the research findings and conclusions to ensure that the data had not been misinterpreted (Brink et al 2006:119). The researcher spent sufficient time with the participants and the interviews took 45 minutes to an hour. The researcher was fully immersed in the participants' world to gain deeper insight into and an understanding of the context (Anney 2014:276). This prolonged engagement enhanced the credibility of the study.

3.5.2 Dependability

Dependability refers to the transparency of the research process and audit trail (Gerrish & Lacey 2010:139; Gillan, Prospeno, Harnett & Holden 2014:143). Polit and Beck (2012:538) describe dependability as the stability of data over time and conditions. The research findings will remain unchanged should the study be repeated in different settings with different participants. In this study the researcher used data triangulation to establish reliability (dependability). The researcher's supervisor and co-supervisor followed the process and procedures used in the study to determine whether they were acceptable (Brink et al 2006:118). In addition, a co-coder assisted the researcher with data coding.

3.5.3 Transferability

Transferability refers to the generalization of data; that is, the extent to which the findings can be transferred to or applied in other settings (Polit & Beck 2012:540). Transferability refers to the probability that the study findings have meaning to others in similar situations (Streubert & Carpenter 2011:49; Holloway & Wheeler 2013:304). The researcher provided sufficient, thick descriptions of the data so that researchers

can transfer the findings to other contexts (Moule & Goodman 2014:466; Polit & Beck 2012:540; Priya & Dalal 2015:168).

3.5.4 Confirmability

Confirmability is a criterion for integrity in qualitative research and refers to the objectivity or neutrality of the data and interpretations (Polit & Beck 2012:585; Gillan et al 2014:144). Confirmability demonstrates credibility, dependability and transferability of a study as the degree to which the results could be confirmed by others as a way to ensure neutrality (Kumar 2011:185). Therefore, confirmability is a means of establishing that the data collected represents the information provided by the participants and that the interpretations are not influenced by the researcher's preconceptions or imagination (Polit & Beck 2012:585). Moreover, the researcher remained objective throughout to ensure confirmability. In addition, the information obtained from data collection and observations made were kept and made available for future reference by other researchers.

3.5.5 Authenticity

Authenticity refers to the degree to which researchers faithfully and fairly show a range of realities. Authenticity in a report conveys the tone of participants' lived experiences and fairly describes the participants' experiences so that it is a truthful picture of their perceptions and experience (Priya & Dalal 2015:169; Polit & Beck 2012:585). In this study the researcher kept field notes and transcribed tape-recorded data.

3.6 ETHICAL CONSIDERATIONS

When humans are used as study participants, care must be taken to ensure that their rights are protected (Polit & Beck 2012:166). Babbie (2015:62) points out that the researcher must adhere to set rules or standards of ethical conduct, in order to safeguard the safety of research participants. Accordingly, the researcher obtained permission to conduct the study, obtained informed consent from the participants, and observed the ethical principles of respect for human dignity, beneficence, and justice (Polit & Beck 2012:748).

- **Permission**

The researcher obtained approval and permission to conduct the study from the University of Pretoria: Faculty of Health Sciences Research Ethics Committee; the Ministry of Health, Botswana, and the participating hospital to conduct the study there (see Annexure D). Further permission was obtained from the hospital and the ICU manager to interview the participants in the ICU (see Annexure D).

- **Informed consent**

The participants had the right to decide whether to participate in the study, or not. The researcher explained the purpose and significance of the study to the participants, what was expected of them, and how data would be collected. The researcher informed them that participation was voluntary and that they were free to withdraw from the study at any time should they so wish, without any negative implications (Polit & Beck 2012:748). Permission to audiotape the interviews also obtained from the participants. Explaining the purpose, significance and steps of the study protected the participants from exploitation.

- **Beneficence**

The principle of beneficence means “do good and no harm” and aims at maximising the benefits and minimising harm for the participants (Polit & Beck 2012:748). Discomfort and harm can be physical, emotional, psychological or social. In this study, there were no risks of exposing the respondents to discomfort or harm. Moreover, the researcher protected the participants from exploitation and unfair treatment by assuring them of privacy, confidentiality and anonymity (Polit & Beck 2012:748).

- **Justice**

The respondents had the right to fair selection and treatment. The hospital and participants were selected fairly, and confidentiality and anonymity were observed during data collection, analysis and publication of results. Confidentiality refers to the researcher’s responsibility to prevent all data collected during the study being linked to any participant or being divulged (Brink

et al 2012:35). The researcher also acted in a sensitive way in respecting participants' cultural beliefs and lifestyle (Polit & Beck 2012:748).

3.7 CONCLUSION

This chapter described the research design and methodology of the study in detail. The methodology included the population, sampling and sample, data collection and analysis, trustworthiness and ethical considerations.

Chapter 4 discusses the data analysis and interpretation, and results, with reference to the literature reviewed.

CHAPTER 4

DATA ANALYSIS AND INTERPRETATION

The mightiest works have been accomplished by men who have kept their ability to dream big dreams.

- Walter Bowie -

4.1 INTRODUCTION

Chapter 3 described the research design and research methodology used in the study. This chapter discusses the data analysis and interpretation and the results. The findings of the study are discussed with reference to the literature reviewed. The aim of the study was to explore and describe the views of family members admitted in a general ICU in Botswana regarding FCC.

4.2 DATA ANALYSES

The researcher used one-to-one interviews with ten family members of patients admitted to the intensive care unit (ICU) in Botswana. The data was organised into themes, categories and sub-categories that emerged from the data. The results are discussed according to the themes, categories and sub-categories.

Question 1 required the participants to reflect on and describe their most satisfying/peak experience of family-centred care.

One main theme and five categories emerged from the participants' most satisfying/peak experience of FCC during their family members' admission to the ICU. Table 4.1 outlines the main theme and the categories that emerged during data analysis.

Table 4.1 Participants' most satisfying/peak experiences of FCC

THEME	CATEGORY
4.2 1 Workplace culture	4.2.1.1 Physical environment
	4.2.1.2 Attitude
	4.2.1.3 Basic needs
	4.2.1.4 Share information
	4.2.1.5 Involvement

4.2.1 Theme 1: Workplace culture

The main theme that emerged from the participants' most satisfying/peak experiences of FCC was workplace culture. The participants appreciated the ICU working environment, the supportive relationships, interactions and communication with HCPs, and the patient care. Despite the stressful, highly technical and complex environment, the HCPs interacted well with the family and were supportive of their needs. According to the participants (see Annexure B, question 1):

I was quite happy with the general care that was given to my father; the nurses always ensured his bed linen was clean. (p 5)

The nurses told us about the progress of my mother during visiting times. (p 6)

The doctor told me the reasons why she is admitting my wife in ICU. (p 2)

Guidet and Roma (2011:312) define culture as “a system of shared values, assumptions and underlying beliefs that influences the way things are done. Soh and Davidson (2013:97) describe the workplace as an environment that enables and supports the achievement of the defined organisational culture. Workplace culture is not the same as organisational culture, but rather the culture that is experienced on micro level, affecting both health care users and providers, and every ICU or unit has its own culture(Hardin 2015:521). The workplace culture is the culture in the local workplace that impacts directly on healthcare users (patients and family members) and healthcare providers (Manley et al 2011:35). According to Manley et al (2011:36), the workplace culture is the “most immediate culture experienced and/or

perceived by staff, patients, users (patients and family members) and other key stakeholders. This is the culture that impacts directly on the delivery of care.”

Workplace culture shapes the decision-making processes and influences the attitude and behaviours of both HCPs and family members. A strong committed workplace culture influences the quality of service delivery and hence patient and family satisfaction (Ng, Johnson, Nguyen & Groth 2014:6). Critically ill patients often stay longer in ICU, compelling family members to interact frequently with HCPs and the workplace environment, therefore improving the organizational culture may also improve family satisfaction. Dodek, Wong, Daren, Heyland, Cook, Rocker, Kutsogiannis, Dale, Fowler, Robinson and Ayas (2012:1507) found that a positive workplace not only improved the well-being of HCPs but also contributed to patients’ positive health outcomes, hence improving family satisfaction with care delivery.

Five categories emerged from workplace culture, namely: *physical environment, attitude, basic needs, share information and involvement.*

4.2.1.1 Physical environment

The participants indicated satisfaction with the general cleanliness of the environment, including floors, surfaces and equipment. The participants were happy that their patients were well cared for in a clean environment which gave them satisfaction and hope for positive outcomes.

The patient was nursed in a clean environment. (p 6)

Everything in the unit is always neat and clean in here (ICU). (p 1)

This environment (ICU) is very clean, Sister. (p 5)

The cleanliness of the environment is critical for keeping patients and families comfortable and at ease during their stay in the ICU. Moreover, the cleanliness of the environment entails not only keeping the surfaces visible clean but also eliminating hospital-acquired infections that can be a risk to patients and families who are in

frequent contact with the environment (Ferreira, Andrade, Rigotti & Ferreira 2011:559). Ramphal, Suzuki, McCracken and Addai (2014:89) found that healthcare-associated infections contributed to 1.7 million infections and 99,000 deaths, and in 2002, approximately 417 946 deaths affected adults and children in the ICU. Cleaning and disinfecting is a way of reducing transmission of pathogens from the environment. Therefore regular disinfection of surfaces and equipment reduces exposure to patients and healthcare personnel. Huffiness et al (2013:57) emphasise that ICU patients are more vulnerable to infections because of their compromised immune system, therefore maintenance of an effective cleaning and disinfection regime will reduce the rate of hospital-acquired infections. Furthermore, a clean and welcoming environment enhances feelings of well-being and trust of the anxious and emotionally unstable family members.

4.2.1.2 Attitude

The participants reported that they appreciated it when the HCPs interacted with them harmoniously and were ready to listen and provide information that they needed. According to the participants, the HCPs portrayed a positive attitude towards them and were willing to assist and answer questions:

The nurses were very helpful and gave me good information. (p 8)

The Sister (nurse) was always friendly. (p 8)

The nurses responded positively to our (family members') needs. (p 9)

According to Oliveira, Fernandez, Vilar, Figueiredo, Ferreira, Martinho, Figueiredo, Andrade, Carvalho and Martins (2011:1334), nurses' attitudes reflect the scale of families' importance in nursing care. Oliveira et al (2011:1335) add further that most nurses still uphold positive attitudes towards caring for the patients' families as evidenced by improved quality care and satisfactory outcomes. Wong, Liamputtong, Koch and Rawson (2015:53) emphasise that "nurses' behaviour that demonstrates commitment encourages a connection that reassures and supports families". HCPs' caring attitude and consistent commitment and regular communication promote good interaction between the parties and create a bond between mothers and their

premature neonates (Guillaume, Michelin, Amrani, Benier, Durrmeyer, Lescure, Bony, Danan, Baud, Jarreau, Tareb & Caeymaex 2013:18).

In a study on nurses' attitudes towards family participation in paediatric nursing care, Angelo, Cruz, Mekitarian, Santos, Martinho and Martins (2014:74) found that the nurses valued family participation which reflected the important role played by the family in care. The nurses defined and established types of supportive behaviour and relationships as a precondition of inviting and engaging families in care (Angelo et al 2014:75). Vaezi, Alimandegari, Farnia and Lotfi (2015:40) found that nurses' behaviour had an impact on family participation in care delivery, therefore reshaping their attitude, addressing nurses' issues of concern and building a support system was beneficial to both patient and family.

4.2.1.3 Basic needs

According to the participants, one of the most satisfying experiences was the nature of care and support offered by the HCPs to the patients. The families expressed their gratitude for the way the HCPs assisted the patients:

My wife always looks very clean and neat when I come and visit her. (p 1)

My husband always had clean linen on his bed. (p 1)

When I came to visit, my husband was bathed and looked very neat and clean. (p 7)

Admission to an ICU is stressful to both the patient and the family. The medical and technological equipment and the environment often trigger feelings of fear, despair, anxiety and depression together with uncertainty about the patient's condition. Therefore the family's physical, emotional and psychosocial needs may be affected if the HCPs fail to recognise family needs and attend to them in time (Shorofi, Jannati, Moghaddam & Charati 2016:12). Gundol et al (2014:313) state that a critical care family needs inventory identified the main psychosocial needs of families with patients in ICU as information, assurance, support, proximity and comfort.

Shamloo (2012:18) emphasises that family members have specific needs that must be identified and met in order to assist and support family members to cope with the stressful admission of their loved one in the ICU. HCPs have a responsibility to accurately identify and prioritize family needs in order to enable effective nursing interventions and assist families to cope with the treatment process (Al Gabeesh et al 2014:3010). Patients and family need comfort on three levels: physical, psycho-spiritual, and socio-cultural. When these are met, the patient and the family experience holistic care and are strengthened to better cope with the treatment process (Nolen 2013:394).

Shamloo (2012:18) points out that family members have specific needs that must be met by the HCPs to enable them to cope with the stressful ICU environment and the critical illness of their loved one. Fateel and O'Neil (2016:58) found that meeting family member basic needs facilitated effective coping mechanisms when dealing with the admission of a family member to ICU.

4.2.1.4 Share information

The participants reported that they appreciated it when the HCPs gave them information on the patient's condition, treatment plan and progress. According to the participants, the shared information made them feel valued and appreciated:

The nurses and doctors explained all the activities to us. (p 1)

During visiting hours the nurse shared the progress of the patient with me. (p 6)

The nurse explained to me that the doctors and nurses were doing their best to reduce the blood pressure. (p 7)

Matlakala (2015:115) found that during admission of critically ill patients in the ICU, nurses, doctors and other healthcare professionals should continuously share information regarding the patient's condition, treatment plan and the prognosis, and extend this information sharing to the family members. Hashim and Hussin (2012:104) emphasise that family members with a critically ill patient admitted in the ICU are under great stress evoked by the environment that is known for its high

mortality rate, therefore HCPs have a responsibility to provide adequate and honest information about the patient's condition to the family members. ICU patients' inability to communicate or make informed decisions illustrates the key role of ICU nurses in providing families with honest and accurate information (Hashim & Hussin, 2012:106).

Good communication is an essential ingredient of quality care in the ICU (Fox 2014:94). As bedside care givers, nurses are consistently in contact with the patient and better positioned to advocate for patients by sharing information about the patient's condition with the family. The information shared with family members should be complete and unbiased in order to enable the family to make informed decisions (Shamloo 2012:7).

4.2.1.5 Involvement

According to the participants, the HCPs engaged them in the care activities and decision making about their critically ill patient. The participants appreciated being part of the care decisions, and participating in basic daily care activities gave them a feeling of fulfilment, reassurance and hope:

My mother was critically ill and the doctors and nurses involved us (family members) in the decision making regarding the way forward. (p 8)

The doctors informed us about the results of the investigations and asked us if they could admit the patient to ICU. (p:1)

According to Al Mutair et al (2013:1812), family involvement in routine patient care activities provides families with emotional reassurance and satisfaction. Family is important in the care of the very sick family member, the mutual interaction and involvement enhances good communication, strengthens relationships, and ultimately promotes positive outcomes and family satisfaction (Al Mutair et al 2013:1812).

In Bahrain, Fateel and O'Neil (2016:65) found that involving family members in the care of their loved ones in the ICU was beneficial to the patient, family and HCP as it promoted holistic nursing; the interactive relationship as part of the care process enhanced the family's overall well-being and self-esteem, and reduced feelings of fear and uncertainty. Kingsinger (2015:14) emphasises that assisting families to participate in care promotes perceived respect, support and collaboration between families and HCPs. Vaughan (2014:4) maintains that family partnership or involvement in the care of their patient in ICU is one of the core components of FCC and an effective way of meeting family needs.

Family system theory describes the family as an interdependent and interactive system therefore an interruption to the system affects the dynamic relationship between family members, as indicated by the admission of a family member in the ICU. Therefore HCPs need to recognize, support and involve families in the care of their critical patient so as to strengthen familial bonds (Fateel & O'Neil 2016: 57).

Regarding the participants' **wishes**, two themes emerged from the data, namely **compassion** and **counselling**. Table 4.2 outlines the themes and categories that emerged on the participants' wishes regarding FCC.

Table 4.2 Participants' wishes relating to FCC

THEME	CATEGORY	SUB-CATEGORY
4.2.2 Compassion	4.2.2.1 Sharing information	Family meeting
	4.2.2.2 Involvement	Caring Decision making
	4.2.2.3 Flexible visiting time	
4.2.3 Counselling	4.2.3.1 Self	
	4.2.3.2 Outcomes	
	4.2.3.3) Long-term care	

The themes and associated categories and sub-categories are discussed next.

4.2.2 Theme 2: Compassion

The second theme that emerged from the data was compassion. The participants wished that the HCPs would all portray kindness, willingness, loving and caring attitudes towards family and patients, because some of the HCPs showed negative attitudes in the daily care activities:

The interaction and the communication by the staff should be warm and comforting. (p 1)

I expect the staff to be compassionate and update us with regular information. (p 4)

They should have time to interact with us. (p 9)

The participants indicated that HCPs did not show willingness and compassion to assist them to support their sick patient. Kvangarsnes, Torheim, Hole and Crawford (2013:1) define compassion as “a strong awareness or sensitivity to the pain of others that result in verbal, non-verbal or physical action to remove or alleviate the impact of such affliction”. Compassion is one of the Christian ideals instilled by Florence Nightingale in the characteristics of a professional nurse and is a very valuable attribute in the ICU, where critically ill patients and their relatives need to be provided with compassionate care in order to alleviate the impact of the disease (Kvangarsnes et al 2013:2).

According to Sinclair, Norris, McConnell, Chochinav, Hack, Hagen, McClement and Bouchal (2016:6), patients and families have always indicated compassion as one of their greatest healthcare needs. Therefore HCPs should provide respectful, committed and attentive care and be able to listen, understand and provide information sensitively and clearly. In the Netherlands, Van Mol, Brackel, Kopanje, Gijbers, Nijkamp, Girbes and Bakker (2016:5) found that compassion required HCPs to pay attention to patients’ cultural aspects, beliefs, behaviours and personal needs.

A family member’s admission in the ICU can be emotionally and physically traumatic to the relatives who at this juncture look to the HCP to provide compassionate care.

Families need to be informed of their patient's condition and prognosis, and their decisions and cultural beliefs must not be ignored.

Three categories emerged from the theme compassion, namely *sharing information*, *involvement*, and *visiting time*.

4.2.2.1 Sharing information

The participants indicated that they wished HCPs would provide them with information on a regular basis about the patient's condition, plan of treatment, and prognosis. According to the participants, most of the time the HCPs did not readily share information unless the family asked for information:

I wish we could have information sessions where doctors and nurses shared information with us regarding our loved ones. (p 2)

I wish doctors and nurses would tell us about the patient's condition, investigations and progress. (p 1)

I wish everything regarding the patient could be discussed and explained to me. (p 7)

One of the core principles of FCC involves honest information sharing between families and HCPs. Information sharing is not only limited to informing the family about the condition of their patient but includes educating the family so that they can actively participate in the care of their sick family member during admission and after discharge. Empowering families enables them to make wiser care decisions that will contribute to a positive outcome (Shirazi, Sharif, Rakhshan, Pishva & Jahanpour 2015:208). Nolen (2013:397) points out that information needs are one of the five basic needs of families and patients. One of the ways to strengthen effective communication and promote information sharing is to give information leaflets to the family to help them understand the current situation and increase their satisfaction.

According to Fateel and O'Neil (2016:58), the sudden illness of a family member often leaves other family members helpless with no clear information about the patient's condition and outcomes. Therefore it is important that HCPs give attention

to the information needs of families as they play a key role in disseminating information to other family members. Meert et al (2013:771) maintains that information sharing should be open, honest and unbiased to enable the family members to effectively contribute to the medical decisions and other health care.

One sub-category emerged from the category sharing information, namely *family meetings*.

Sub-category 1: Family meetings

The participants wished they could have scheduled meetings with the HCPs where information related to the patient's condition and plan of care was shared with the family. The participants indicated that most information was given to them during the process of admission, but then there was less sharing of information unless the patient's condition changed or the participants asked for information:

I wish we could have regular meetings with the medical team (nurses and doctors), not only on admission. (p 2)

I wish we and the nurses and doctors could sit together and discuss the condition of the patient. (p 1)

Boss, Donohue, Larson, Arnold and Roter (2016:223) describe family meetings as sessions where the HCP and the family come together for various purposes, such as psychological support, discussion of the patient's goal of care, treatment and discharge plan. In Canada, Joshi (2013:637) found that family meetings were an important part of a patient's treatment and care plan in the ICU. However, family members often arrived late during admission or at a critical decision-making junction, particularly when the patient was admitted as a result of an accident. Family meetings have been found to reduce the time patients spend in ICU. Structured family meetings can be implemented as part of the overall plan to improve communication with families in the ICU and a strategy to address family needs beyond information sharing (Boss et al 2016:224).

Scheduling regular meetings between HCPs and families is advocated for in critical care for quality improvement and bioethics, because family meetings contribute to reduced family emotional distress and reduced patient stay in the ICU, hence promoting family satisfaction with care (Scheunemann & Arnold 2016:46). A retrospective survey of 457 families in the Netherlands found that family meetings and participation in family meetings improved ICU survival (Salins, Deodhar & Muckaden, 2016:98). Hudson, Girgis, Mitchell, Phillip, Parker, Currow, Liew, Thomas, Moran and Brand (2015:7) recommend family meetings as the most important clinical intervention in hospitalised critical palliative care patients.

4.2.2.2 Involvement

The participants wished they could be part of the activities carried out by the HCP on their patient so that they could understand the extent of the situation and be in a better position to assist the patient after the patient had been discharged home. According to the participants,

I wish we could have daily information sessions where doctors and nurses share information with us regarding our loved ones. (p5)

I wish doctors and nurses would tell us about the patient's condition, investigations and progress. (p 1)

A holistic approach to nursing care rendered in the ICU enhances an interactive culture between HCP and family, and promotes communication and engagement of both parties in the care provision and decision making (Shirazi et al 2015:208). In a study on how critical care nurses' caring attitudes and beliefs influenced family members' perceptions of FCC, in Kennesaw, USA, Shamloo (2012:2) found that it was common practice to leave family members out of the care planning process and decision making until the patient's condition was at the end stage.

According to Olding et al (2015:1187), involvement has five components, namely involvement as being present; as receiving care and having needs met; as communicating and receiving information; in decision making, and in receiving care. Vaughan (2014:2) maintains that family involvement in care is a core component of

FCC and an effective way of meeting family needs, reducing stress, and enhancing family satisfaction. Inadequate involvement, support and communication often result in anxiety and depression for the family (Fateel & O'Neil 2016:60). Moreover, limited involvement of the family in patient care activities has a negative impact on their expected role when the patient is discharged.

Two sub-categories emerged from the category involvement namely: **caring** and **decision making**.

Sub-category 1: Caring

The participants wished that HCPs would show more empathy, compassion and sensitivity as they consistently interacted with patients and families. The HCPs' attitude of caring should be portrayed in their daily interaction and communication with the patient and family. According to the participants,

I wish the nurses would involve me more in caring for my mother. (p 8)

I wish that nurses would schedule activities for family members to do during visiting time.
(p 4)

Caring is a way for people to relate to others through a foundation of personal commitment and responsibility. According to Adams (2016:3), nursing is a caring science because "human beings are connected to each other in the caring process; a nurse's humanity embraces the humanity of others to preserve the dignity of self and others". The concept of caring has always been considered a part of nursing, and is characterised by an empathetic approach, attentiveness and sensitivity. Where caring exists, effective communication prevails and sharing of information ultimately results in emotional and psychosocial support (Drahosova & Jarosova 2016:453). Gelinas (2015:1) maintains that a caring culture can also be described as "a culture of curing". Consequently, in their frequent interaction with the patient and family, HCPs should show a caring attitude by ensuring that patient and family needs are met (Gelinas 2015:2). Al-Mutair et al (2013:1813) emphasise that "caring for the family is an important component of caring for the patient" which can be achieved when the family is involved.

Sub-category 2: Decision making

The participants wished that they could be part of the decision making in the patient's care processes. They felt that HCPs did not adequately involve them in information sharing sessions that would empower them to make informed decisions and assist them to cope with the stressful illness of their patient. According to the participants,

I wish the nurses and doctors would involve us in decisions and not inform us of decisions. (p 9)

We would like to be part of the treatment team and have inputs in decisions. (p 4)

Patients admitted in the ICU are often unable to communicate because they are critically ill and sometimes on mechanical ventilation, therefore they cannot make informed care decisions (Pascual 2014:11). In such instances, the family acts as surrogate decision maker therefore clinical family communication becomes a central component of medical decision making. HCPs in the ICU must develop a partnership with the family that is not only proactive but also context sensitive (Azoulay, Chaize & Barnes 2014:39). The family members often assume responsibility in care decisions, including choices about diagnostics, treatment and therapeutic care (Olding et al 2015:1189). Aarthun and Akerjordet (2014:178) point out that the perception of health care and the role of the HCP has shifted from a paternalistic model to one of shared decisions which promote partnership by sharing information and reaching consensus.

Shared decision making is one of the core components of FCC and HCPs and the family need to strengthen their partnership and engage in regular communication and information sharing as it is key to shared decision making (Huffiness et al 2013:58; Kon, Davidson, Morrison, Danis & White 2016:189).

4.2.2.3 Flexible visiting time

The participants wished that they could be allowed to spend more time with the patients during visiting time as it gave them a feeling of reassurance and strengthened family bonds through supporting them in meeting their daily basic needs. The participants indicated that restricted visiting times felt as though a door had been closed in front of them that acted as a barrier between the family and the patient. The participants suggested that open visitation would allow them to space their visit instead of all the family members visiting at the same time. According to the participants,

I wish I could spend more time with my mother. (p 8)

I wish visiting times were not restricted. (p 1)

I wish family members were not so restricted by the visiting times. (p 9)

Times for visiting the patient should be extended and according to the needs of the patients. (p 6)

In Ontario, Canada it was found that unrestricted presence or visitation of a family member in the ICU could enhance patient and family satisfaction, through improved interaction and communication with HCPs, allowing opportunities for family education and involvement in care, ultimately promoting FCC and enhancing family satisfaction (CACCN 2009:12).

An open visitation policy complies with the family's need to be with the patient frequently furthermore open visitation has been associated with reduction in symptoms of anxiety, depression strengthens familial bonds and improves family satisfaction (Da Silva Ramos, Fumis, Azevedo & Schettino, 2013:34; Fateel & O'Neil 2016:57). In the USA, Chapman, Collingridge, Mitchell, Wright, Hopkins, Butler and Brown (2016:48) found that "watching the clock has become an outdated part of visiting a patient in ICU" and flexible policies were now being implemented that focused on patient and family needs and preferences. The elimination of visitation restrictions in a mixed profile ICU had increasingly contributed to reduction of

cardiovascular complications in critically ill patients as well as a reduction in rates of anxiety and depression (Chapman et al 2016:48).

4.2.3 Theme 3: Counselling

The third theme that emerged from the data was counselling. The participants wished that they could be emotionally supported through information sharing sessions provided by HCPs throughout the patient's admission period. Information sharing sessions would assist the family emotionally to adjust to the circumstances of the process and also prepare the family psychologically and physically to handle the patient at home after discharge.

The participants wished that HCPs would provide them with information to better understand the on-going process in the ICU environment and the critical illness of their family member. In Tanzania, Kohi, Obongo and Mselle (2016:1) found that the admission of a family member in the ICU often occurred without warning, leaving the family feeling vulnerable and helpless with little knowledge of what was happening and what to expect from the healthcare system. Kohi et al (2016:7) emphasise that it is the responsibility of the HCPs to identify family needs and provide psychological support by frequent engagement and information sharing sessions with family members. Munyinginya and Brysiewicz (2014:6) state that in Kigali, Rwanda the perspective in ICU management has shifted from patient-focused nursing care to holistic care, which includes identifying and meeting family needs thereby reducing anxiety and stress.

Three categories emerged from this theme, namely *personal counselling*, *outcome of the patient*, and *long-term care*.

4.2.3.1 Personal counselling

The participants indicated that they wished to be reassured that their patient was being well cared for and that everything possible was being done to ensure their recovery. According to the participants,

I wish we could have information sessions where doctors and nurses share information with us regarding our loved ones. (p 2)

I wish doctors and nurses would tell us about the patient's condition, investigations and progress during each visit .(p 4)

I wish everything regarding the patient could be discussed and explained to me. (p 7)

The participants indicated that they wished the HCPs would regularly give them information on the patient's progress rather than having to enquire every time from them. They stated that the waiting for information was emotionally distressing and felt unnecessarily long.

Munyinginya and Brysiewicz (2014:7) found that families expressed the need to be reassured of the condition of their loved one and that the HCPs were committed to providing the best care possible. Munyinginya and Brysiewicz (2014:7) emphasise the value of compassion and effective communication to family adjustment regardless of the outcome. Kynoch (2016:146) maintains that lack of information to the family increases depression and anxiety, therefore providing consistent information to the family will assist them to better cope with the situation and outcome.

4.2.3.2 Patient's outcome

The participants indicated that they wished to be informed about the patient's condition, severity and prognosis and the treatment plan during the admission process and throughout the patient's stay in the ICU. HCPs should regularly share open, honest information with the family and not only at the time the condition changes. According to the participants,

I wish doctors and nurses would tell us about the patient's condition, investigations and the prognosis during admission and throughout the admission period (p 3)

I wish everything regarding the patient would be discussed and explained to me. (p 7)

The participants indicated that knowing the condition and the outcomes would reduce their anxiety and better assist them to cope mentally and physically with the outcome. Most family members with patients admitted in the ICU are either spouses or parents, therefore the need to know the outcome of the patient's condition was important (Hashim & Hussin 2012:108). Family members need to be well informed of the possible outcomes in order to prepare them mentally and physically as well as to enable them to plan for alternative care. In an Iranian study, Sahardi, Navidiyan, Harandi and Kheykhaee (2014:257) found that families with patients on mechanical ventilation needed to be informed about the condition and treatment plan, potential complications and alternative treatment.

4.2.3.3 Long-term care

The participants indicated that they wished to know what would happen with regard to treatment, care and medical review when the patient was discharged. According to the participants,

I wish we could have information sharing meeting with the doctors before discharge to better understand how I should care for my patient at home(p 8)

I wish the condition of the patient and treatment plan on discharge could be discussed and explained to me. (p10)

The participants indicated their need to be educated on the patient's plan of care after discharge since it would be the family's responsibility to continue with the treatment plan at home. Sarhadi et al (2014:258) emphasise that ICU hospitalised patients usually take long to recover and at times the recovery has to be continued at home under the supervision and care of the family. For this reason, HCPs need to inform the family about the post-discharge plans and any other related information.

4.3 CONCLUSION

This chapter discussed the data analysis and the findings. The findings were discussed with reference to relevant literature from the literature review.

Chapter 5 briefly discusses the conclusions and limitations of the study, and makes recommendations for practice and further research. The researcher also shares her personal reflection.

CHAPTER 5

CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS

Though no one can go back and make a brand new start, anyone can start from now and make a brand new ending.

- Carl Bard -

5.1 INTRODUCTION

Chapter 4 presented the data analysis and the findings, with reference to the literature review. This chapter summarises the findings and makes recommendations for each one; presents the participants' recommended strategies for "an ideal ICU"; briefly describes the limitations of the study; makes recommendations for future research, and concludes with the researcher's personal reflection.

5.2 AIM OF THE STUDY

As a registered nurse in a general ICU in Botswana, the researcher observed that nurses' and physicians' plan of care was guided by set standards and policies approved by the hospital management. However, the policies do not recognise or acknowledge family-centred care (FCC) as crucial to patient outcomes or to increased family satisfaction (Brooke & Warren 2014:47). Consequently, the aim of the study was to explore the views of family members of patients admitted in a general ICU in Botswana regarding FCC.

5.3 FINDINGS AND RECOMMENDATIONS

This section summarises the findings according to the questions in the AI interview guide. Recommendations are made for each finding.

5.3.1 Question 1: Discover "what is" the best experience you had regarding family-centred care in the ICU?

The first question wished to discover the participants' peak or most satisfying experience regarding FCC. One theme, namely workplace culture, and five categories, namely physical environment, attitude, basic needs, shared information, and involvement emerged from this question.

The participants who spent most of their time in the ICU and interacted with HCPs discovered that the environment was not as frightening as it looked, because the reception by the staff was warm and welcoming. The participants appreciated the timely information they were given about the patient's condition on admission and throughout the process of admission. The presence of the nurses and doctors and their willingness to assist helped them to adapt more easily to the stressful ICU environment and most of their stress, anxiety, fear and uncertainty were reduced.

The participants appreciated the cleanliness of the environment which gave them assurance and hope for a positive outcome of their patients' illness. At every visit they were asked to use over-gowns and to wash their hands before coming in contact with the patient. They considered the ICU as a learning and non-threatening environment; it equipped them with basic knowledge about the disease process, prognosis and the patient's treatment plan. The positive attitude displayed by the HCPs helped the participants to be hopeful and confident of the outcomes of their critically ill patient.

Although the participants initially expressed fear and uncertainty related to the complexity of the environment and the family member's critical illness, they appreciated the physical, emotional and psychological support provided by the HCPs. They appreciated the information sharing, warm interaction with the family members and the reassurance received from HCPs. The participants further stated that their frustrations were eased because they were able to freely ask questions and state their concerns. The HCPs also assisted their patients with the daily activities, such as bathing, change of linen, and feeding. The supportive workplace environment promoted good working relations between the participants and the HCPs thereby reducing complaints and leading to improved service satisfaction.

5.3.1.1 Recommendations

The researcher recommends the following strategies to ensure a good ICU experience for families and patients:

- Ensure general neatness of the ICU environment as well as the patients' immediate bed space.
- Raise awareness on the importance of personal hygiene and general neatness of patients prior to visiting time.
- Emphasise the importance of sharing information with family members relating to their relative's progress and procedures to ensure they stay informed at all times.
- Portray a positive attitude towards the family members at all times.
- Allocate time during visiting time to answer family members' questions and concerns regarding their relative.

5.3.2 Question 2: Explore "what could be" the ideal family-centred ICU?

The second question wished to explore the participants' expectations of an ideal FCC ICU. Two themes and six categories emerged from question 2. Theme 2 was **compassion** with three categories, namely *sharing information*, *involvement*, and *flexible visiting time*. Theme 3 was **counselling** with three categories, namely *self*, *outcomes*, and *long-term care*.

The participants wished the HCPs would be consistent in their information sharing, not only sharing patient information when the condition changed, at admission and discharge. Information sharing should include all activities related to the patient's plan of treatment and procedures carried out on a daily basis, including the outcomes. According to the participants, complete information sharing would promote understanding of the progress; leave them with fewer questions to ask, and make them feel part of the care team.

The participants wished they could be involved in decision making on the care of their critically ill loved ones as well as in basic activities such as bed bathing with the

assistance of the nurses. The participants also suggested introducing family meetings to improve information sharing and education. Family meetings with HCPs would improve relationships through regular interaction that could be beneficial to the patient, family and HCP. The participants indicated that flexible visiting times would enhance good interaction with the HCPs because with no time restriction, they would have enough time to be with their sick family member. The participants also wished that HCPs could provide scheduled counselling to emotionally traumatised family members about the patient's condition, prognosis and long-term care to enable them to cope during admission and after discharge.

5.3.2.1 Recommendations

With regard to compassion and counselling, the researcher recommends the following:

- HCPs should focus at all times on involving the family members in decision making regarding their family member.
- Inform family members off any changes in the patient's condition.
- HCPs (doctors and nurses) should reach consensus in ICU meetings to accommodate family members outside scheduled visiting times.
- HCPs and management should develop policies that allow for more flexible or open family visiting times.
- Plan weekly family meetings between HCPs (doctors and nurses) and identified family representatives to address challenges, answer questions and concerns about the patient's progress, and discuss treatment plans for the patient.

5.3.3 Question 3: Describe "what should be" the ideal family-centred ICU?

Describe "what should be" focused on the challenges related to FCC that should be addressed in order to enhance a family-centred environment in the ICU. Three themes emerged in question 3: **restrictive visiting times, lack of family involvement in care decisions, and inadequate communication by HCPs.**

At present, the hospital policy has stipulated visiting times that should be strictly adhered to and the number of visitors per patient is also controlled. There are four scheduled visiting times in a day: morning time is 30 minutes; lunch time is 1 hour; afternoon time is 1 hour, and evening time is 30 minutes. The participants indicated that they found the given times inadequate for spending with the patients. Furthermore, the frequent trips to the hospital were costly for them and sometimes they were unable to visit on a daily basis. The participants pointed out that they would appreciate it if visiting times were kept flexible; depending on the planned patient activities for the day and ensuring that patients' routine care activities were given priority. At the same time, the participants advocated for open communication and good interpersonal relationships between HCPs and families.

Although the participants appreciated the support and commitment of some HCPs, they indicated that they were not fully involved in the decision making on their patients. They felt that they should be part of the day-to-day interaction with the HCPs in order to feel they belonged, understood the patient's progress, and could better cope with the situation. HCPs should create time in their busy schedule to engage family members as this would also contribute to positive patient outcomes and improve family satisfaction. The families indicated that even though there was interaction between the HCPs and the families, communication needed to be improved and increased. Some HCPs seemed to lack commitment to their work and sometimes the participants were not offered the support they needed in the form of information and reassurance. The participants felt that HCPs should be educated on the basic principles of FCC and the importance of identifying and meeting family needs.

5.3.3.1 Recommendations

The researcher recommends that

- Nurses should confirm that family members' telephone numbers are on patients' files to ensure family can be reached in case of emergency or to inform family members of changes in their condition.

- Nurses and doctors should encourage and practise open communication with family members at all times, keep family members informed on the progress of their relatives.
- HCPs show a supportive attitude towards the family members to alleviate their stress about their relatives' condition.

5.3.4 Question 4: Compile “what must be” the ideal family-centred ICU?

In compiling “*what must be*” the participants were asked to recommend strategies implemented by nurses in the ICU to enhance FCC. The participants recommended the following strategies to guide the specific ICU in Botswana to improve FCC and achieve quality service delivery.

5.3.4.1 Recommended strategies

The participants recommended the following strategies:

- Weekly family meetings should be held with doctors to have face-to-face conversations regarding concerns about their family members' condition and progress.
- Information brochures/leaflets should be readily available for families about the ICU environment, equipment and general rules and regulations that will be important for them as family members.
- HCPs should include a family member in decision making on patient management and planned procedures.
- Family members should be informed of any changes in the patient's condition, and positive and negative outcomes.
- Flexible visiting times should be introduced to enable family members to visit the patient when they are free.
- Nurses should involve family members in caring for the patients during visiting hours; for example, by brushing their hair, cutting their nails, etc.

5.4 LIMITATIONS

The study was limited to family members with a patient admitted to a selected general ICU in Botswana for at least 72 hours, therefore the results cannot be generalised. The researcher focused on the views of family members only and did not include the views of HCPs or of patients.

5.5 FUTURE RESEARCH

The researcher recommends that further research be conducted on the following topics:

- An investigation into the challenges and barriers to the implementation of family-centred care in ICUs
- ICU nurses' perceptions of family-centred care
- Doctors' and nurses' perspectives on restricted versus open visiting times
- Health professionals' views on the value of meetings with family members who have patients in ICU

5.6 PERSONAL REFLECTION

This study was a journey of discovery, growth and perseverance for me. Looking back, I feel as if I am standing on the top of a mountain and wish to express my appreciation and gratitude to my colleague, **(Moitshepi Phiri)** and my supervisors. I was reluctant to pursue my Master's degree because I knew it would not be easy, especially doing it part-time and the long distances I would have to travel for classes and contact sessions with my supervisors. However, with my colleague's confidence in me and persuasion, we started the journey together.

At first I felt lost and confused at the prospect of developing and formulating a research proposal. My supervisors' positive motivation and encouragement kept me going – even though sometimes I could not understand why they kept saying they were proud of my work. I have learned so much from the many articles that I read for this study. Immersing myself in other scholars' work enriched my knowledge, spurred me on and enabled me to see myself as a researcher contributing to the pool of knowledge and making a difference to the nursing profession.

Pursuing this programme has unveiled the bravery and potential hidden within me and revealed the talent that I did not know I had. The support and encouragement from my colleague and co-traveller not only carried me through the difficult times but deepened our friendship. At this point I feel I have developed tremendously in the area of nursing research and wish to continue with my studies for a Doctoral degree. I have found that with dedication and commitment one can achieve success. Moreover, I feel that my tireless effort and sacrifice of much of my personal and work time as well as quality time with my family was worthwhile.

5.7 SUMMARY

This chapter concluded the study, summarised the findings, briefly described the limitations of the study, and made recommendations for improving FCC in ICUs and for further research. The findings of this study should benefit the families of patients admitted in ICUs to make the experience more family-centred and enhance their satisfaction with the care delivered. The researcher's personal reflection shows that the study has enriched the researcher, her colleagues and the participants. The following quotation represents what family-centred care should represent to family members:

Change is a law of life and those who look to the past or present are certain to miss the future.

- John F Kennedy -

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